A Path Toward Health Equity:

Strategies to Strengthen Community Advocacy

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COMMUNITY CATALYST

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About Community Catalyst

Community Catalyst is a national non-profit advocacy organization dedicated to making quality, affordable health care accessible to everyone. Since 1997, Community Catalyst has worked to build consumer and community leadership to transform the American health system. With the belief that this transformation will happen when consumers are fully engaged and have an organized voice, Community Catalyst works in partnership with national, state and local consumer organizations, policymakers, and foundations, providing leadership and support to change the health care system so it serves everyone – especially vulnerable members of society.

For more information about Community Catalyst projects and publications, visit www.communitycatalyst.org.

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Community Catalyst

Executive Summary

The number and breadth of community-based activities to address racial and ethnic health disparities is burgeoning nationwide, driven by the belief that increasing the health and lifespan of people of color requires empowering them to create systemic change. National health care reform will provide additional opportunities to advance health equity by expanding coverage and by fostering community-level efforts to address social and environmental factors that cause health disparities. Yet, significant advances to such entrenched problems will not come easy.

In this context, Community Catalyst sought to determine how funders and advocates could strengthen community-based work to reduce health disparities, with special focus on policy advocacy that can bring broad and lasting change. We studied community organizations either led by or focused on minorities in six states: California, Massachusetts, Michigan, Mississippi, New Mexico, and Ohio. Using in-depth telephone interviews and online surveys, we explored their activities, their partnerships, what they identified as successes, and the extent to which they engaged in policy change. We asked about barriers to advancing health equity and ways to overcome those barriers. We also interviewed statewide organizations working on access or disparities, health providers, researchers and government officials.

The community-based organizations focus their health disparities work on four areas: preventing or reducing chronic diseases and medical conditions; increasing language access and cultural competency; improving access to health care and coverage; and addressing social determinants of health. Much of the work is local, with the most common activities including health education, health screenings, and assistance navigating the health system. Many of the groups are working in isolation from each other. They are also disconnected from broader health reform efforts and from statewide organizations that lead those initiatives and that are just beginning to engage in health equity work. In four of the study states – California, Massachusetts, New Mexico, and Ohio – some community-based organizations, state advocacy groups and other stakeholders have joined health equity coalitions or groups, but these vary greatly in capacity and effectiveness.

In all the states, community organizations described local successes, such as improved access to care, better health outcomes, or chipping away at environment barriers to health. Only one-fifth of the groups said they had engaged in advocacy to change laws or policies affecting health or health care. Most of this advocacy focused on local officials, rather than on state leaders. For example, in Albuquerque, New Mexico, a coalition of organizations successfully advocated for development of an outpatient clinic operated by the University of New Mexico Hospital in the city's most diverse, underserved neighborhood. In Chelsea, Massachusetts, a relatively poor community with a large population of people of color, community members organized to stop a diesel power plant from opening.

Challenges to progress identified by the community-based organizations and other stakeholders include:

- The inherent difficulty of addressing social determinants of health
- Lack of coordination among community-based organizations, even in the same city
- Lack of organizational capacity, especially in fund-raising, communications, and policy advocacy
- Lack of broad leadership needed to bridge differences and foster development of a shared policy agenda

- Lack of funding
- Lack of connection between health reform and disparities reduction work, and mistrust between organizations
- Racism – structural, institutional and attitudinal

While our sample size for this study was small, many of the same challenges were raised at our national and regional convenings of health equity advocates.

Recommendations

These challenges and the persistence of disparities suggest a more coordinated and sweeping strategy is needed to advance health equity. A range of tactics should be deployed, but more emphasis needs to shift to policy advocacy to attain the broadest, most sustainable change. Community-based organizations are integral to ensure change is meaningful and effective.

In a previous study of statewide consumer health advocacy, we developed a policy advocacy approach that is now used in other arenas and call for systems of advocacy to bring together the power of many stakeholders with complementary capacities.

We propose five strategies for building systems of advocacy, with minority-led and minority-focused community organizations at their core, that could develop and advance a health equity policy agenda.

- **Build and strengthen community-based organizations**
    - Facilitate connections among community-based organizations
    - Build organizational capacity
    - Foster leadership development
- **Encourage statewide health access groups to prioritize equity work**
    - Deepen and broaden their understanding of health equity issues
    - Learn from community-based organizations
    - Diversify their leadership and staff
- **Build coalitions of strengthened community-based groups and statewide and national organizations**
    - Acknowledge differences in values, mission and approach
    - Recognize and respect complementary skills
    - Bridge differences through openness and search for common ground
- **Connect to other stakeholders,** including government agencies, academic researchers and policy institutes
- **Develop a disparities reduction/health equity policy agenda**
    - Maximize the impact of national health care reform
    - Fill in the gaps and address social determinants

Funders can play a significant role by:

- Supporting capacity building of community-based groups
- Underwriting convenings of community groups, and of broader coalitions
- Funding partnerships for policy advocacy among community groups, and with state groups and broader stakeholders
- Supporting long-term health equity projects

Introduction

Across the country, community-based initiatives to address racial and ethnic health disparities are on the rise. From coast to coast and north to south, this growth reflects the critical need to tackle the high rates of illness and early death suffered by people of color. The activity is also spurred by expert analysis showing that progress to achieve health equity requires deep engagement by the communities most affected, and connecting them to the levers of power within the health system and beyond.[1]

Some of the work is fueled by national programs aimed at the root causes of disparities. These causes include societal racism that leads to poorer housing, education and nutrition; barriers to quality health care such as lack of health insurance, high out-of-pocket costs and inadequate facilities; and outright discrimination. National programs addressing these causes at the community level include the federally supported Racial and Ethnic Approaches to Community Health (REACH) operating in 40 communities under the auspices of the Centers for Disease Control and Prevention; the Kellogg Foundation-funded Place Matters initiative of the Joint Center for Political and Economic Studies operating in 24 counties and cities; and the Healthy Eating Active Living Convergence Partnership of five major health funders supporting initiatives in communities across the nation.[2] Many other efforts are supported by local funders or are springing up on their own as community members come together to help each other.

In the context of this burgeoning work, Community Catalyst in 2009 examined efforts by community-based organizations to reduce racial and ethnic health disparities. We were particularly interested in the extent to which these organizations were working with each other, with statewide advocacy groups, and with other interested stakeholders, including research institutions, providers and government. We also explored what the organizations identified as successes and whether they were engaged in institutionalizing their work through policy change. Our goal was to determine how these efforts might be strengthened. We focused on those organizations led by or focused on minorities in six very different states: California, Massachusetts, Michigan, Mississippi, New Mexico, and Ohio. Most of the organizations were incorporated as 501c3 charitable organizations and had been in existence for at least six years. They ranged from all volunteer organizations with budgets of less than $25,000 a year, to those with more than 15 paid staff members and budgets over $1 million.

Our focus grew out of an approach we developed to advance consumer health advocacy that is now used in other arenas, as well. This approach calls for creating systems of advocacy to bring together the power of many stakeholders to effect systemic policy change. In an advocacy system, the complementary capacities of different organizations are knit together to create a coherent whole.

Given the magnitude of racial and ethnic disparities and the complexity of the causes, we hypothesized that a similar approach might be useful in advancing health equity. In this study we wanted to explore that possibility.

We found that most community-based organizations are struggling in isolation from each other, removed from the policy arena. Nonetheless, these organizations reported many local and a few statewide advances – such as California's passage of legislation requiring health plans to provide culturally and linguistically appropriate services. We also found widespread interest in building a stronger health equity movement, with a larger focus on policy advocacy.

National health care reform helps set the stage with major expansions of health insurance that will cover millions of people of color. To further improve access to care, the new reform law also provides incentives for expansion of primary care and diversification of the health workforce. It launches national quality and prevention strategies aimed, in part, at reducing disparities. And it establishes community transformation grants aimed at the social and economic determinants of health.

Separate from reform, President Obama's administration soon plans to launch a National Partnership for Action to end health disparities. The Partnership aims to connect and mobilize individuals and organizations nationwide, with special focus on the community level.

This combination of national initiatives and local interest presents a significant opportunity to advance health equity nationally. We offer this report to further that goal. Part 1 describes our study approach and explains how the organizations interviewed define their work. Part 2 details the organizations, activities and interactions with other stakeholders. Part 3 discusses successes and the strategies that groups said helped them achieve those advances, as well as the challenges that groups said slowed their progress. Part 4 provides recommendations to advocates and funders for addressing those challenges.

Part 1: Methods and definitions

Our study approach

Our overarching goal for this study was to understand what is needed to advance community-based health equity work in order to make recommendations to funders and to advocates. Specifically, we wanted to know:

- How organizations define racial and ethnic health disparities
- What disparities issues they focus on
- Who the groups are and what type of work they do to reduce disparities
- Who they partner with and who is missing from the partnerships
- What successes organizations identify and what strategies contributed to those successes
- What challenges organizations have faced that slow their work
- What would help advance work to reduce disparities

The methodology used in this study is modeled on prior analyses by Community Catalyst of state-based consumer health advocacy capacity.[3] The six states included in this study were selected because they represent a broad range of geographic, racial, ethnic and political diversity. Community Catalyst also had consumer advocacy contacts in each of the six states, which facilitated identification of other individuals and organizations working on health disparities-related issues. We began with a review of published data on demographics, political environment and health status for each of the six states. A summary of this data is attached as **Appendix A**.

We then conducted a total of 96 in-depth telephone interviews using a protocol we developed. Our principal interest was speaking with representatives of community-based groups that are engaged in disparities reduction work and that are either minority-led or minority-focused.[4] We also sought out statewide coalitions of organizations focused on disparities reduction and statewide advocacy organizations that focus on health coverage and access. Finally, we interviewed other stakeholders in each state, including state agencies that focus on minority health-related issues; research-focused organizations, including those affiliated with academic institutions, and independent policy institutes; health care providers such as community health centers, hospitals and health systems; and funders whose programs include disparities reduction efforts. Our interest in these stakeholders grew out of our previous work on systems of advocacy in which these types of partners made significant and sometimes unique contributions.

A list of those interviewed and the interview protocol are attached as **Appendices B and C** respectively.

Additionally, we developed an online survey that was distributed to the community-based and state advocacy organizations that participated in the telephone interviews. A copy of the survey is attached as **Appendix D**. Of the 48 online surveys that were distributed, 40 organizations responded, enabling us to gain a better understanding of their work, including organizational characteristics, strategies, and self-identified needs.

Our state sample size was small, and within each of the study states there were some organizations, policy institutes and academics that were not responsive to interview requests or declined to participate. In addition, there was variation from state to state in the number and types of groups interviewed. As a result, we know we have not captured the full breadth of disparities reduction efforts that are underway.

Accordingly, we would characterize the contents of this report as a qualitative exploration and assessment of activities and concerns. Nevertheless, we believe it is possible to extract important information from the conversations, survey responses, and available quantitative data that will be useful in designing efforts to strengthen community-based health equity work.

Defining health disparities

Many organizations and stakeholders interviewed for this study define racial and ethnic health disparities as differences in health care access and outcomes among different population groups, with racial and ethnic minorities faring worst. However, some do not use the term to define their work, instead saying they focus on improving the health of their community. Among others, there is a growing preference for the term "health equity." This term is viewed as more appropriately attaching the values of justice and fairness to the need to address racially- and ethnically-based differences in health outcomes and, simultaneously, incorporating the necessity of addressing the social and economic determinants of health – such as access to clean air, secure housing, good jobs, safe places to play and exercise, and high-quality, affordable food. Most of those interviewed view efforts to expand access to – and quality of – health care as being essential, but not sufficient to eliminate disparities. This view is increasingly prevalent in policy debates – a need to get at the root causes.

> "We've moved away from the notion that fixing the health system itself will fix health care for minorities. We've moved upstream to look at structural aspects in communities that actually create disparities. The health care system can't fix these problems. We have to get into communities way before people need health care... We're trying to get to the place where we wouldn't need the health system to fix disparities."

Focus of health disparities work

The organizations we interviewed focus their health disparities or health equity work on four areas: preventing or reducing chronic diseases and medical conditions that disproportionately affect racial and ethnic minorities; increasing language access and cultural competency; improving access to health care and coverage; and addressing the social determinants of health.

The chronic diseases and medical conditions these organizations most commonly target are diabetes, obesity, cardiovascular disease, infant mortality, and HIV/AIDS. Language access in health care facilities and within health plans, and cultural competency among health care providers, are priorities in all of the states, but they appear to be the highest priority in California and New Mexico, the two states with the largest non-English speaking populations. Access to care primarily focuses on connecting individuals to medical services or, in some cases, providing the care or services directly. Work on access to coverage typically is the focus of statewide organizations that don't have a specific disparities reduction focus. Work that addresses the social and environmental determinants of health is increasing. The most common initiatives were increasing access to healthy foods, providing safe places for play and exercise, and improving air quality.

Part 2: Organizations and activities

Community-based organizations

In each of the study states, numerous community-based organizations are working on health system disparities and on social determinants of health, and their numbers appear to be growing. We interviewed organizations formed within the last two years, as well as those that have been in existence for more than a decade.

