

From the Ground Up:

Grassroots Perspectives on Philanthropic
Support for Health Reform

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Support for Health Reform

Consumers Union of United States, Inc.

Acknowledgments

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The survey on which this report is based was created by a team from Consumers Union that included Chuck Bell, Elena Chavez, Betsy Imholz, Lauren Sobel, and Lauren Zeichner. Diana Bianco, a health policy consultant, assisted in drafting the survey and wrote the report, with significant assistance from Chuck Bell and Betsy Imholz. Mark Kotkin of the Consumer Reports National Research Center provided keen insights and suggestions on survey technique and framing. Follow-up telephone interviews with health advocates in selected locations were conducted by Diana Bianco, Chuck Bell, and Betsy Imholz. Lauren Zeichner and Evaluz Barrameda compiled the databases of survey recipients and tracked the responses. Layout and design credit goes to Evaluz Barrameda. Carolina Rivas Pollard provided able production support.

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Consumers Union is a nonprofit membership organization chartered in 1936 under the laws of New York State to provide consumers with education, information and counsel about goods, services, health and personal finance; and to initiate and cooperate with individual and group efforts to maintain and enhance the quality of life for consumers. Consumers Union is the nonprofit publisher of Consumer Reports, Consumer Reports.org, and Consumer Reports onHealth, with a combined paid circulation of nearly 8 million subscribers. Consumers Union's publications carry no outside advertising and receive no commercial support.

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Foreward

Health reform is in the wind. In each state, community groups and consumer advocates are spearheading campaigns and creating coalitions to shape health policy. These substantial efforts run the gamut from stopping cuts to Medicaid budgets, to organizing coalitions for comprehensive health reform, to improving health care safety and fighting medical debt. Resource-strapped nonprofits, though, are at an obvious financial disadvantage compared to other stakeholders in the system. From year to year, many nonprofit advocacy groups struggle to find the funds to hire, train, and retain experienced staff to work.

Keeping up on policy developments and engaging in analysis and research demand dedicated, knowledgeable staff. And running effective health campaigns can be expensive. Resources are needed for messaging expertise, travel, printing campaign materials, conference calls that hold a coalition together, and web sites to get information out to the public and policymakers -- to take just a few examples.

Foundations have been, and continue to be, essential supporters of community-driven health care organizing. Without their grantmaking, much of the consumer engagement and advocacy work to date would not have happened. But taking these successes to scale requires an even greater commitment. Our challenge is to go both deeper -- building capacity for grassroots organizations and policy networks -- and wider -- by including more consumer voices representing diverse population segments. All kinds of foundations -- family, community, national, local, "conversion" foundations -- can make a significant contribution.

The truth is, our current national and state health care policymaking environments are riven with special interest money and commercial agendas. Grassroots participation in state-based health reform and the upcoming national debate on health system change cannot only help to improve the health care system, it can also help foster a more inclusive and vibrant democracy.

With support from the Ford Foundation, Consumers Union surveyed community groups and consumer advocates from around the nation to learn from them about their successes and challenges in working to improve our health care system, and their experiences in seeking foundation funding to do so. Their frank and thoughtful responses are summarized in this report. Their concrete suggestions can pave the way for even more responsive philanthropic practices.

We hope this report serves as a springboard to conversation between foundations and the communities they serve; among foundations; and among nonprofits with each other. Ultimately, we also hope it will result in action -- greater openness between foundations and potential grantees; higher philanthropic priority on funding state and local groups to engage in public education and health advocacy; and grants that build state and local consumer organizations' capacity to initiate and achieve major health system improvements.

The growing experience of community advocates with new health foundations, and some recent national foundation initiatives, suggest a possible trend in this direction. We intend for this report to support that trend for a promising new direction in philanthropic accountability and responsiveness.

James A. Guest
President and CEO
Consumers Union of United States, Inc.

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“I think this is the key challenge we face -- bringing foundations into the idea of what advocacy is, getting them comfortable with it, and getting them to make an investment. The biggest thing that seems to make them comfortable is if they’ve done it before – so taking the first steps is key.”