The organizations ran the gamut in size and funding. About one-sixth of those we interviewed had all-volunteer staffs and annual budgets under $25,000. Sixty percent had six or fewer paid staff members and budgets under $500,000, while several had more than 15 paid staff and budgets over $1 million. Most of the organizations hold 501c3 charitable status. By design of the study, most of the groups interviewed are led by minorities and focused on improving the life of minority populations. Some of the groups have a formal mechanism, such as an advisory committee, for community input, but many do not. Most of the organizations focus on single ethnic or racial populations, including blacks, Hispanics or Asians, while a few are multiracial. We were not able to identify any Native American community-based groups, although we did interview several tribal councils and organizations.

Government is a major funder of these organizations. Nearly all of the states make grants to community groups working to reduce disparities, although these funds have been reduced because of state fiscal problems. Some local and county public health agencies also fund community-based organizations. For example, the Boston Public Health Commission – the agency that oversees and coordinates most public health activities within the city – provides grants that support community initiatives to reduce disparities and address social determinants of health. At the federal level, the Health Resources and Services Administration, the Office of Minority Health, the Centers for Disease Control and Prevention and the Agency for Healthcare Research and Quality are the lead agencies in providing funding.

Other financial support for community-based disparities reduction efforts comes from national and state chapters of voluntary health associations, such as the American Diabetes Association and the American Heart Association. Some organizations also receive individual donations.

Many of the community-based organizations reported being connected to initiatives of national grantmakers such as the Robert Wood Johnson Foundation and the W. K. Kellogg Foundation. State-based and community foundations also fund disparities reduction efforts, particularly those targeting education and disease prevention.

> " Everybody and his brother has something going in this area... Personally, I think we have too many initiatives and not enough focus."

The organizations' work generally is local, since many have an explicit mission to serve their local communities. The most common activities include health education and promotion, health screenings and referrals, and assistance navigating the health system. These efforts focus on specific chronic conditions or risk factors that are most prevalent among racial and ethnic minorities. Providers, particularly community health centers and hospitals, and churches are partners in many of these health education and screening initiatives. In some cities, such as Cleveland, Ohio, groups serving people of different races or ethnicities work in parallel to provide similar services but say they do not interact with each other. Some of the organizations also provide direct services, again generally with a focus on the chronic conditions or risk factors. Direct services range from mobile vans that provide diabetes and cancer screenings, to a full spectrum of primary care services. Other organizations work to educate health care providers, particularly about cultural competence, by conducting their own "grand rounds" or other means.

A number of the organizations work on multiple issues beyond the health care system, including housing, employment, schooling and violence. Some of this work is explicitly designed to address social determinants of health care, while some is described as just focusing on urgent community needs.

Examples of activities aimed at health education, bridging cultural gaps, and social determinants include:

- Community Outreach for Health Awareness (COHA): This Jackson, Mississippi-based program focuses on community education and prevention in connection with chronic diseases and social issues such as teen pregnancy and substance abuse. It targets underserved populations in the Jackson community. Activities include health screenings and health fairs, health curriculum development, and health services referrals. A high-profile achievement was convincing the governor to declare an annual Mississippi Health Awareness Day, the first of which was held in 2006. In 2008, Health Awareness Day volunteer health professionals at 26 sites provided free health screening/services to over 3,000 Mississippi residents.

- Latino Outreach and Empowerment Network: This group worked with other organizations to create two programs that help new immigrants in Columbus, Ohio navigate the health care system. The Abrete Sesamo program, (Open, Sesame), teaches immigrants about the health system and their rights. The Latino Health Connector provides screening and navigator services, including referrals to Spanish-speaking providers.

- Neighborhood Food Watch: Advocates in South Los Angeles launched community conversations to gather ideas about ways to reduce heart disease and diabetes among blacks. This lead to establishment of community gardens, food co-ops and farmers markets in the neighborhoods. In addition, they designed pledges to hold local retailers accountable for the quality of food they sell.

Only one-fifth of the community-based groups said they had engaged in advocacy to change laws or policies affecting health or health care. Most of these groups focused this advocacy on local officials or powerbrokers, rather than on state leaders. The policy advocacy was about evenly split between efforts to address health system issues and those to address social determinants. Efforts have included negotiations with hospitals to improve their financial assistance programs and campaigns to improve services for teens.

For example:

- Latino Health Access (LHA): In 2002, this Santa Ana, California-based non-profit began organizing community members and lobbying city officials for a community park to provide a safe outdoor space for play and exercise. The campaign was spearheaded by a *promotora*, or community health worker, who organized other mothers to participate in rallies and advocate with city officials. In 2004, the city agreed to provide land for a park, but no funding. LHA and community members raised the money to develop the recreational space and build a community center on the site. In November 2009, seven years after the effort began, the park was officially opened.
- Universal Community Voices Eliminating Disparities: This Springfield, Massachusetts, community-based organization determined that one factor in the poor health of some predominantly minority neighborhoods was the distance – up to a mile – of supermarkets from the nearest bus stop. The organization, along with other Springfield groups, worked with the local transit agency to reroute buses to stop near the markets.

Many of the organizations said they did not know how to engage in policy advocacy, believed they were restricted from legislative advocacy by their funding sources, or said they did not have the staff to add policy advocacy to their current work. One paid executive director, who is short-staffed, said she does the work "on her own time."

Statewide disparities-focused coalitions and advocacy organizations

In four of the study states – California, Massachusetts, New Mexico, and Ohio – community-based organizations, advocacy groups and other stakeholders have come together to form statewide advocacy organizations or coalitions that focus principally on health disparities reduction efforts and/or explicitly represent the interests of racial and ethnic minorities. These vary greatly in capacity, reach, clout and effectiveness. The organizations in California and Massachusetts are the most developed. They differ from the others in that they have an infrastructure that can support coalition work, and they operate in environments with a tradition of collaboration. In contrast, Ohio advocates say that its coalition has had difficulty achieving consensus on specific policy goals, which has slowed its ability to act. New Mexico's effort faces unique demographic challenges that make it difficult to work effectively statewide. In Michigan, the Minority Health Coalition exists to create partnerships among organizations, but its volunteer leader says the members are mainly from the East Lansing area and the organization currently lacks the visibility or resources to bring people together. Several states also have statewide coalitions of Asian or Hispanic organizations, which have largely not had the resources to engage in statewide policy change.

The statewide multicultural organizations/coalitions are described below.

- California's Pan-Ethnic Health Network (CPEHN) is the oldest, established in the 1990s. Founded by four ethnic organizations – the Asian Pacific Islander American Health Forum, California Black Health Network, California Rural Indian Health Board, and the Latino Coalition for a Healthy California, CPEHN works to improve policies affecting the health of communities of color. It also brings together diverse stakeholders – community, government, academia, and the private sector – to engage in dialogue and build advocacy efforts to achieve health equity. Its four priority areas are: advocating for cultural and linguistic competency, improving access to health care, promoting data and research, and addressing social and environmental determinants of health. It has a well-established reputation statewide as a credible, effective convener and advocate on health equity issues, and has achieved significant policy advances, most notably a state law requiring health plans to provide language access (see page 16). CPEHN sits on the board of Health Access California, the state's largest access group.

- Massachusetts' Disparities Action Network (DAN) was established in 2006 by the state's principal consumer health advocacy organization, Health Care For All. Its goal was to convene groups from across the state working on health disparities to develop a shared policy agenda and advocate for state-level policy change. The DAN has more than 50 organizational members, including community-based groups that engage in policy advocacy through the network. The DAN has demonstrated its political power by turning out hundreds of people at legislative advocacy events, and by getting the Legislature to establish an Office of Health Equity, although they have not yet secured funding for the office. A number of its members and others would like to see the DAN expand its focus beyond policy change to organizing convenings on various issues. They also want the DAN to expand its membership and decision-making to include more community-based organizations and their constituents.
- The New Mexico Health Equity Working Group was established in 2007 by the state's major health funder, the Con Alma Health Foundation. It was created to promote health equity and to encourage state partners to use resources effectively. The small but diverse group of advocates in its membership meets monthly. The Working Group has screened the PBS series *Unnatural Causes* throughout the state and facilitated discussion. It is moving slowly and has yet to build a significant coalition.
- The Ohio Statewide Health Disparities Collaborative was founded in 2007 to address the fragmentation of disparities activities by coordinating policy advocacy at the state and local level, and by serving as a clearinghouse. It is organized and staffed by Children's Defense Fund-Ohio, with the help of the Ohio Commission on Minority Health. The collaborative has an advisory board that includes many of the key players statewide, and a membership of more than 50 organizations. It has brought people together statewide at two major convenings, but has faced challenges bridging the varying agendas and capacities of stakeholders to reach agreement on policy goals.

More informal coalitions have come together in some of the states to address specific issues. In some cases, they can point to significant achievements that resulted from the combining of resources. For example, in New Mexico, advocates from five community-based and statewide organizations came together to improve access to care and interpreter services at the largest public hospital in the state. After several years of advocacy and negotiation, they sued the hospital over lack of interpreter services and won. Additional negotiations with the hospital resulted in an expansion of the hospital's charity care program.

Statewide access advocacy groups

Five of the six states – all except Michigan – have statewide consumer health advocacy groups that focus primarily on access and coverage issues, often working apart from community-based groups focused on racial and ethnic health disparities. (MichUHCAN is seeking to grow to statewide status, but has worked mainly in the greater Detroit area.) These consumer health advocacy groups are skilled at the kind of statewide policy advocacy that can foster systemic change, and that is needed to advance health equity. Their statewide work typically entails promoting broad health reform that expands private and public coverage, or defending public programs such as Medicaid and CHIP from cuts in benefits and eligibility. While this work focuses on helping vulnerable populations, including many people of color, most of the access groups are only beginning to focus directly on health disparities. In the past, they have seen their access and coverage work as fulfilling their missions of helping ensure quality affordable care for all, and as an overwhelming task that left no time for other endeavors. Some consider the access advocacy to be health disparities work. Most of the groups said health care reform will provide new opportunities for work on health equity. Regarding staffing, people of color head two of the six organizations (California and Mississippi) but much of the staff are white, with the exception of Mississippi.

All the statewide organizations are exploring new relationships with groups working on disparities, and the statewide access groups in California, Massachusetts and to some extent Ohio, regularly work with community-based organizations focused on reducing disparities.

Community groups in several states, however, said they do not always feel they are respected by statewide groups. They said the statewide groups solicit their presence on access issues, but often do not listen to their community-based agendas. In addition, some said the larger groups are "moving very quickly," particularly on policy issues, and don't take the time to help community groups catch up.

The statewide groups most frequently use lobbying or education of state lawmakers and policymakers to affect change, in contrast to the grassroots organizing and community education strategies favored by the community-based groups.

> " At CPEHN, we follow a multicultural model, making sure that everyone has an equal voice in all phases of any advocacy campaign. We work on the whole spectrum of health from prevention, racism and social determinants, to access and quality of care, according to the needs of communities of color. Our principle is to put the relationship first, even if it means slowing down or changing the organization's work and policy agenda."

In California, the Having Our Say Coalition, a group of over 50 minority-led and minority-focused groups, was formed in 2007 by CPEHN (mentioned above), the California Immigrant Policy Center and the Latino Issues Forum. Its initial purpose was to ensure that the interests and concerns of racial and ethnic minorities were well-represented in a major campaign for broad-based state health reform. During the campaign CPEHN worked side-by-side with Health Access California (HAC), a statewide consumer health advocacy organization. The effort to achieve state health reform failed because of differences between the governor and legislature, but the coalition continues to work collaboratively with HAC on issues including Medicaid/CHIP access, safety net providers, and culturally and linguistically appropriate services. The coalition also worked to advance health equity provisions in national health care reform. In its role on HAC's board, CPEHN has participated in discussions about how else HAC should engage in health equity work. HAC leaders said they do not have the expertise to work on social determinants.

In Massachusetts, the principal statewide consumer health advocacy organization, Health Care For All (HCFA), provided the infrastructure and staffing that helped create the Disparities Action Network (DAN, described above). HCFA and the network partner on policy issues. While HCFA has stepped back from its initial leadership role in the DAN, some of the DAN's community-based members still feel HCFA plays too big a role. In Ohio, UHCAN, the lead statewide consumer health advocacy group, worked in Columbus with several disparities-focused groups in years past to save community clinics and expand translation and other language services. The leadership reports more recent outreach to minority-led organizations in other parts of the state, mostly in attempts to engage groups in statewide coverage and quality initiatives. But they acknowledge – and other groups report – that these efforts have not always been effective due to differences in goals and approaches.

> “There is not enough grassroots networking. If we are all serving communities... we must touch back in with one another and see how we can send the message uniformly to support one another in our efforts.”

Besides these consumer health advocacy groups, other statewide advocacy groups are working on health disparities in most of the study states, but few are connected with other organizations and efforts. For example, the School-Community Health Alliance of Michigan works to address the causes of disparities by using school clinics to connect families to providers, educate families about healthy living, empower youths to speak out, and draw links between health, education and work. The Michigan League for Human Services published a report last August on the impact budget cuts would have on health disparities, and has advocated for continued funding of many health prevention programs. Both organizations see a need for more networking and coalition work, but no organization has stepped forward to take the lead.

Research institutions and policy institutes

Some of the community-based organizations we interviewed look to academic researchers and policy institutes in their states for data on disparities and for research on innovative programs. These institutions are often seen as powerful influences in the states, major contributors to increased awareness of disparities, and potential resources. But many community groups and most of the researchers interviewed said there was little interaction between the groups and institutions, with a few exceptions. Many of the community leaders also said that research findings don’t have the impact that they could because those findings are not routinely disseminated or explained to the populations that are affected. This view was shared by some, but not all, of the researchers interviewed.

All six of the study states have several academic institutions that research health disparities, and at least one policy institute that collects, analyzes and produces health data. The academic research focuses primarily on developing chronic disease-related prevention programs and clinical interventions. Many of those interviewed – both community group leaders and researchers – say that research topics are dictated primarily by the interests of faculty or policy specialists and by available funding. The audiences for this research and data typically are the medical and public health communities, and state agencies. Some of this research feeds into policymaking.

Examples of research entities and their interactions with community groups include:

- The Case Center for Reducing Health Disparities: The center, which was created in 2007, is part of Case Western Reserve University in Cleveland, Ohio. Recent projects include studies of disparities in organ donation and tumors, and interventions to improve management of hypertension in city clinics. It also offers courses and conferences on disparities targeted to students, providers and policymakers. It has engaged in some collaboration with Cleveland area agencies to help them design and evaluate projects. It generally does not interact with community-based groups, although its director has expressed an interest in broadening the center’s reach and connecting more with those groups.

- Prevention Institute: This California-based national policy and action institute is an exception to the pattern we found, since it explicitly seeks to provide policy analysis and tools for community action to address health disparities. The agency helps community-based organizations with strategic planning, although this is not the main focus of its work. Rather, the Institute convenes broad coalitions and helps national, state and local policymakers advance strategies to address the underlying social and economic causes of illness. Several groups interviewed said they had used the institute's resources but did not work extensively with them.

Public agencies

Each of the six study states has at least one state-level government agency, office or commission charged with working on disparities reduction, but their relative positions within state government, mandates, funding and impact vary, according to our interviews with officials in those offices, community group leaders and others. As a result, the interaction of these offices with and influence on community-based organizations also varies. Some function as leaders of health disparities work and/or influence activities through funding or in-kind support, including encouraging policy advocacy. Others focus more on research or the education of government officials and have fewer and weaker connections with community-based groups. Some large cities and counties also have public health agencies that address disparities and that engage with, or fund, community-based groups. Many interviewees affiliated with community-based and state groups see the existence of these offices as acknowledgement that health disparities cannot be ignored. But the minimal funding of many of these offices, even in better economic times, leads some of those interviewed to question the strength of public commitment to disparities reduction.

The state agencies are:

- ***Ohio Commission on Minority Health:*** An independent state agency created by the legislature in 1987, the commission and its long-time executive director Cheryl Boyce are seen as statewide leaders on disparities reduction. The commission's principal work is providing and managing grants for disparities reduction efforts by community-based groups, and providing technical assistance with organizational issues such as staffing, fundraising, and bookkeeping. In this capacity, the commission has nurtured the growth of many organizations and spurred connections among them. Most of the Ohio community-based organizations interviewed in connection with this report have received funding from the commission, which has a two-year budget of $4,475,000.

- ***Michigan Health Disparities/Minority Health Section:*** This branch of the Michigan Department of Community Health is charged with coordinating, monitoring and reporting on disparities efforts in Michigan, using an annual budget of $1,316,000. It funds community-based activities and has distributed mini-grants to organizations statewide to sponsor "community conversations" to elicit the concerns and needs of racial and ethnic minorities. These conversations culminated in a health disparities summit in the fall of 2009 to identify local and state actions needed to eliminate disparities. However, several leaders of community and state-based organizations said leadership from the section has been inconsistent. The section director acknowledges that the state could do more to boost and coordinate disparities reduction efforts. In 2006, the Michigan legislature required the state to develop a structure that addresses disparities, funds minority-specific programs and research, and coordinates community-based coalitions. But no funding has been appropriated.

- ***Massachusetts Offices of Health Equity:*** Massachusetts has two state offices focused on health equity. A longstanding office in the Department of Public Health commissions and conducts research and programs to address disparities within public health. The office previously funded some community-based groups, but funding was eliminated as part of statewide budget cuts. In FY 2009, the legislature created a second health equity office reporting directly to the secretary of Health and Human Services (HHS) to coordinate state actions addressing social determinants of health. Advocates are pressing lawmakers to fund the office. Meanwhile, an HHS staff member works part-time to evaluate state programs with an equity lens. Working with the office, a separate state Health Disparities Council is preparing a report card on health outcomes and social factors. Government officials and health industry stakeholders outnumber community members on the council.

- ***New Mexico Office of Health Equity:*** This office within the Department of Public Health is funded with a five-year federal grant of $159,000 annually. In 2006, it began issuing an annual Health Disparities Report Card to raise awareness and monitor the state's progress in eliminating disparities. The office also provides training for Spanish and Navajo medical interpreters and online resources for providers about cultural and linguistic competency. It recently issued six small grants to community-based organizations working to reduce health disparities. The office is helping implement recommendations of the New Mexico Comprehensive Strategic Health Plan, including improving data collection on disparities, and expanding the use of community health workers.

- ***California Office of Multicultural Health:*** The office was established in 1993 to coordinate state efforts related to reducing disparities. The office was a significant force in its early days, but now has fewer resources and less clout. Although it has a 25-member advisory council drawn from community-based organizations, several interviewees did not know the office existed, while others said its limited capacity has diminished its work with external partners and within the department. A representative of the office acknowledged the need to help community members engage in policy change, but said the reduction in funding has limited the office's activities to encouraging state and local agencies to address health equity, and joint research projects with other institutions, such as commissioning a curriculum on cultural and linguistic diversity. The office also recently sponsored a social marketing campaign on black infant health.

- ***Mississippi Office of Minority Health Disparities Elimination:*** The office, located within the Department of Health, was established in 2003. Several of the community-based organizations interviewed regard the office and its director, Dr. Lovetta Brown, as a leader in promoting better health outcomes and reducing health disparities. Despite a limited budget of $300,000, the office engages in research, education, and public/private partnerships. It provides seed grants to community groups for programming and runs capacity building training for these groups that focus on grant writing, achieving 501c3 status, partnering with other groups, conducting needs assessments and program evaluation. One community group interviewed attributed its success with a public education campaign on diabetes directly to the office's help. The office also recently provided cultural competency training for 2,600 Department of Health employees, and a medical needs assessment for the state's Hispanic population. It also works with the legislature on health disparities bills.

Health care providers

Many of the community-based groups said they partnered with local health care providers, including hospitals, community health centers and organizations of health professionals in their health disparities work. Others targeted advocacy at providers to encourage or force needed health equity improvements. And a number of organizations interacted with providers in both roles, noting the difficulty of being both partner and advocate for internal change.

In all of the study states, health care providers spoke of their engagement in research, education, care coordination and other efforts related to reducing disparities. Providers in some communities have come together to sponsor health fairs and to promote models of care that can help reduce disparities, such as medical homes. The most common partnerships with community-based groups were to provide health screenings and education. Some providers also have joined advocacy efforts to expand access to care, and indicated they could be allies in policy advocacy to reduce health disparities.

> “It’s time for disparities work to move out of the public health realm and focus more on the many decisions made in – and about – our neighborhoods and cities that are affecting residents’ health.”

Who’s missing

As part of our inquiry, we asked interviewees to tell us which parties or stakeholders, if any, they thought were missing in disparities reduction work. While there was no consensus, many people identified the business sector as an important interest that was missing. They noted that business could play a big role as an employer, a purchaser of services, and a producer of beneficial products, such as healthy food, or potentially harmful byproducts, such as pollution. Others interviewed said they hoped to see move involvement from state and local chapters of national civil rights organizations such as the NAACP and the Urban League, whose engagement could enhance the credibility and clout of advocacy efforts. Finally, a few mentioned state and local transportation departments, which may not be cognizant of the environmental impact of their decisions, and the corrections system, which may not be providing adequate care to a prison population that is disproportionately composed of racial and ethnic minorities.

Part 3: Successes and challenges

Successes and the strategies behind them

Organizations in all six states identified local successes in their work to address racial and ethnic health disparities. Many of these successes improved access to care or particular health outcomes for community members, according to the organizations. Similarly, some efforts to address social or environmental barriers to good health achieved local policy changes – rerouting of buses or introduction of new sources of good food. The organizations and advocates who worked on these initiatives justifiably see their work as filling a gap.

Examples of local achievements include the following:

- In Albuquerque, New Mexico, a coalition of more than 30 organizations organized and successfully advocated for development of an outpatient clinic operated by the University of New Mexico Hospital in the city’s most diverse, underserved neighborhood. The relationship advocates built with hospital personnel during the clinic campaign endured, and the coalition ultimately was able to convince the hospital to expand the clinic’s hours of operation to better meet the needs of the neighborhood.

- In Mississippi, the Jackson Medical Mall Foundation, the leading minority-led, community-based organization in Jackson, worked in successful collaboration with four Jackson-area hospitals and the state Medicaid agency to reduce inappropriate emergency room use and connect patients to primary care services.
- In Massachusetts, Alternatives for Community and Environment organized community members to stop a diesel power plant from opening in Chelsea, a relatively poor community outside of Boston with a large population of people of color. They successfully used data showing high levels of asthma among Chelsea children and testimony from residents about other potential problems from the plant.

At the state level, the organizations identified less progress. Although the groundwork has been laid in some places for forward movement, community-based groups and state advocates took credit for only one major statewide success – a state campaign in California to improve language access throughout the health care system.

The California Pan-Ethnic Health Network (CPEHN) led the campaign to pass the law, which requires health plans to provide culturally and linguistically appropriate services. After a hard-fought battle, a broad coalition of organizations secured passage of the Health Care Language Assistance Act in 2003. Establishing the regulations to implement the law was also challenging, due in part to state budget deficits and changes in administration, but the law finally went into effect on January 1, 2009. CPEHN continues to monitor compliance and enforcement by regulators.

In general, however, advocates agree that systemic change has yet to occur. Those interviewed do note that public and policymaker awareness of the existence of disparities has increased significantly over the last several years. Interviewees believe this heightened awareness could set the stage for new phases of work that will produce fundamental system change.

> “We have a way of operating where the leadership is shared; information is transferred between and among us.”

When asked to identify the factors that contributed to progress, community-based groups and statewide advocacy groups provided strikingly different answers that reflect their activities. The community groups emphasized directly involving community members in the planning, execution and leadership of their efforts, and building collaborations with other stakeholders, including providers. The statewide groups most often cited using effective policy strategies, building broad-based coalitions and garnering support from politicians and government officials. CPEHN, for example, attributes its success in the language law campaign to: the collaborative efforts of a diverse and cohesive coalition; identification and cultivation of a legislative champion; the ability to mobilize community members; and persistence in monitoring implementation.

Challenges that slow health equity work

A key aspect of our inquiry was to understand impediments to the health equity work of community-based organizations. The challenges they identified – both during the interviews and in their online survey responses – were strikingly similar across states. Near the top of the list was the challenge inherent in trying to alter deeply entrenched and wide-reaching social determinants of health. This challenge, more than the others, speaks to the need for a coordinated and collective effort that includes a full range of strategies, but especially a focus on policy change. The other challenges, enumerated here, can more readily be managed or overcome. Doing so would build the broad-based, locally-grounded effort needed to make greater advances. Those challenges include:

> “Everyone is trying to do their own thing or reinvent the wheel. They’re working individually instead of as a group.”

Lack of coordination among organizations and efforts. While all of the study states had multiple disparities-reduction activities underway, there appeared – with a few exceptions – to be limited coordination among them. In some larger cities, the organizations are networked with each other to some degree. In California and Massachusetts, there are some coordinated campaigns, and in Ohio and New Mexico, there are statewide gatherings of some organizations. But except in California, the networking is relatively weak. Strong linkages between statewide advocacy organizations focused on health access and coverage, and local and state disparities-focused organizations are also generally lacking. Moreover, there does not appear to be much information sharing or coordination among disparities reduction activists *across* state lines except in the context of a small number of national initiatives such as Place Matters, Health Through Action,[5] and the Healthy Eating Active Living Convergence Partnership.

Many of those interviewed also observed that policy and research-focused institutes and organizations often are not connected to community-based groups or, in some cases, to the statewide efforts. Thus their research agendas may not reflect experience on the ground, and their research findings are not supporting the efforts of those working in communities. When asked what prevented coordination and information sharing, a few respondents suggested it could be related to competition for scarce financial resources. Another reason, described in more detail subsequently, may be that different racial and ethnic communities have different interests and needs, so they may not perceive a benefit in working collaboratively. Nevertheless, many of those interviewed believe that the lack of coordination hurts the ability to make progress.