“The truth is, we can’t write project grants ahead of time that really outline all the challenges and opportunities we face in any given year. Issues come up quickly and someone needs to be there to convene the group and mount a response. Funders tend to focus on issue-specific initiatives and measurable gains, which leads to all these ‘high-impact, signature projects.’ They should recognize that effective health advocacy requires a bedrock infrastructure, a secure base from which to defend, build and consolidate our gains.”

“Some grant officers understand the importance of consistent funding over time. They also understand that policy is not made by waving a magic wand...Policy gains are only made by slugging it out in the trenches with well-heeled opponents. Multi-year, general operating support grants are critical. General operating support grants enable a funder to view the work of the grantee over time, develop a long-term relationship to demonstrate the outcomes and impact of their funding, and to demonstrate the potential of collaborative funding from multiple like-minded funders.”

Introduction

Calls are ringing out across the nation to fix our broken health care system. There is growing momentum to create a system that delivers better health care to more Americans at a reasonable cost. From state capitols to presidential campaigns, from corporate boardrooms to union offices, diverse voices are demanding reform. Proposals for system change are moving through state legislatures, and in some states, such as Massachusetts and Maine, health reform is underway. Strong majorities of Americans fear rising health care costs and say they want guaranteed health care for all. And health reform is a priority for every presidential contender.

Foundations are crucial to system reform. Philanthropic organizations provide resources for advocacy, research, policy analysis, collaboration, communication, and many other strategies to advance the health care debate and support policy change. With the momentum for reform comes a more pressing need and opportunity for foundations to leverage their resources to foster change and support organizations working for it.

To help realize this opportunity, Consumers Union, with support from the Ford Foundation, surveyed nonprofit organizations that engage in health advocacy and policy work about their experiences with foundations. We conducted an online survey and heard from 117 health policy organizations in 37 states. We also interviewed more than a dozen advocates who had responded to the survey for more in-depth discussion. In reporting the results, we offer a collective perspective from advocates on the ground in almost every state about their experiences seeking foundation funding for policy change in the health arena.

A number of organizations which focus on the activities of foundations, including Independent Sector, the Alliance for Justice, and the National Committee for Responsive Philanthropy have addressed philanthropic efforts to fund social change -- sometimes referred to as “social justice philanthropy”-- in fields including health, the environment, civil rights, and education reform. This report complements their discussions and provides a particular perspective-- that of the grantee working for policy change in the health arena.

When Consumers Union embarked on this endeavor, we did not know how willing advocates would be to discuss their experiences seeking funding for health reform. Among competing demands for attention, would this inquiry warrant the time required to answer? Would recipients not participate in the survey for fear of retribution for speaking frankly about their experiences?

We assured recipients that their input would not carry attribution. More than 20% of organizations we contacted responded to the survey. The response demonstrates that nonprofits were eager to share their experiences, both the positive and the problematic, with foundation funding of health policy and advocacy. The passion conveyed in the survey responses and interviews shows that the hunger for health reform and for constructive partnerships with funders -- and the need for resources -- runs deep and wide.

Many advocates have collaborated productively with foundations for years on policy change, and numerous policy successes would not have been possible without the support of the philanthropic sector. The organizations we heard from appreciate the foundations that fund health work. At the same time, we heard frustration and concern about how dollars are, or are not, allocated to fundamentally change a health care system that is fragmented, costly, and does not meet the needs of so many consumers, especially the most vulnerable.

This report seeks to increase dialogue among funders, foster conversations among grant applicants, and improve communication between funders and grantees. The report first summarizes the amount and distribution of health funding in the United States and provides background about the need for systemic reform in the health care system and the role of nonprofits in making change. After describing our methodology, we summarize our findings and make recommendations for next steps. Appended is the entire set of responses to the query that evoked the largest outpouring of ideas: "If you could be a confidential advisor to foundations that fund health-related programs and projects, what advice would you give them?"