Lack of organizational capacity. A key piece of our research was a survey of community-based organizations, which included a self-assessment of capacity gaps. Three-quarters of respondents identified lack of development/fundraising capacity as their greatest organizational weakness. They report needing help developing grant writing skills as well as evaluation skills to help set measurable benchmarks for themselves and for funders. Other significant capacity deficits were in communications, policy analysis and policy strategy. Most of the community-based organizations that currently focus on education and direct service said they would like to engage in policy advocacy, but lacked the skills and the resources to do so. Better coordination among the many groups engaging in disparities reduction work could fill some of these gaps, but most of the organizations interviewed still perceive a need to enhance many of their own skills in order to work more effectively.

> “This movement needs a leader who can pull together folks working on the ground and folks working at the 30,000 foot level.”

Lack of leadership. Interviewees identified a number of people they considered local leaders, but in most states said they lacked the broad leadership needed to bring people to the table and keep them there by breaking down silos, bridging differences, building trust, facilitating articulation of a shared strategic vision, and fostering development of a unified policy agenda. This type of leadership exists in California – in the California Pan-Ethnic Health Network – and to some degree in Massachusetts in the Disparities Action Network. With the right kind of support, there is potential to develop it in the other states. Interviewees acknowledged that this leadership is hard work. Some statewide efforts are having difficulties negotiating the differences among the agendas of the various groups engaged in disparities work in part because different racial and ethnic communities face distinct challenges. Others have developed ways of operating that seem to bridge those differences and focus on the ultimate remedy – advocating for policy and system change.

Identifying the "right" kind of leadership can also be a challenge. A few interviewees noted that civic leaders (e.g. health systems executives, chamber of commerce leaders, union officials) are regularly recruited to serve on task forces that are supposed to develop action plans for reducing disparities. While these leaders agree that disparities are a serious problem, some don't seem to know how to develop effective approaches because they are not the people who have the genuine community relationships or the necessary operational and organizational capabilities.

Lack of funding. A fundamental and universal challenge is lack of funding. Community-based organizations, in particular, are hard-pressed to locate resources to support their ongoing work, let alone participate in broader efforts. Each of the six study states is dealing with a significant state budget deficit, and many of those interviewed believe that health and human services programs are being disproportionately affected by budget cuts. This means fewer public resources for their work, and it also exacerbates existing disparities. Public funding also often comes with restrictions or prohibitions on legislative advocacy. Private resources are also harder to locate in the current economic environment. Organizations and institutions that depend on foundation funding are seeing reductions because of the recession's impact on funders' portfolios. Community-based organizations, many of which operate on small budgets anyway, are seeing their support from local individuals and businesses dwindle as the economic downturn takes its toll.

> " Many funders see a person with a cut and say, "Let's buy Band-Aids and patch it up." They're not addressing how the person got cut in the first place."

With regard to philanthropic support, many of those interviewed suggested that funders' priorities are off the mark even in better economic times. A number of respondents perceive a funder preference for "safe" recipients, such as academic or other mainstream institutions or organizations, and valuable but "safe" activities, such as academic research and direct services or disease prevention rather than advocacy for policy and system change. Even when a funder requires an institutional recipient to partner with community-based organizations, the predominant view is that true partnerships, those that embrace joint decision-making, respect for input from the community, and equitable sharing of resources, rarely result. A number of those interviewed also observed that, with a few exceptions, it can be a challenge to find funding for efforts that address the broader social determinants of health. For the most part, interviewees also said, funders do not invest in building the capacity of the community- and state-based organizations working to reduce disparities. Exceptions identified by those interviewed include The California Endowment, New Mexico's Con Alma Health Foundation, and the Blue Cross Blue Shield of Massachusetts Foundation.

Many interviewees expressed frustration that funder expectations about measurable progress may be unrealistic. They note that eradicating the root causes of disparities, such as racism and poverty, will not happen during a standard grant funding cycle.

A model for funder engagement already underway in one study state is the California Convergence[6], a branch of the Healthy Eating Active Living Conversion Partnership. This collective effort by seven leading national health foundations and health agencies seeks to reduce obesity and related chronic diseases by supporting community efforts to overhaul food and fitness environments. The California Convergence builds connections and capacity by linking these community initiatives with each other and with state advocates. A leader in this effort is The California Endowment, which has committed itself to addressing the social determinants of health. The other funders are Kaiser Permanente, the Robert Wood

Johnson Foundation and the W.K. Kellogg Foundation, which funds two other community-based disparities projects, Place Matters and the capacity-building Health Through Action.

Among local funders, an earlier-cited example is the Boston Public Health Commission's Center of Excellence in the Elimination of Disparities grant program, which is part of the CDC's REACH program. The three-year grants are made to Boston communities which are required to spend the first year conducting trainings on health equity and mapping community needs. The initial planning leads to identification of a specific health equity-related project within the community, and then the coalition of participating community groups receives an additional two years of funding to execute the project. All these models are based on the premise that real change must be rooted in the community, and will take time to develop fully.

Disconnect between broader health reform and disparities reduction work. Five of the study states have statewide consumer health advocacy organizations that have been actively involved in access expansion efforts at both the state and federal level. But there has not been a lot of joint work with community-based groups. In some states, there is a lack of trust and understanding between the "access" people and the "disparities" people.

The reasons are manifold. They include differences in mission, culture, capacity and working styles that lead the groups to work in different spheres and to fumble when they come together. Some in each camp are reluctant to reach beyond their comfort zones. Among some access groups, there is also a lack of understanding about health equity work, and about the value that community-based groups bring to the table. Meanwhile, some community-based groups don't see their work in the larger context of health equity, and are too focused on meeting immediate needs to attach value to statewide goals.

This is not an insurmountable barrier, but it does require each side to understand and respect the other's strengths, agendas, decision-making processes and working styles, and also to understand how coordination will be mutually beneficial. Bridging the gap is important because each camp brings essential skills to the work.

Racism. This is one of the greatest challenges. Racism – structural, institutional and attitudinal – is a fundamental cause of racial and ethnic disparities. Addressing the structural and institutional manifestations of racism is a monumental task, as noted above. Racist attitudes also get in the way of developing effective collaborations across the spectrum of interests engaged in disparities reduction work. Many of those interviewed observed that sometimes difficult conversations about racism and privilege need to take place before collaborative efforts can move forward. Many leaders are not equipped to have these conversations, or they may avoid open and direct discussion because they fear it will drive some stakeholders from the table.

Complex social dynamics and different issue agendas. Tensions between and among various racial and ethnic groups can affect efforts to reduce disparities. For example, New Mexico advocates noted tensions between newer Hispanic immigrants, primarily from Mexico, and native New Mexicans of Hispanic origin whose families had lived in the state for generations. There can also be tension between legal immigrants and those who are undocumented. A divide was also noted between Native Americans who still live on tribal lands and those who don't. In California and Ohio, interviewees noted collective efforts can be a challenge because organizations working with different racial and ethnic populations may have different agendas. For example, organizations working primarily with Asian populations are more focused on ensuring language access and culturally competent care, while organizations that work with black communities are more focused on the chronic diseases and outcomes that disproportionately affect blacks. Both California (CPEHN) and Massachusetts (DAN) advocates have sought to bridge these differences by identifying and focusing on common issues and goals.

Lack of meaningful, consistent, current data. There is broad agreement that good data is essential to identifying vulnerabilities and making the case for targeting resources appropriately. Ideally state governments, through their health departments, Medicaid programs, or health planning agencies would be the principal collectors and analysts of data, and that is the case in most of the study states. There are differences, however, among the types of data collected, and the resources and rigor that are applied to the task. These differences may stem from budgetary constraints, or they could be related to political preferences. It may be that in some cases, independent policy institutes, like the Mississippi Health Policy Institute, are the best mechanism for producing reliable data and analysis.

> "If you are from outside the community, your own agenda needs to take a back seat. Talking to community leaders and conducting qualitative research before beginning a project is an important way to develop the critical relationships that are essential to the project's success."

Externally imposed agendas. Many of those interviewed commented that too often, people from outside the community, – i.e. funders, research institutions, academics, government officials, or others – dictate what health disparities issues should be addressed and how. This is perceived as disempowering and also as a recipe for failure since it will be more difficult to get community buy-in. Community engagement requires genuine community participation from the outset.

Political structures. Several interviewees also identified challenges that may or may not be susceptible to change, but that can hamper disparities reduction efforts. They include term limits and decentralized public program administration. With respect to term limits, advocates say it takes time to bring elected officials up to speed on complex issues like health disparities, and once they've become educated, their terms are up, and the education process has to start over again with the new officeholder. On program administration, some states like Ohio and New Mexico give governmental subdivisions like counties significant authority to administer Medicaid and health care safety net programs. Depending on the political inclinations of the local power structure, this can affect the resources and attention that are paid to issues like health disparities that may arise in the context of those programs.

Geographic challenges. All of the study states present geographic challenges to health equity work. The bulk of work appears to take place in urban areas, although most of the study states have rural areas with significant rates of disparities and limited public transportation. This makes organizing difficult, and it also hampers rural resident participation. In California, for example, activity is concentrated in Los Angeles and the San Francisco area, although the Central Valley is a large region with a growing minority population and substantial poverty. In Mississippi, some of the most significant disparities are found in the Delta, a vast and relatively remote rural area. Even in Massachusetts, there is a divide between those operating in the eastern and western parts of the state.

Part 4: Recommendations

Across all of the study states, the amount and breadth of disparities reduction initiatives is growing, along with the depth of commitment to achieving health equity. There are many local advances and some statewide achievements. But there are also many challenges. While this was a limited study, our familiarity with health equity and health access work in other locations suggests that what we found may well be the norm across the country. At national and regional convenings of health equity advocates that we sponsored in the last two years, many of the same issues arose. We have also heard related concerns as we worked in 40 states with state consumer health advocates on community issues.

The magnitude and persistence of disparities in the six study states and the country as a whole suggests that a more coordinated and more sweeping strategy is needed. While a full range of tactics should be deployed, more emphasis needs to shift to policy advocacy – at the local, state, or federal level – which is the best means of securing the broadest, most sustainable change. Community-based organizations are integral to this effort because for such change to be both meaningful and effective, it must be rooted in the community and involve community residents.

What can be done, then, to strengthen and lift the work of these organizations and foster their leadership of system change? In addition, since state policymaking is such an important part of system change, how can state advocacy groups increase their engagement in health equity work and develop respectful collaborations with community-based organizations? And how can funders facilitate these advances?

The ongoing implementation of national health care reform lends urgency to these questions. Health care reform will extend health insurance to millions of people of color, expand primary care services and foster diversity in the health workforce. It also authorizes national quality and prevention initiatives, including some aimed at the social and economic determinants of health. Strong engagement from community groups is essential to ensuring these initiatives meet the needs of communities of color. In an earlier study of consumer health advocacy in 16 states,[7] we identified six organizational capacities as key to building the power necessary for effective advocacy at any governmental level. They are the ability to:

- analyze complex legal and policy issues in order to develop winnable policy alternatives that will attract broad support
- design and implement media and other communications strategies to build timely public and political support for an issue and to weaken opposition arguments
- develop and implement issue campaigns
- build a strong grassroots base of support
- build and sustain strong broad-based coalitions and maintain strategic alliances with other stakeholders
- generate resources – from diverse sources – for infrastructure and core functions, as well as for campaigns

We also noted that it is unrealistic to expect most community-based organizations to have expertise in each of these capacities, although it is important for them to understand the universe of skills essential to effective advocacy. We suggested that an alternative approach is to develop *systems* of advocacy. In an advocacy system, the complementary capacities of different organizations are knit together to create a coherent whole. Advocacy is a shared task, with each participant bringing its skills to the table.

While originally conceived as an approach to expand consumer health advocacy, this model has gained currency in other realms and could be applied to a broad-based effort to promote health equity. We propose five strategies for building systems of advocacy – with minority-led and minority-focused community organizations at their core – that could develop and advance a health equity policy agenda.

Strategy 1. Build and strengthen community-based organizations

An initial step is to build solidarity and power among community-based health equity organizations so that their concerns capture the attention and their abilities command the respect of their potential allies. We propose the following steps:

- ***Identify existing health equity work.*** It is important to learn about disparities reduction activity already underway at both the community and state levels. A survey similar to the one used for this report is a useful mechanism for extracting this information. It can serve as a window into the unique issues that face people of color in a particular geographic environment, and it provides an opportunity for the organizations to identify their organizational strengths and challenges.

- ***Facilitate connections among community-based organizations.*** The limited coordination – or even information sharing – we found is largely attributable to the lack of resources and infrastructure that enable communication and coordination. When organizations are brought together, the energy and excitement that comes from sharing strategies and discussing the potential for collective work is palpable. A cohesive group of organizations with a similar focus is better positioned to participate in an advocacy system on equal footing with other participants. To build that cohesion, they need support to develop the necessary infrastructure.

- ***Build organizational capacity.*** In our survey, community-based groups identified fundraising, communications and policy analysis as weaknesses. Even within a system of advocacy, they will need help building these skills to ensure they thrive. Fundraising skills, in particular, are essential to organizational survival. In addition, the groups need stronger ability to craft messages to connect with the general public, as well as members of their own communities. They also need to build their policy knowledge, their ability to identify opportunities to move policy forward, their connections with policymakers and their legislative advocacy skills.

- ***Foster leadership development.*** Community-based organizations exist because community members have stepped forward to address problems facing their family, friends and neighbors. Many of these local leaders need training to equip them to assert the needs, interests and concerns of their community constituents within an advocacy system and on a larger stage. In the coming policy debates, those leaders will also be called on to understand the policymaking arena and its demands, and communicate that and other policy-related information to their constituents. They will also need honed skills in developing partnerships and bridging differences among and between racial and ethnic groups with different interests and agendas. This may require training to address racism in all its forms.

Needs identified by community-based groups

Type of Support	Most Needed	Somewhat Needed
Fundraising assistance and support	76%	17%
Communications support	61%	32%
Organizational and staff development	57%	29%
Advice on effective policy strategies	54%	39%
State and federal policy analysis and updates	52%	41%
Coalition building support	45%	41%
Legal analysis	39%	36%

Funders can play a key role in implementing this strategy. For example, they can conduct or underwrite the initial environmental assessment. They also can provide the support necessary to organize and facilitate convenings of community-based organizations in a particular state, and ensure that concrete plans are in place for follow-up. Funders can offer support for trainings on the less-developed capacities, to enhance organizational expertise and connect community-based groups to the policy advocacy process. Funders can directly support policy advocacy by minority-led community-based organizations and extend funding for the longer periods necessary for systemic change. Finally, they can support leadership development by funding trainings.

Strategy 2. Encourage statewide health access groups to prioritize equity work

A second step is for statewide health access groups to address the barriers that have kept their memberships predominantly white, their activities generally weak on health equity, and their relationships with community-based disparities groups sparse and strained. Many of these organizations are beginning to understand that to fulfill their mission of quality health care for all, they must encourage and enable disenfranchised communities to advocate for their own needs and to help craft a health delivery system that meets those needs. That requires not only diversifying the consumer health advocacy movement, but extending the focus to new areas and supporting the work and goals of disparities-focused organizations. (In states where consumer health advocacy groups do not exist, these groups can be fostered, or other organizations may provide expertise in statewide policy advocacy.)

To make this shift, we propose that health access advocates take the following steps:

- ***Deepen and broaden their understanding of health equity issues.*** Many lack knowledge about the causes and possible avenues to address health disparities. Yet they have the skills to develop this knowledge by studying available research and by establishing new relationships with national, state and local policy experts, public health officials, and other groups working on these issues. Learning about the role structural and institutional racism play in health inequities, and addressing attitudinal racism will be an important part of this work. Statewide advocates can then share their knowledge with other organizations and with the public through accessible handouts and policy papers.

- ***Learn from community-based organizations.*** These relationships can begin with the access advocates attending community meetings or seeking out one-on-one conversations to listen and learn. Engaging with respect for differences and establishing two-way sharing of information is crucial. The relationships are likely to help statewide advocates value the strengths of community-based organizations.

- ***Diversify their leadership and staff.*** As statewide organizations develop their knowledge base and build relationships with disparities-focused community groups, they may find it easier to attract more diversity to their own ranks. Their new connections may introduce them to potential candidates, and their new knowledge and respectful manner may make them more welcoming. Even organizations with little money for new staff may be able to take on graduate fellows or interns, who may in turn become future community leaders.

- ***Develop funded partnerships with individual community-based groups.*** Statewide advocacy groups may have better access to larger funders with interest in supporting joint work between statewide and community-based organizations. Sharing resources is a key way to build strong connections, especially when the result is activities or educational materials that are jointly planned and carried out. These partnerships will prepare both community-based groups and health access groups for working together in larger coalitions.

Funders can help by sponsoring conferences that connect advocates to health disparities experts. They can sponsor anti-racism training that includes institutional and structural racism. They can also condition project funding on outreach to and partnership with community-based groups.

Strategy 3. Build coalitions of community-based groups and statewide and national organizations

A key step in building a system of advocacy is to connect organizations, networks and coalitions that have similar interests and goals – natural allies. Bridging the gap that currently exists between many community-based health disparities groups and statewide advocacy organizations requires both types of organizations to understand how coming together can be mutually beneficial. This will be more evident when community-based organizations come to the table with stronger capacities and leadership, and when access advocates come with more knowledge of health equity and the crucial role that community-based organizations play.

In our study, community-based organizations rated coalition building and grassroots organizing/mobilizing as their strengths, and fundraising, communications, and policy analysis as their weaknesses. In our previous assessments of health access advocacy capacity, the self-identified capacity strengths and weaknesses were reversed (with the exception of fundraising, which was universally identified as an area of weakness).

Community-based organizations can also provide valuable input, direction and leadership to statewide advocates on policy priorities that further common goals. For example, based on direct experience, health equity-focused community organizations may view a robust supply of community health workers as key to mitigating disparities and improving access. Access advocates may not fully appreciate the importance of this provider role without that input. Working hand-in-hand, they might be able to develop and promote policy solutions that expand this segment of the workforce and provide for reimbursement.

There are other important benefits to collaboration. Because they are operating on the ground, community-based organizations are particularly well-positioned to demonstrate the impact of health system shortcomings and socioeconomic inequities on the lives of individuals and families. The ability to present these stories in a compelling way at the right time is key to building the public and political momentum for action.

To work together effectively, community-based organizations and statewide advocacy groups will also need to acknowledge their differences in values, mission and approach. They will need to learn to bridge those differences over time through respectful discussion, openness and a search for common ground on issues or goals.

To build a robust statewide effort, it will also be essential to connect both community-based organizations and statewide health advocacy groups with statewide organizations working on health equity. These groups bring a depth of issue knowledge and experience that is invaluable.

In light of the current volume of high-stakes federal activity, it is also important to ensure that community-based groups are connected with national organizations engaged in health equity advocacy. Community-based organizations have much to share about what works from a policy perspective and where public dollars might best be targeted. But some of those interviewed said their contacts with national organizations have been episodic and not always collaborative. (Interestingly, state access advocates have made similar observations about national access-focused organizations.) To facilitate development of more consistent and stable relationships, community-based organizations must be provided with the skills and infrastructure to ensure that they are treated as equal partners by these organizations, and not simply included when the organizations need to demonstrate that they have community representation.

Funders can play an important role in fostering these connections. They can underwrite facilitated convenings of the organizations, initially to build trust and subsequently to plan joint work. They also can make substantial funding commitments to health equity-related projects or programs jointly developed by local and state-based organizations, leveraging resources that will be made available through implementation of federal reform and through the National Partnership for Action. To address historical concerns about resource and power imbalances among various groups, they can condition project funding on development and demonstration of collaborations in which both resources and decision-making are shared.

Strategy 4. Connect to other stakeholders

Our study also found that connections and collaborations between community-based organizations and other key disparities-focused stakeholders, including government agencies, academic researchers and policy institutes, are not as strong as they might be.

These disconnects mean valuable opportunities to promote system change never arise. All of these interests could – and should – be recruited to a system of advocacy focused on promoting a health equity agenda.

Funders can facilitate better communication, planning and organizational reciprocity in a few ways. First, they can sponsor regular opportunities for the parties to come together, share information about their respective activities, develop mechanisms for ongoing consultation about research topics and design, devise effective ways to disseminate research results, and develop and promote policy agendas. Second, and as suggested in connection with the prior strategy, funders can condition their support of policy institutes and research institutions on the development of genuine partnerships with community-based organizations, and also with other system participants, as appropriate. Government funders can support stronger connections between state offices of minority health and community-based and statewide organizations working on health equity.

Strategy 5. Develop a disparities reduction/health equity policy agenda

The new health reform law contains numerous measures that have the potential to reduce health disparities and promote health equity through changes in the health care system. Critical areas include Medicaid expansion and outreach, extension of hospital community benefit requirements, the availability of primary care services, the diversity and cultural competency of the health care workforce, and the targeting of quality and prevention goals. It will be essential for community-based and statewide advocates to participate in policy decisions and carefully monitor implementation so that the law fulfills its promise. But the law leaves many without coverage, only begins delivery system reform, and contains few provisions to address the social determinants of health. This leaves much work to be done.

Funders can support the development and promotion of a policy agenda that integrates health system reform and work on social and economic determinants of health. They can also support engagement of community-based advocates and their systems of advocacy in pursuing this agenda.

Conclusion

Despite the limited coordination, funding challenges, and primarily local nature of disparities reduction efforts to date, there is much to be hopeful about. Public and policymaker awareness of racial and ethnic health disparities is on the rise, and programmatic attention at the federal level is greater than it has ever been. At the state and community levels, there are numerous smart and dedicated activists who would like to take their work to new levels. Across the country, a number of academic institutions are engaged in cutting-edge research that could lead to significant improvements in health outcomes. The convergence of all these factors suggests *this is the time* to invest in building systems of advocacy – with community needs and interests at their core – that will lead to meaningful and durable policy change. We have sequenced a set of recommendations for doing that, and suggested ways in which funders can champion the effort. Success in this undertaking will move us substantially closer to the ideal of a society whose health system serves all its members equitably.

Endnotes

[1] Kate Meyers. Issue Brief: Racial and Ethnic Health Disparities. Kaiser Permanente Institute for Health Policy. 2007.
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http://www.convergencepartnership.org/site/c.fhLOK6PELmF/b.3917533/k.BDC8/Home.htm

[3] Consumer Health Advocacy: A View from 16 States, Community Catalyst, Boston, MA. October 2006.
http://www.communitycatalyst.org/doc_store/publications/consumer_health_advocacy_a_view_from_16_states_oct06.pdf

[4] We defined an organization as minority-led if 50 percent or more of the staff and board of directors are minorities. We defined an organization as minority-focused if its mission and charitable programs aim to predominantly serve and empower minority communities or populations.

[5] Health Through Action. http://www.wkkf.org/knowledge-center/resources/2010/Health-Through-Action-Partnership-Program-Brochure.aspx

[6] California Convergence. http://californiaconvergence.org/

[7] Consumer Health Advocacy: A View from 16 States, Community Catalyst, Boston, MA. October 2006.
http://www.communitycatalyst.org/doc_store/publications/consumer_health_advocacy_a_view_from_16_states_oct06.pdf

Appendix A: State Health Equity Profiles

California Health Equity Profile

Political, social and economic environment

- Majority minority state
- Strong community of health equity advocates helped secure landmark legislation that requires all health plans to provide linguistically appropriate services
- Attempt to pass comprehensive state health care reform failed in 2006
- More than $2 billion in cuts statewide to health and human services in 2009 eliminated coverage and benefits in public programs that serve many people of color. The governor has proposed additional deep cuts this year.

Key data

Total population*

Total Population	White	Black	Hispanic	Asian	American Indian/ Alaskan Native
California 36,961,664	42%	7%	37%	13%	1%
United States 307,006,550	66%	13%	15%	5%	1%

**If a group is less than one percent of the total population, they are not listed in tables.*
Source: US Census Bureau, State and County Quick Facts, 2010

Urban versus rural population

- 94 percent of Californians live in urban areas
- The six percent that live rurally include approximately equal numbers of racial and ethnic minorities and whites

People living in poverty

Percent living below poverty level	Total	White	Black	Hispanic	Asian	American Indian/ Alaskan Native
California	13%	8%	20%	19%	10%	17%
United States	13%	9%	25%	21%	11%	25%

Source: US Census Bureau, 2006-2008 American Community Survey

Education

Percent whose highest level of education is high school degree/GED	Total	White	Black	Hispanic
California	43%	42%	50%	NA*
United States	39%	35%	48%	55%

**Data not available*
Source: Behavioral Risk Factor Surveillance Survey (BRFSS), 2008

Direct barriers to health care access

Lack of insurance among nonelderly population

Total number of uninsured	Total percent of population uninsured	White	Black	Hispanic
California 6,610,000	20%	12%	18%	30%
United States 45,693,300	17%	13%	21%	32%

Source: Kaiser State Health Facts, 2007-2008

Language and provider access

- 20 percent of Californians speak English less than very well, compared to nine percent in the United States[1]
- Two of California's 58 counties face shortages of primary care providers; two face shortages of dental care providers; and 22 face shortages of mental health care providers[2]

Health Disparities

- Blacks die from preventable diseases at a significantly higher rate than all other populations
- Fewer Hispanics and Asians die from cancer and heart disease

Disease Indicator	California						Total United States
	White	Black	Hispanic	Asian/ Pacific Islander	American Indian/ Alaskan Native	Total	
Diabetes deaths per 100,000	17	43	37	17	26	21	25
Cancer deaths per 100,000	194	245	128	127	116	179	196
Heart disease deaths per 100,000	243	339	178	146	157	230	247
Infant mortality per 1,000	5	12	5	3	6	5	7

Sources: Disease Indicators are from The Burden of Chronic Disease, Department of Health and Human Services, 2004
Infant Mortality is from Annie E. Casey Foundation, Kids Count Data Center, 2006

[1] *US Census Bureau, 2006-2008 American Community Survey*

[2] *Health Resources and Services Administration, Geospatial Data Warehouse, 2009*