To also give the reader the flavor of the responses throughout the report, we have included a significant number of direct quotes from respondents. To protect the anonymity of the many respondents who continue to rely on foundation support, the report does not provide attribution for quotes, nor does it identify specific organizations or foundations. Instead, the report highlights common themes from the people on the ground working to revamp the health care system to meet consumer needs. Our hope is that over the coming year, with health reform at the top of the domestic agenda, the philanthropic sector will seize the opportunity to engage potential grantees in determining how best to support the kinds of local, state and national efforts, as reflected in these survey responses, to achieve consumer-friendly, comprehensive health care reform.

“Systemic change—the only answer to the healthcare crisis—will not occur without [foundation] support.”

“Our best experience comes from foundations that feel we’re impacting those most in need with programs and services that will institute long-term change.”

“I would like to think that in a democracy, foundations would lift up the voices of those who have little or no voice in decisionmaking. But I’m not sure if they see this as their role or responsibility.”

“There’s a big disparity in grant seeking resources between big healthcare institutions and community groups. Some of these groups don’t have any fundraising staff – it’s the same front line advocates that are raising the money AND doing the work. Foundations need to recognize that it’s the small community groups and the advocacy groups and coalitions who really need grant support. If they don’t get it, the community won’t have a voice.”

Background

Health funding

Foundations target a significant amount of resources to the health field¹ – health ranks second only to education in total foundation giving in the United States. Between 2002 and 2005, the health field benefited from the fastest annual rate of growth in philanthropic giving. According to the Foundation Center, in 2005, grant dollars directed to health totaled approximately \$3.42 billion.² More than half of the grants (54.6%) went to program support³ or specific projects. Research grants accounted for the second largest share (22.9%). Sixteen percent of grants were for capital support, while general support accounted for 10.8% of grant dollars. See Figure 1.

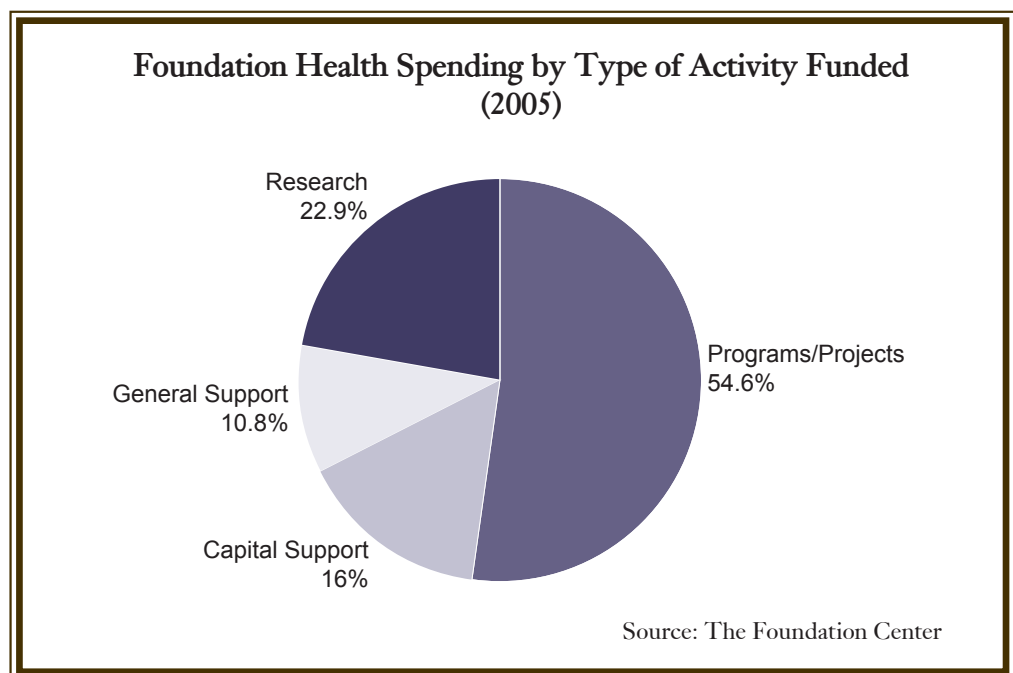


Figure 1.

The Foundation Center also breaks out philanthropic giving into subject matter categories. In 2005, the smallest percentage of health dollars was directed to policy and management (2%), though this figure captures only a portion of policy-related grantmaking by foundations.⁴ About a quarter of dollars directed to health funded hospitals and medical care (26%). Public health and medical research received slightly less (22% and 21% respectively). Fourteen percent of dollars went to specific diseases, while mental health received seven percent. Both reproductive health care and other general rehabilitative efforts each received four percent of grant dollars. See Figure 2.

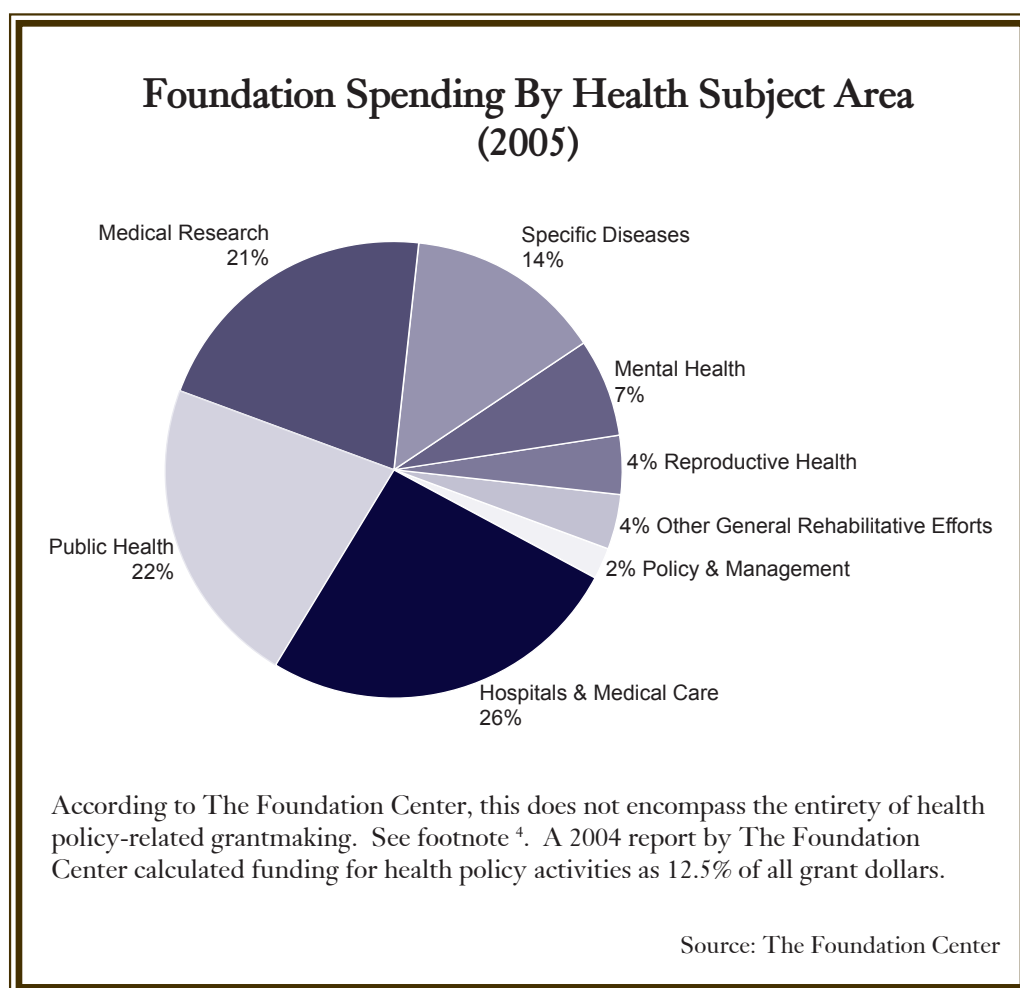


Figure 2.