Massachusetts Health Equity Profile

Political, social and economic environment

- Lowest rate of uninsured residents in the nation – just 3 percent, due to a major coverage expansion passed in 2006
- Much of the state's economy is tied to the health care system, with more than a dozen academic medical centers and over 100 hospitals
- A large number of community-based organizations work to reduce health disparities in Massachusetts. Community groups work on a mix of improvements to health care access and social determinants of health.
- Addressing health disparities is a high priority for the governor, the secretary of Health and Human Services, the state legislature, the Boston Public Health Commission and the mayor of Boston

Key data

Total population*

Total Population	White	Black	Hispanic	Asian
Massachusetts 6,593,587	79%	7%	9%	5%
United States 307,006,550	66%	13%	15%	5%

**If a group is less than one percent of the total population, they are not listed in tables.*
Source: US Census Bureau, State and County Quick Facts, 2010

Urban versus rural population

- 91 percent of people in Massachusetts live in urban areas
- Of those who live in rural areas, 96 percent are white

People living in poverty

Percent living below poverty level	Total	White	Black	Hispanic	Asian
Massachusetts	10%	7%	20%	29%	14%
United States	13%	9%	25%	21%	11%

Source: US Census Bureau, 2006-2008 American Community Survey

Education

Percent whose highest level of education is high school degree/GED	Total	White	Black	Hispanic
Massachusetts	33%	30%	44%	59%
United States	39%	35%	48%	55%

Source: Behavioral Risk Factor Surveillance Survey (BRFSS), 2008

Direct barriers to health care access

Lack of insurance among nonelderly population

Total number of uninsured	Total percent of population uninsured	White	Black	Hispanic
Massachusetts 337,600	6%*	6%	NA**	NA**
United States 45,693,300	17%	13%	21%	32%

**More recent data from the MA Division of Health Care Finance and Policy report that the total percent of uninsured is 3%, white 2%, black 4%, and Hispanic 5% in 2009.*
*** Data not available*
Source: Kaiser State Health Facts, 2007-2008

Language and provider access

- Nine percent of Massachusetts residents speak English less than very well, the same as the national average[1]
- Two of Massachusetts' 14 counties face shortages of primary care providers, and two face shortages of dental care providers[2]

Health Disparities

- Blacks die from preventable diseases at a higher rate than whites in Massachusetts
- Fewer Hispanics and Asians die of cancer and heart disease than whites

Disease Indicator	Massachusetts					Total United States
	Whites	Black	Hispanic	Asian/ Pacific Islander	Total	
Diabetes deaths per 100,000	20	45	27	21	20	25
Cancer deaths per 100,000	203	214	119	101	199	196
Heart disease deaths per 100,000	213	230	129	82	210	247
Infant mortality per 1,000	4	8	6	NA*	5	7

**Data not available*
Sources: Disease Indicators are from The Burden of Chronic Disease, Department of HHS, 2004
Infant Mortality is from Annie E. Casey Foundation, Kids Count Data Center, 2006

[1] *US Census Bureau, 2006-2008 American Community Survey*
[2] *Health Resources and Services Administration, Geospatial Data Warehouse, 2009*

Michigan Health Equity Profile

Political, social and economic environment

- Hard hit by the recession due to its car manufacturing base; highest unemployment rate in the country – over 14 percent in March
- One of the most concentrated Arab American communities in the country, concentrated near Detroit
- Among the first states to pass legislation (Public Act 653, 2006) specifically aimed at reducing racial and ethnic disparities in health, requiring monitoring and public reporting
- Deep cuts to health and human services are placing racial and ethnic minorities at risk

Key data

*Total population**

Total Population	White	Black	Hispanic	Asian
Michigan 9,969,727	78%	14%	4%	2%
United States 307,006,550	66%	13%	15%	5%

**If a group is less than one percent of the total population, they are not listed in tables.*
Source: US Census Bureau, State and County Quick Facts, 2010

Urban versus rural population

- 75 percent of the population lives in urban areas
- 98 percent of blacks and 95 percent of Asians live in urban areas

People living in poverty

Percent living below poverty level	Total	White	Black	Hispanic	Asian
Michigan	14%	10%	30%	25%	12%
United States	13%	9%	25%	21%	11%

Source: US Census Bureau, 2006-2008 American Community Survey

Education

Percent whose highest level of education is high school degree/GED	Total	White	Black	Hispanic
Michigan	38%	36%	42%	53%
United States	39%	35%	48%	55%

Source: Behavioral Risk Factor Surveillance Survey (BRFSS), 2008

Direct barriers to health care access

Lack of insurance among nonelderly population

Total number of uninsured	Total percent of population uninsured	White	Black	Hispanic
Michigan 1,126,000	13%	11%	20%	24%
United States 45,693,300	17%	13%	21%	32%

Source: Kaiser State Health Facts, 2007-2008

Language and provider access

- Three percent of Michiganders speak English less than very well, compared to nine percent of people in the United States[1]
- 10 of Michigan's 83 counties face shortages of primary care providers; two face shortages of dental providers; and 22 face shortages of mental health care providers.[2]

Health Disparities

- Blacks and American Indians die from preventable diseases at a much higher rate than whites, while for Hispanics, the picture is mixed
- Asians fare better than all other groups

Disease Indicator	Michigan					Total United States
	Whites	Black	Hispanic	Asian	Total	
Diabetes deaths per 100,000	25	41	42	NA*	27	25
Cancer deaths per 100,000	195	243	127	98	199	196
Heart disease deaths per 100,000	263	372	174	100	274	247
Infant mortality per 1,000	6	15	11	NA*	7	7

**Data not available*
Sources: Disease Indicators are from The Burden of Chronic Disease, Department of HHS, 2004
Infant Mortality is from Annie E. Casey Foundation, Kids Count Data Center, 2006

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[1] *US Census Bureau, 2006-2008 American Community Survey*

[2] *Health Resources and Services Administration, Geospatial Data Warehouse, 2009*

Mississippi Health Equity Profile

Political, social and economic environment

- Highest percentage of black residents – 37 percent of the population – in the nation
- Political establishment views public programs as a burden and has shown little interest in health equity
- Only state to require Medicaid beneficiaries to meet face-to-face with state officials every six months to prove they are still eligible
- Nearly one-third of the population lives in areas with primary care shortages

Key data

Total population*

Total Population	White	Black	Hispanic
Mississippi 2,951,996	59%	37%	2%
United States 307,006,550	66%	13%	15%

**If a group is less than one percent of the total population, they are not listed in tables.*
Source: US Census Bureau, State and County Quick Facts, 2010

Urban versus rural population

- Nearly half of Mississippians live in urban areas
- 57 percent of whites and 42 percent of blacks live in rural areas

People living in poverty

Percent living below poverty level	Total	White	Black	Hispanic
Mississippi	21%	12%	36%	23%
United States	13%	9%	25%	21%

Source: US Census Bureau, 2006-2008 American Community Survey

Education

Percent whose highest level of education is high school degree/GED	Total	White	Black	Hispanic
Mississippi	48%	41%	61%	15%
United States	39%	35%	48%	55%

Source: Behavioral Risk Factor Surveillance Survey (BRFSS), 2008

Community Catalyst

Direct barriers to health care access

Lack of insurance among nonelderly population

Total number of uninsured	Total percent of population uninsured	White	Black	Hispanic
Mississippi 532,000	21%	15%	26%	49%
United States 45,693,300	17%	13%	21%	32%

Source: Kaiser State Health Facts, 2007-2008

Language and provider access

- Only one percent of Mississippians speak English less than very well, compared to nine percent of persons in the United States[1]
- 52 of Mississippi's 82 counties face shortages of primary care providers, and 54 face shortages of dental care providers[2]

Health Disparities

- Blacks die from preventable diseases at a significantly higher rate than whites

Disease Indicator	Mississippi			Total United States
	Whites	Black	Total	
Diabetes deaths per 100,000	18	41	24	25
Cancer deaths per 100,000	204	255	216	196
Heart disease deaths per 100,000	312	383	329	247
Infant mortality per 1,000	7	15	11	7

Sources: Disease Indicators are from The Burden of Chronic Disease, Department of Health and Human Services, 2004 and Infant Mortality is from Annie E. Casey Foundation, Kids Count Data Center, 2006 (Not sufficient data for other ethnicities)

[1] *US Census Bureau, 2006-2008 American Community Survey*
[2] *Health Resources and Services Administration, Geospatial Data Warehouse, 2009*

New Mexico Health Equity Profile

Political, social and economic environment

- Majority minority state and home to the second-largest population of American Indians in the nation
- Recent state government commitment to reduce health disparities
- Second highest uninsurance rate in the nation
- Severe provider shortages, including only one tertiary hospital statewide

Key data

*Total population**

Total Population	White	Black	Hispanic	Asian	American Indian/ Alaskan Native
New Mexico 2,009,671	42%	3%	45%	1%	10%
United States 307,006,550	66%	13%	15%	5%	1%

**If a group is less than one percent of the total population, they are not listed in tables.*
Source: US Census Bureau, State and County Quick Facts, 2010

Urban versus rural population

- 75 percent of New Mexico residents live in urban areas
- Almost 60 percent of American Indians live in rural areas

People living in poverty

Percent living below poverty level	Total	White	Black	Hispanic	Asian	American Indian/ Alaskan Native
New Mexico	18%	11%	24%	22%	8%	31%
United States	13%	9%	25%	21%	11%	25%

Source: US Census Bureau, 2006-2008 American Community Survey

Education

Percent whose highest level of education is high school degree/GED	Total	White	Black	Hispanic
New Mexico	43%	24%	41%	69%
United States	39%	35%	48%	55%

Source: Behavioral Risk Factor Surveillance Survey (BRFSS), 2008

Direct barriers to health care access

Lack of insurance among nonelderly population

Total number of uninsured	Total percent of population uninsured	White	Black	Hispanic
New Mexico 446,200	26%	18%	NA*	30%
United States 45,693,300	17%	13%	21%	32%

**Data not available*

Note: Data from the 2005 Insure New Mexico! Council report that 28% American Indians are uninsured.
Source: Kaiser State Health Facts, 2007-2008

Language and provider access

- 10 percent of New Mexico residents speak English less than very well, compared to nine percent in the United States.[1]
- Two of New Mexico's 58 counties face shortages of primary care providers, two face shortages of dental care providers, and 22 face shortages of mental health care providers.[2]

Health Disparities

- Blacks die from preventable diseases at a higher rate than all other populations.

Disease Indicator	New Mexico						Total United States
	White	Black	Hispanic	Asian/ Pacific Islander	American Indian/ Alaskan Native	Total	
Diabetes deaths per 100,000	21	NA*	46	NA*	83	31	25
Cancer deaths per 100,000	175	249	148	NA*	170	167	196
Heart disease deaths per 100,000	209	261	194	NA*	186	203	247
Infant mortality per 1,000	6	NA*	6	NA*	5	6	7

**Data not available*
Sources: The Burden of Chronic Disease, Department of Health and Human Services, 2004
Infant Mortality is from Annie E. Casey Foundation, Kids Count Data Center, 2006

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[1] *US Census Bureau, 2006-2008 American Community Survey*
[2] *Health Resources and Services Administration, Geospatial Data Warehouse, 2009*

Ohio Health Equity Profile

Political, social and economic environment

- First state to establish state agency on minority health
- Governor Ted Strickland has made health a priority, increasing coverage, launching a quality improvement initiative and convening an infant mortality task force. Health equity is one of three core programs in his Healthy Ohio initiative.
- Home rule policy gives county or local governments much of the decision-making power over health policy
- Tied for the fifth highest black infant mortality rate in the nation

Key data

Total population*

Total Population	White	Black	Hispanic	Asian
Ohio 11,542,645	83%	12%	3%	2%
United States 307,006,550	66%	13%	15%	5%

**If a group is less than one percent of the total population, they are not listed in tables.*
Source: US Census Bureau, State and County Quick Facts, 2010

Urban versus rural population

- 77 percent of Ohioans live in urban areas
- 26 percent of white and 23 percent of American Indian Ohioans live in rural areas

People living in poverty

Percent living below poverty level	Total	White	Black	Hispanic	Asian
Ohio	13%	10%	30%	24%	11%
United States	13%	9%	25%	21%	11%

Source: US Census Bureau, 2006-2008 American Community Survey

Education

Percent whose highest level of education is high school degree/GED	Total	White	Black	Hispanic
Ohio	43%	42%	50%	NA*
United States	39%	35%	48%	55%

**Data not available*
Source: Behavioral Risk Factor Surveillance Survey (BRFSS), 2008

Community Catalyst

Direct barriers to health care access

Lack of insurance among nonelderly population

Total number of uninsured	Total percent of population uninsured	White	Black	Hispanic
Ohio 1,304,900	13%	12%	16%	32%
United States 45,693,300	17%	13%	21%	32%

Source: Kaiser State Health Facts, 2007-2008

Language and provider access

- Two percent of Ohioans speak English less than very well, compared to nine percent in the US[1]
- 11 of Ohio's 88 counties face shortages of primary care providers; one faces a shortage of dental care providers; and five face shortages of mental health care providers[2]

Health Disparities

- Blacks die from preventable diseases at a higher rate than all other populations
- Hispanics and Asians, overall, fare better than whites