An earlier 2004 Foundation Center report provides more detail about philanthropic support for health policy work. According to that report, in 2002 health policy activities accounted for 12.5% of all health grant dollars.^{5, 6} Further, between 1995 and 2002, the amount of philanthropic funding for health policy activities tripled from under \$100 million to almost \$360 million, while the number of philanthropies making health policy grants increased by more than half.⁷ Some of this increase is certainly attributable to the creation of “conversion foundations”

over the past decade. These foundations are formed with the assets preserved when a nonprofit health plan or hospital converts to a for-profit corporation.⁸ Health care cost, quality, and reform accounted for the largest share of health policy giving in 2002, followed by health care access.⁹

The rise in funding for and attention to health and health policy activities is heartening.¹⁰ And as more foundations have become interested in funding health policy work, Grantmakers in Health along with a number of foundations have provided guidance and input to health funders.¹¹ At the same time, the data highlights the lack of substantial funding for health policy work. Twelve percent of health grant dollars seems inadequate to initiate and sustain long-term health system change. Medical research, hospitals, and capital needs all are worthy of support. But the relatively low level of funding for health policy activities limits significant and widespread health system change.

The case for health reform in the United States

While increasing philanthropic dollars have been targeted to health, the needs have continued to grow. The World Health Organization has rated the U.S. health care system near the bottom of industrialized nations. The deficiencies in the U.S. health system are significant:

Lack of insurance coverage

At least 46 million Americans lack health insurance coverage, and millions more are underinsured. Among industrialized nations, the U.S. spends the highest percentage of its Gross Domestic Product on health care, yet it is the only country that fails to assure comprehensive health coverage for all people who are living and working here. In 2002, the Institute of Medicine estimated that more than 18,000 people die prematurely each year because they don't have health insurance coverage.¹²

Poor access to care

Many people living in the U.S. have difficulty obtaining access to needed care. A shrinking supply of primary care physicians and a lack of infrastructure in many communities means that even people who have insurance may not be able to find a provider. Many primary care doctors are retiring and the replacement pipeline is inadequate: the United States trains a smaller percentage of primary care providers than other industrialized nations.¹³

Health disparities

The Commonwealth Fund recently documented the prevalence of economic disparities in health and found that lower-income Americans were much more likely than their counterparts in other countries to report not getting needed care or tests, not filling a prescription, or not seeing a dentist when needed because of costs.¹⁴

Racial disparities in health also continue to plague the United States. Compared to whites, people of color have higher incidences of chronic diseases, higher mortality, and poorer health outcomes. On average, whites live more than 5.5 years longer than African Americans. African Americans die from stroke 41% more often than whites; from heart disease 30 % more often; and from cancer 25% more often. Compared with white adults, African Americans are 50% more likely, and Hispanics are 60% more likely, to have diagnosed diabetes.¹⁵

Unsafe and poor quality care

Unsafe and poor quality care affects the entire population, with low-income and minority patients often at higher risk. An estimated two million individuals suffer from hospital-acquired infections each year, leading to nearly 90,000 deaths. As many as 44,000 to 98,000 people die in hospitals each year as the result of medical errors. Even using the lower estimate would make medical errors the eighth leading cause of death in this country – higher than motor vehicle accidents (43,458), breast cancer (42,297), or AIDS (16,516). Sixteen percent of consumers report that they or a family member were the victim of a medication error, with over 20% resulting in a serious problem.¹⁶

“[Nonprofit organizations] provide critical vehicles for advocacy and civic action, ensuring a free and open ‘civil society’ in which different groupings of individuals can make their views known in the policy process at both the national and local levels. Nonprofit organizations are in this sense ‘empowering’ institutions, providing a mechanism for joint action on behalf of even the least well-represented groups or views.”²⁰

*From Lester Salamon,
American’s Nonprofit
Section: A Primer*

Given the myriad systemic problems plaguing the U.S. health care system, well-funded and coordinated reform efforts are critical.

Social justice philanthropy

Funding health reform falls under a larger rubric of funding social change work, sometimes referred to as “social justice philanthropy.” During the past decade, a number of organizations, including foundations and associations of funders, have described the challenges foundations face in funding systemic and structural change, not only in health, but also in economic and community development, civil rights and civil liberties, educational reform, and housing.

In 2005, Independent Sector and The Foundation Center summarized the perspectives of a cross-section of foundations about social justice grantmaking and provided a comprehensive study of social justice philanthropy.¹⁷ The report discussed the challenges of

defining social justice grantmaking, described trends in specific areas, summarized funder perspectives, and profiled twenty-six foundations. Also in 2005, the National Committee for Responsive Philanthropy (NCRP) issued the results of a survey of foundations about social justice philanthropy and its challenges, with the goal of encouraging philanthropic institutions to re-think their approaches.¹⁸ Both of these reports offered the perspective of funders and made recommendations for increasing social justice philanthropy.

The role of nonprofit advocacy groups in health system change

Like foundations, nonprofit advocacy organizations play an important role in organizing and propelling movements for social change. They are an instrument for achieving collective goals, and a means for expressing community views and shared social values. In the health arena, nonprofit advocacy organizations are responsible for much of the progress made in the last decade in increased access to care, insurance reform, and improvements in health quality. They have worked in a variety of ways -- through direct service delivery, counseling and referral, policy analysis, research, advocacy, and legal services. Their role in the ongoing effort to improve the health of all Americans cannot be overestimated.

Despite their important role, the capacity of nonprofit health care organizations to represent their communities is strained by many factors related to inadequate resources. The overwhelming influence and resources of large institutional players such as insurance companies, drug companies, hospitals and physicians can drown out the voice of smaller, less financially secure nonprofits. Limited dollars available for policy work hinder the ability of nonprofits to make change. And regional disparities in funding mean some groups are significantly under-resourced in the places that need the most help.¹⁹

Strategies for change

Health advocacy organizations influence policy through multiple strategies. Those who have worked on health reform for decades know that there is no boilerplate recipe for successful policy change. In fact, policy and advocacy may be viewed as a continuum encompassing activities as diverse as legal research, surveys of the public, report writing, neighborhood house parties, television appearances and public testimony.

For this survey and report, we considered the full continuum of policy work including:²¹

- Research and analysis
- Community organizing
- Polling
- Issue framing and messaging
- Media advocacy
- Public education and information campaigns

- Stakeholder engagement
- Coalition building
- Developing educational materials for opinion leaders and policymakers
- Lobbying
- Litigation
- Evaluation

The variety of activities gives foundations leeway to vary their funding strategies, depending upon their mission, vision, and priorities. All of these activities are necessary to identify the policy problem, get community input and support, build public pressure, find solutions, and advocate for change. But funding even one or two of these activities can still make a significant impact.²²

For example, a multi-faceted funding strategy supported a nascent consumer coalition for California health reform in 2007.²³ Funded activities included:

- Staff and equipment, including cameras, to gather consumer health insurance stories;
- Support for work with small business allies;
- Web site development and outreach;
- Staff and travel money to support inclusion of communities of color in the larger consumer coalition;
- House parties to build public awareness and promote consumer engagement;
- Leadership training for local consumer leaders;
- Media training for organizers.

This funding allowed the It's our Healthcare! Coalition to grow to over 100 member organizations, to engage in policy analysis, and to sustain itself through a prolonged battle. Although a key reform bill was defeated in January 2008, the relationships and expertise built over a year of funded activity leaves the coalition well positioned to continue the work on reform. Foundations in other parts of the U.S. have pursued similar multi-pronged funding strategies. These efforts demonstrate that “policy work” can happen in multiple venues at various levels, and that foundations play, and must continue to play, a crucial role in supporting that work.

The Survey

Methodology

We surveyed individuals at organizations that define themselves as working for policy change in the health arena. We created a draft survey based on information gleaned from a variety of reports addressing foundation funding of social justice efforts.²⁴ We refined the instrument based on feedback from a dozen “beta testers” from nonprofit organizations and from the Consumer Reports National Research Center. We emailed the electronic survey to more than 500 individuals and received responses from 117.²⁵

The instructions asked recipients to complete the survey if their organization solicits funds from foundations and works for policy change in the health care arena. For purposes of the survey instructions, policy change was defined as a decision or action by a government official or body (e.g. a budget decision or administrative rule) or by an organization (e.g. a private organization’s decision to change the way it does business) that directly affects people’s lives—getting from “what is” to “what should be.” (See Appendix A for the survey and instructions.)