Disease Indicator	Ohio					Total United States
	Whites	Black	Hispanic	Asian/ Pacific Islander	Total	
Diabetes deaths per 100,000	29	55	27	NA*	31	25
Cancer deaths per 100,000	205	263	118	111	208	196
Heart disease deaths per 100,000	267	328	135	95	271	247
Infant mortality per 1,000	6	17	4	NA*	8	7

**Data not available*
Sources: The Burden of Chronic Disease, Department of Health and Human Services, 2004
Infant Mortality is from Annie E. Casey Foundation, Kids Count Data Center, 2006

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[1] *US Census Bureau, 2006-2008 American Community Survey*

[2] *Health Resources and Services Administration, Geospatial Data Warehouse, 2009*

Appendix B: People Interviewed

California

Organization **Name of interviewee*** **City or town**	**Type of organization**	**Type of work**	**Target population or area**
Asian Health Services *Dong Suh* Oakland	Provider	Direct service	Asian & Pacific Islanders
California Immigrant Policy Center *Reshma Shamasunder* Sacramento	Policy institute	Advocacy	Low-income immigrants
California Office of Multicultural Health Sacramento	Government		Communities of color
California Pan-Ethnic Health Network *Ellen Wu* Oakland	Disparities coalition	Advocacy	Communities of color
California Partnership *Mari Lopez* Los Angeles	State advocacy group	Advocacy	Communities of color
California Rural Indian Health Board *Mark LeBeau* Sacramento	Network of tribal health plans	Direct service, education, advocacy	American Indians
Community Health Councils *Lark Galloway-Gilliam* Los Angeles	Community-based organization	Advocacy	Blacks
Greenlining Institute *Hector Preciado* Berkeley	Policy institute	Education	Vulnerable populations
Health Access California *Anthony Wright* Sacramento	State advocacy group	Advocacy	Vulnerable populations
The Health Justice Network *Scott Chan* Los Angeles	Community-based organization	Education, advocacy	Asian & Pacific Islanders
Korean Resource Center *Dae Joong Yoon* Los Angeles	Community-based organization	Advocacy	Low-income Koreans
Latino Coalition for a Healthy California *Al Hernández-Santana* Sacramento	Disparities coalition	Advocacy	Latinos
Latino Health Access *Ana Carricchi* Santa Ana	Community-based organization	Advocacy, direct service	Latinos

California continued

PICO California *Rebecca Stark* Sacramento	State advocacy group	Advocacy	Vulnerable populations
Prevention Institute *Rachel Davis* Oakland	Policy institute	Advocacy	United States
The California Endowment *Marion Standish* Los Angeles	Funder		

Massachusetts

Organization Name of interviewee* City or town	Type of organization	Type of work	Target population or area
African Community Health Initiatives *Anne Medinus* Boston	Community-based organization	Outreach, advocacy	Africans
Alternatives for Community and Environment *Eugene Benson* Boston	Community-based organization	Advocacy	Low-income communities of color
Blue Cross Blue Shield of Massachusetts Foundation *Phillip O. Gonzalez* *Miriam Messinger* Boston	Funder		
Boston Public Health Commission *Meghan Patterson* Boston	Government		Boston focus, also statewide
Center for Community Health Education Research and Service (CCHERS) *Elmer Freeman* Boston	Community-based organization	Advocacy	Boston neighborhoods
Critical MASS *Kerone Anderson* Boston	Community-based organization	Advocacy, organizing, training	Lawrence, Fitchburg, Springfield
Department of Public Health Office of Health Equity *Georgia Simpson May* *Sam Lewis* *Diane Hagan* Boston	Government		State residents
Disparities Action Network *Camille Watson* Boston	Disparities coalition	Policy advocacy	State residents

Massachusetts continued

Disparities Solutions Center *Joseph Betancourt* Boston	Policy institute	Research, evaluation	Medical centers and their communities
Haitian Health Institute *Michele David* Boston	Community-based organization	Education, outreach, advocacy	Haitians
Henry Lee Willis Center *Keesha LaTuillipe* Worcester	Community-based organization	Social services	Worcester
International Medical Interpreters Association *Izabel Arocha* Boston	Professional association	Professional support, advocacy	Medical interpreters
Latin American Health Institute *Robert Pomales* Boston	Community-based organization	Advocacy, direct service	Latinos in Eastern Massachusetts
Massachusetts Asian and Pacific Islanders for Health *Jacob Smith Yang* Boston	Community-based organization	Advocacy, outreach, education	Asian & Pacific Islanders
Massachusetts Association of Community Health Workers *Cindy Marti* *Lisa Renee Holderby* Boston	Professional association	Professional support, advocacy, education	Community health workers statewide
Massachusetts Immigrant and Refugee Advocacy Coalition (MIRA) *Eva Millona* Boston	Disparities coalition	Advocacy	Immigrants and refugees
Partners for a Healthier Community *Frank Robinson* Springfield	Community-based organization	Advocacy	Springfield
Universal Community Voices Eliminating Disparities *Betty Agin* Springfield	Community-based organization	Advocacy, education, organizing	Springfield
UTEC (United Teen Equality Center) *Gregg Croteau* Lowell	Community-based organization	Organizing, outreach, education, safe space for youth	Lowell youths

Michigan

Organization Name of interviewee* City or town	Type of organization	Type of work	Target population or area
Detroit and Michigan NAACP *Yvonne White* Detroit	State advocacy group	Legal advocacy	Blacks
Inter-Tribal Council of Michigan *Richard Haverkate* Sault Ste. Marie	Government		American Indians
Kresge Foundation *Phyllis Meadows* Troy	Funder		
Metro Health Foundation *Randy Walainis* Detroit	Funder		
Michigan Health Disparities/ Minority Health Section, Department of Community Health *Sheryl Weir* Lansing	Government		Minorities statewide
Michigan League for Human Services *Karen Holcomb-Merrill* Lansing	State advocacy group	Advocacy, policy research	Statewide minority populations
Michigan Minority Health Coalition *Othelia Pryor* East Lansing	Disparities coalition	Advocacy	Racial and ethnic minorities
Michigan Public Health Institute *Jeffrey Taylor* Okemos	Policy Institute	Research	State residents
MichUHCAN *Marjorie Mitchell* Livonia	State advocacy group, in development	Advocacy	State residents
Migrant Health Promotion *Tori Booker* Saline	Community-based organization	Health promotion, advocacy	Migrant workers
Parish Nurse Program Kalamazoo	Provider	Direct care, advocacy	Minority populations in Michigan churches
School-Community Health Alliance *Deborah Riddick* Lansing	State advocacy group	Advocacy	Statewide minority populations
Voices of Detroit Initiative *Lucille Smith* Detroit	Organization of providers	Direct care, advocacy	Blacks

Mississippi

Organization Name of interviewee* City or town	Type of organization	Type of work	Target population or area
Community Outreach for Health Awareness *Elloris Cooper* Jackson	Community-based organization	Education, direct service	Underserved
Delta Citizens Alliance *Larry Williams* Greenville	Community-based organization	Education, advocacy	Vulnerable populations in Delta regions in Louisiana, Arkansas, and Mississippi
Delta Health Alliance *Anna Lyn Whitt* Stoneville	Community-based organization	Education, research	Underserved in Delta region
Foundation for the Mid South *Necole Irvin* Jackson	Funder		
Get One Check One Block Program *Margaret Davis* Jackson	Community-based organization	Education, direct service	Underserved
Jackson Medical Mall Foundation *Dr. Aaron Shirley* Jackson	Community-based organization	Education, direct service	Underserved in Jackson
Mississippi Bower Foundation Ridgeland	Funder		
Mississippi Health Advocacy Program *Jacquelyn Agho* Jackson	State advocacy group	Policy analysis, advocacy	Statewide vulnerable populations
Mississippi State Department of Health Office of Health Disparity Elimination *Dr. Lovetta Brown* Jackson	Government		Vulnerable populations
Mississippi Urban League *Willie Cole* Jackson	State advocacy group	Education, direct service	Low-income in Jackson
Unity Health Services *Melinda Todd* Jackson	Community-based organization	Direct service	Underserved in Jackson

New Mexico

Organization Name of interviewee* City or town	Type of organization	Type of work	Target population or area
Albuquerque Community Foundation *Randall Royster* Albuquerque	Funder		
Albuquerque Health Care for the Homeless *Jennifer Metzler* Albuquerque	Provider	Direct service, advocacy	Homeless statewide
Bernalillo County Off-Reservation Native American Health Commission *Roxane Spruce Bly* Albuquerque	Government		
New Mexico Center on Law and Poverty *Kim Posich* Albuquerque	State advocacy group	Legal services, policy advocacy	Low-income populations
Con Alma Health Foundation *Dolores Roybal* Santa Fe	Funder		
Community Coalition for Health Care Access *Alma Olivas* Albuquerque	Community-based organization	Advocacy	Immigrants, non-English speakers and the uninsured.
Concilio Campesino del Sudoeste *Josefina Mata* Las Cruces	Community-based organization	Organizing, advocacy	Racial and ethnic minorities of Doña Ana County
Enlace Comunitario *Claudia Medina* Albuquerque	Community-based organization	Domestic violence direct service, advocacy	Immigrant women
Health Action New Mexico *Roxane Spruce Bly* *Barbara Webber* Albuquerque	State advocacy group	Policy analysis, advocacy, education	Uninsured and underinsured statewide
Health Disparities Workgroup *Kristine Suozzi* Albuquerque	Disparities coalition	Education, advocacy	Racial and ethnic minorities statewide
McKinley Community Health Alliance *Ophelia Reeder* Gallup	Government		Racial and ethnic minorities in McKinley County
New Mexico Voices for Children *Bill Jordan* Albuquerque	State advocacy group	Policy analysis, advocacy	Low-income children
Office of Health Equity, New Mexico Department of Public Health *Paul Romero* Albuquerque	Government		Racial and ethnic minorities statewide

New Mexico continued

SouthWest Organizing Project *Marjorie Childress* Albuquerque	Community-based organization	Organizing	Low-income racial and ethnic minorities
St. Joseph Community Health Albuquerque	State advocacy group	Advocacy, health education	Children
Southwest Tribal Tobacco Coalition *Natalie Thomas* Laguna	State advocacy group	Policy advocacy	American Indians
University of New Mexico Hospital, Office of Community Affairs *Leah Steimel* Albuquerque	Provider	Direct service	New Mexicans

Ohio

Organization Name of interviewee* City or town	Type of organization	Type of work	Target population or area
Asian Community Alliance *Bo-Kyung Kim Kirby* Cincinnati	Community-based organization	Education, direct service	Asians in greater Cincinnati
Asian Services in Action, Inc. *Michael Byun* Akron & Cleveland	Community-based organization	Direct service, education, policy advocacy	Asian Americans and Pacific Islanders in Northeastern Ohio
Center for Closing the Health Gap *Dwight Tillery* Cincinnati	Community-based organization	Outreach, education	Minority and underserved populations in greater Cincinnati
Case Center for Reducing Health Disparities at Case Western Reserve University *Dr. Ashwini Sehgal* Cleveland	Policy institute	Research, education, program evaluation	Greater Cleveland
Center for Health Equity, Cleveland State University *Peter Whitt* Cleveland	Policy Institute	Research, education	Greater Cleveland
Center for Latin Hope *Gianella Martinez* Columbus	Community-based organization	Direct service, education	Latinos in Franklin County
City of Refuge, Point of Impact *YoLanda S. Lewis* Columbus	Community-based organization	Education, outreach, prevention	Low-income residents in greater Columbus
Health Policy Institute of Ohio *Tim Sahr* *Lisa Frazier* Columbus	Policy institute	Research, education	Ohio residents

Ohio continued

Latino Outreach and Empowerment Network *Ivette Diaz* *Nora Hesse* Columbus	Community-based organization	Education, direct service, policy advocacy	Latinos in Central Ohio
Minority Health Alliance *Kristina Austin* Cleveland	Community-based organization	Education, outreach, referrals	Underserved populations in Cuyahoga County
Minority Health Roundtable *Dietrich Evege* *Edward Demond Scott* Akron	Community-based organization	Policy advocacy, education, research	Minority populations in Summit County
Multiethnic Advocates for Cultural Competence *Charleta Tavares* Columbus	Disparities coalition	Education, research, policy advocacy	Vulnerable populations statewide
Ohio Commission on Minority Health *Cheryl Boyce* Columbus	Government		Minority populations statewide
Ohio Community Health Workers Association *Jewel Bell* Kettering & Dayton	Professional association	Education, policy advocacy	Community health workers
Ohio Hispanic Coalition *Josue Vicente* *Jesus Ovalle* Columbus	Community-based organization	Education, policy advocacy, direct service	Latinos in central Ohio
Ohio Latino Health Coalition *Mary Isa Garayua* Youngstown	Disparities coalition	Education, outreach	Latinos statewide
Ohio Statewide Health Disparities Collaborative *Ronald Browder* *Megan Davis* Columbus	Disparities coalition	Policy advocacy, clearinghouse	Underserved communities statewide
Somali Community Access Network *Jibril Hirsi* Columbus	Community-based organization	Direct service, education, policy advocacy	Somali refugees in central Ohio
The Hispanic Health Committee of the Hispanic Roundtable *Jessica Verbic* Cleveland	Community-based organization	Education, outreach	Latinos in greater Cleveland
UHCAN – Ohio *Cathy Levine* Cleveland, Columbus & Cincinnati	State advocacy group	Policy advocacy, education	State residents

** Interviewees not listed by name requested anonymity*

Appendix C:

Telephone Interview Protocol

During 2009 and early 2010, Community Catalyst staff and consultants conducted in-depth telephone interviews with leaders of 96 organizations and institutions in the six states that are the focus of this report. The majority of the questions about their work on health care disparities or health equity were the same, with some variation based on the type of organization. Below is a compilation of the different questionnaires we used; we have outlined when additional questions were used with specific groups.