We used a multi-phase survey strategy that occurred over three months. We first sent an initial email inviting individuals to complete the survey in February 2007. In the first week of the survey, we sent individuals a reminder postcard via mail. Two weeks after the first survey request, we sent a reminder email to the entire list. The third time we emailed the survey, we focused on geographical representation. We grouped the emails by state, specifically telling individuals we wanted to hear more from organizations based in their state. Each time we sent the survey, we offered an incentive to respondents – a free subscription to *Consumer Reports OnHealth* newsletter.

We subsequently gave respondents the opportunity to be listed in this report as survey participants. One-third agreed to have their organization listed, but the vast majority did not agree. To ensure anonymity of respondents, we determined to omit all organizational names.

Following the survey, we conducted in-depth interviews with 14 respondents from ten states in order to gain a deeper understanding of some of the issues raised in survey responses. As well, we sought to clarify some of the divergent opinions expressed in survey responses. We targeted interviews in states where there has been recent activity around health reform: California, Illinois, Maine, Massachusetts, Minnesota, New Mexico, New York, Ohio, Oregon, and Vermont. The results from these interviews are integrated with the survey results, summarized below.

Who responded

We received 117 responses to the survey, from organizations in 37 states.²⁶ (See Appendix B for a map detailing the number of responses from each state.) The vast majority of respondents work to improve access to care (79%) and for comprehensive reform (75%). And nearly all work for changes in health care policy or practices (93%), as opposed to strictly working on research or direct services. Almost all work on the state level (95%). A majority also work on the federal level (72%), with 48% engaging on the local level and more than one-quarter working on corporate campaigns, such as pressuring health plans or hospitals for change.

The majority of organizations that responded to the survey have budgets greater than \$200,000. Forty percent have budgets greater than one million dollars and are more than twenty years old. For many of the responding organizations, funding from national, state, local and regional foundations averaged half of their total budget, though large numbers also have government contracts and grants and receive donations from individuals. A smaller number receive dollars from family foundations and corporate foundations. More than half have received grants from conversion foundations (foundations formed when a nonprofit health insurer or hospital converts to a for-profit entity or changes its nonprofit mission).

Respondents were equally divided between those that focus on a specific segment of the population, such as children or the disabled, and those that serve both the general population and a specific group. Most of those that help a specific group serve people with low-incomes. About half of the organizations surveyed work solely on health issues, while the rest address other issues as well.

The organizations that responded to the survey work on multiple health policy issues. The most common are comprehensive health reform, increasing access to health insurance coverage, and Medicaid. Over 70% of organizational respondents are engaged with these issues. Many also address health quality and patient safety (46%), Medicare (44%), mental health (41%), racial/ethnic/gender disparities (52%), and prescription drugs (49%). A smaller percentage of organizations focus on medical debt, nutrition/obesity, and private insurance reform.

How they do policy work

We asked organizations about the strategies they use to change policy. All affirmed the need for multiple approaches. The top strategies they employ are coalition building (88%) and educating policymakers (82%). Close behind are convening interested organizations (80%), advocating before administrative agencies (80%), issue framing and messaging (79%) and policy analysis (78%). Other popular strategies for survey respondents are public education campaigns (72%), lobbying legislative bodies (71%), media strategy (71%), and report writing and dissemination (70%). More than half of the groups also engage in research (58%), community organizing (51%) and using the Internet for organizing and action (51%). Polling and focus groups, generally expensive undertakings, were used by 37% of the respondents. More than one-quarter used litigation to bring about health care improvements for their constituents.

The organizations surveyed shared with pride many stories of successful policy change they had helped achieve, and the strategies they used to accomplish it. (See Policy Change in Action p. 13) They have increased health insurance coverage for children, expanded prescription drug coverage and addressed the rising costs of pharmaceuticals, improved Medicaid coverage, expanded the safety net, and increased protections for vulnerable populations. Many organizations have engaged in advocacy around state budgets – protecting programs, restoring budget cuts, or supplementing existing budgets to serve more people. Organizations have promoted legislation and worked to halt legislation that would have been harmful to constituencies they serve. And they have engaged in successful campaigns to press hospitals to improve language access and expand charity care.