Primary questionnaire used in more than half of the interviews (those conducted with minority-led, minority-focused, or other community-based organizations, as well as statewide groups focusing on health advocacy or health disparities)

Your organization and its work

1. What is the mission of your organization?

2. Who are the members of your organization or its primary constituency?

   a. How do they play a role in decision-making?

   b. How do you involve community members in your organization?

3. Would you define your organization as minority-led and focused, in that your staff and board of directors is 50 percent or more minority, and your mission statement and charitable programs aim to predominantly serve and empower minority communities or populations?

   a. If not, would you describe your organization as minority-focused? One whose mission and goals primarily focus on direct engagement and outreach to racial and ethnic minority communities or populations?

   b. If your organization is neither minority-led or minority-focused, to what extent does your organization ever specifically focus on ethnic minority communities or populations?

4. How does your organization define "health disparities?"

5. Does your organization address racial and ethnic disparities in health?

   a. If not, why not?

   b. If yes, what issues is your organization working on? Please be as specific as possible.

      - For ______ what programs and activities do you use?
      - For ______ what programs and activities do you use?
      - For ______ what programs and activities do you use?

6. If yes, does your organization focus its health disparities work on a specific part of the population? Please explain.

7. For your health disparities efforts, are you working at the local level? State level? National level? How does your work at these levels differ?

8. What successes or milestones has your organization achieved in addressing racial and ethnic health disparities? Please describe in detail.
    a. How did you achieve that success?
    b. What strengths of your group and your community also helped you to make progress?
9. What has made it difficult to accomplish your goals related to reducing racial and ethnic health disparities or slowed down your progress?
    a. What strategies has your organization developed, if any, to deal with those obstacles?
10. What support, assistance, or resources do you need to make your work related to reducing health disparities more effective and increase its impact?
11. What non-disparities health-related issues are addressed by your organization?
    a. At what level (local, state, or national)?
    b. What are your goals on these issues?

Other groups and your work with them

12. What other organizations, government agencies, policy institutes, universities or health care institutions have you worked with on health disparities?
13. Are there groups addressing health disparities that you are not interested in working with? Why not?
14. Have you worked with (the main health access group in your state)?
    a. If yes, on what specific issues? How did the collaboration go?
    b. If no, why not?
    c. Are they working on health disparities?
15. Have you worked with national groups on disparities? Which ones? How did it go?
16. How did some of your best collaborations start?
    a. If you were to give other groups advice about building relationships, what would you say?
17. Is there any assistance or resources that would help you further build your network of collaborators?
18. Who funds your racial and ethnic disparities work? Who funds this work for other groups?
19. Are funders focusing on the right efforts in reducing racial and ethnic disparities?
20. Who else would you like to see working to reduce racial and ethnic health disparities in your community and state?

Beyond your group

21. What health disparities issues have received attention in your state?
    a. Of these issues, which ones receive the most attention and why?
22. Overall, are there signs of progress in reducing racial and ethnic health disparities in your community and state, or an increase in awareness of the problem? Please explain.
    a. What led to that progress?
    b. Who are the champions who helped move the issues forward?

23. Have there been unsuccessful attempts to address racial and ethnic health disparities in your community and state? Please explain.
    a. What led to those failures?
    b. What or who were the roadblocks and challenges?
    c. Are there groups or agencies already working on disparities that could be more effective? If yes, what would make them more effective?
24. What other activities or programs need to take place locally, statewide, and nationally to reduce or eliminate racial and ethnic health disparities?

Additional questions specific to interviews with government offices, policy institutes, universities or think tanks

1. Overall, are there signs of progress in reducing racial and ethnic health disparities in your community and state, or an increase in awareness of the problem? Please explain.
    a. What led to that progress?
    b. Who are the champions who helped move the issues forward?
    c. What was your organization's role?
2. In your view, how effective are community organizations at influencing policy and promoting health disparities efforts in your state?
    a. How coordinated are their efforts with other community groups?
    b. How coordinated are they with stakeholders, including academics, providers, foundations, government agencies?
    c. How can their work be strengthened?
    d. Are there any groups that are particularly effective?
    e. What direct support do you provide community groups?
3. What recent (last two years) or pending policy changes have affected racial / ethnic health disparities in your state?
4. Please give me an overview of your office's programs and activities.

Additional questions specific to interviews with government offices

1. What direct support do you provide community groups?
2. Compared to other states, are you ahead, behind or on a par in your work on disparities? Is there anything about your state that makes it particularly difficult or easy to address health disparities?
    a. What strategies do you think can make it easier?
3. When was your office established?
4. Does your office have specific priority issues or focuses with regard to health disparities?
5. What non-financial supports, if any, do you provide to organizations other than community groups?
6. Do you get funding from sources other than the state budget?

Additional questions specific to interviews with policy institutes, universities or think tanks

1. Are there features of your state that make it harder or easier to engage health disparities?
    a. What strategies do you think can make it easier?
2. Do you have priority issues in the area of racial and ethnic health disparities? Please be as specific as possible.
3. What community groups have you worked with? How did those collaborations start?

Additional questions specific to interviews with funders

1. Does your foundation take direct action on health disparities issues? If so, what are some examples of roles the foundation has played?
2. Does your foundation have specific priority issues or focuses with regard to health disparities?
3. Does your foundation focus on a specific part of the population when addressing the issue of health disparities?
4. For your health disparities efforts, are you funding organizations at the local level? Regional? State level? How does your funding at these levels differ?
5. What successes or milestones has the foundation achieved in addressing racial and ethnic disparities? Please describe in detail.
    a. How did you achieve that success?
6. What has made it difficult to get your goals accomplished or slowed down your progress?
7. Does the foundation encounter internal or external challenges in supporting consumer- and community-based advocacy efforts and groups in their efforts to eliminate disparities? If so, how would you describe them?
8. Are funders focusing on the right efforts in reducing racial and ethnic disparities?
9. Is funding for health disparities work going to the right organizations and right issues?
10. What do you think would help increase involvement and support for consumer-based racial disparities advocacy from your foundation and/or other foundations?

Appendix D:

Online Survey

Community Catalyst developed the following online survey. We contacted community-based and state advocacy organizations that we had interviewed for the report and asked them to take the survey. Forty of the 48 organizations completed the survey.

Six State Disparities Report

Part A: Organizational Infrastructure

1. Your State:

2. Please provide the name, organization and title for the person completing this survey. In addition, please provide your email and phone number.

3. How long has your organization been in operation?

☐ Less than 1 year
☐ 1-2 years
☐ 3-5 years
☐ 6-8 years
☐ 9-11 years
☐ 12-14 years
☐ 15 years or more

4. How many full-time equivalent employees (FTEs) does the organization have?

☐ Volunteer staff only
☐ 1-3
☐ 4-6
☐ 7-9
☐ 10-12
☐ 13-15
☐ More than 15

5. How many of those employees are working on racial and ethnic health disparities?

☐ Volunteer staff only
☐ 1-3
☐ 4-6
☐ 7-9
☐ 10-12
☐ 13-15
☐ More than 15

6. Approximately how much is your organization's annual budget?

☐ Less than $25,000
☐ $25,000 to less than $50,000
☐ $50,000 to less than $100,000
☐ $100,000 to less than $200,000
☐ $200,000 to less then $300,000
☐ $300,000 to less than $500,000
☐ $500,000 to less than $750,000
☐ $750,000 to less than $1 million
☐ $1 million or more

7. If you work on issues in addition to health (housing, education, employment), what percentage of your work is devoted to health?

☐ Less than 20%
☐ 21-40%
☐ 41-60%
☐ 61-80%
☐ More than 80%
☐ 100%

8. What percentage of your organization's work on health is devoted to reducing racial and ethnic health disparities?

☐ Less than 20%
☐ 21-40%
☐ 41-60%
☐ 61-80%
☐ More than 80%
v100%

Part B: Your organization's strengths and strategies

9. How would you rate your organization's capacity in the following areas?

	Strong capacity	Some capacity	Do not do this
Grassroots organizing/mobilizing	☐	☐	☐
Coalition-building	☐	☐	☐
Media relations	☐	☐	☐
Policy research and analysis	☐	☐	☐
Lobbying and legislative advocacy	☐	☐	☐
Fundraising and development	☐	☐	☐

10. Which of these strategies has your organization used in its work to reduce health disparities?

	Major strategy	Minor strategy	Not used
Grassroots community organizing/mobilizing	☐	☐	☐
Research and writing reports	☐	☐	☐
Community outreach and education	☐	☐	☐
Lobbying to change laws or policies	☐	☐	☐
Education of hospitals, doctors and other care providers	☐	☐	☐
Media campaigns	☐	☐	☐
Direct service (health screenings, case management)	☐	☐	☐
Forming coalitions	☐	☐	☐
Other (please specify):			

11. What factors have helped YOUR organization make progress toward its goals on health disparities?

	Major factor	Minor factor	Not a significant factor
Involvement of funders	☐	☐	☐
Staff commitment and dedication	☐	☐	☐
Involving the community	☐	☐	☐
Gaining community trust	☐	☐	☐
Collaborations with other organizations (groups, universities, institutes)	☐	☐	☐
Support from hospitals and other health care providers	☐	☐	☐
Support from politicians	☐	☐	☐
Support from government officials	☐	☐	☐
Effective policy strategies	☐	☐	☐
Other (please specify):			

12. What factors have made it difficult to accomplish YOUR organization's goals on health disparities?

	Major factor	Minor factor	Not a significant factor
Lack of funding	☐	☐	☐
Staff and organizational issues	☐	☐	☐
Competing priorities within your organization	☐	☐	☐
Your organization's lack of knowledge about disparities and what causes them	☐	☐	☐
Difficulties building strong collaborations/coalitions	☐	☐	☐
Lack of time	☐	☐	☐
Ineffective policy strategies	☐	☐	☐
Racism	☐	☐	☐
Lack of community involvement or trust	☐	☐	☐
State or local politics	☐	☐	☐
Lack of available medical services	☐	☐	☐
Lack of interest from hospitals and other health care providers	☐	☐	☐
Powerful opponents	☐	☐	☐
Other (please specify):			

13. What support would help YOUR organization achieve its goals on health disparities?

	Help a lot	Help somewhat	Not a significant need
State and federal policy analysis and updates	☐	☐	☐
Advice on effective policy strategies	☐	☐	☐
Communications support	☐	☐	☐
Legal analysis	☐	☐	☐
Fundraising assistance and support	☐	☐	☐
Coalition-building support	☐	☐	☐
Organizational and staff development	☐	☐	☐

Part C: Other groups working on health disparities in your state

14. Considering the work of other groups and institutions as well as your own, has there been progress toward addressing and/or eliminating racial and ethnic disparities in health in your state?

☐ Yes
☐ No

15. Focusing now on OTHER organizations, institutes and government agencies in your state working on racial and ethnic health disparities, (excluding your own organization), what factors have enabled them to make progress in addressing health disparities?

	Major factor	Minor factor	Not a significant factor
Involvement of funders	☐	☐	☐
Involvement of the community	☐	☐	☐
Community trust	☐	☐	☐
Collaborations with other groups, universities and institutes	☐	☐	☐
Support from hospitals and other health care providers	☐	☐	☐
Support from politicians	☐	☐	☐
Support from government officials	☐	☐	☐
Effective policy strategies	☐	☐	☐
Strong leadership	☐	☐	☐
Other (please specify):			

16. Focusing on OTHER organizations, institutes and government agencies in your state working on racial and ethnic health disparities, (excluding your own organization), what factors have made it difficult for them to make progress?

	Major factor	Minor factor	Not a significant factor
Lack of funding	☐	☐	☐
Staff and organizational issues	☐	☐	☐
Lack of community involvement or trust	☐	☐	☐
Competing priorities or agendas among groups	☐	☐	☐
Racism	☐	☐	☐
Lack of diverse workforce	☐	☐	☐
The public's lack of knowledge about disparities and what causes them	☐	☐	☐
Difficulty of addressing social determinants of health such as education and housing	☐	☐	☐
Difficulties building strong collaborations/coalitions	☐	☐	☐
Lack of time	☐	☐	☐
Ineffective policy strategies	☐	☐	☐
State or local politics	☐	☐	☐
Lack of available medical services	☐	☐	☐
Lack of interest from hospitals and other health care providers	☐	☐	☐
Powerful opponents	☐	☐	☐
Other (please specify):			

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