Policy Change in Action

The organizations we surveyed shared numerous policy success stories. The following partial list demonstrates the breadth and depth of the important work undertaken by these groups.

Medicaid and Medicare

- Worked in collaboration with other advocates to increase Medicaid coverage for low-income seniors, undocumented children, childless individuals, and people with HIV through federal waivers.
- Took the lead within a coalition to reverse cuts to Medicaid and wrote legislation to that end.
- Advocated for changes in administrative procedures to make the state's Medicaid application and renewal more user-friendly.
- Conducted an integrated campaign to reverse Medicaid cuts -- using a qualitative study, grassroots organizing, and legislative advocacy.
- Supported a research effort to examine the consequences of a Section 1115 waiver for Medicaid patients.
- Eliminated the state's Medicaid co-payment requirement.
- Ended door-to-door marketing by Medicaid managed care companies.
- Led a coalition that expanded Medicaid eligibility for parents.
- Stopped Medicaid discrimination by certain hospitals.
- Conducted a survey that received extensive media coverage and helped galvanize opposition to a change in Medicaid law.
- Built a stronger safety net for low-income people and won fairer reimbursement for physicians treating Medicaid patients.

Children's health

- Streamlined the application process for children's health insurance.
- Developed and disseminated a statewide strategic plan for adolescent health.
- Conducted a statewide survey of providers about perceptions of factors affecting low birth weight and poor perinatal outcomes; led to legislative resolution to further study and address these problems.
- Worked successfully to educate business leaders on advocating for health coverage for children.
- Wrote legislation to insure more children.

Prescription drugs

- Successfully advocated for implementation of a safety net program to cover prescription drugs for seniors.
- Conducted research, did media outreach and decisionmaker education, and worked in coalition to raise awareness about prescription drug issues, resulting in a major prescription drug discount program.
- Launched an initiative to allow U.S. citizens to legally and safely purchase prescription drugs through partnership with Canadian pharmacies.

Charity care, community benefits and other hospital policies

- Strengthened charity care policies at local hospitals.
- Campaigned to get hospitals to adopt uniform charity care and improve community benefits.
- Gained passage of a law to prevent hospital overcharging of the uninsured.
- Conducted hospital campaigns to increase language access for people with limited-English proficiency.

Insurance coverage and reform

- Used a bill to get media attention about insurance for low-income residents and to pressure legislators to address the issue.
- Secured passage of state-level reform to establish greater accountability to the public by private insurers.
- Helped pass health insurance reforms, including community rating, guaranteed issuance and renewal, continuity of coverage, travel and access standards, and a patient's bill of rights.
- Conducted town hall meetings in several cities to press local governments for coverage for the uninsured and to keep hospitals serving the poor open.

Other success stories

- Organized a health forum of national, state and local health experts on health care reform.
- Created a network to bring together the public, private and non-profit sectors to eliminate health disparities.
- Enacted legislation to require reporting of adverse medical events.
- Organized consumers and health care providers to work together to pass one of the first state health care consumer bill of rights.
- Helped prevent a nonprofit health plan conversion that could have limited access to care.
- Successfully advocated for a state-level family medical leave act before one was enacted by the federal government.
- Organized and maintained a long-standing organizing project made up of many different groups including organized labor, health care providers, non-profit insurers, and patient advocacy groups.
- Through a grassroots campaign, prevented massive state budget cuts to state health programs for the poor.
- Started an initiative to fund health information technology for safety net clinics.
- Changed requirements for state dental licensing to improve recruitment of dental professionals working at community health centers.
- Created an advocacy campaign for health reform that grew to more than 400 paid members and a mailing list of several thousand.

Survey and Interview Results

The survey results and interviews provide a rich knowledge base about the experiences of organizations that seek philanthropic funding for their health policy work. Respondents expressed many common themes, and offered both praise and criticism of the philanthropic sector. Most respondents felt that the foundations with which they work could have a better understanding of the challenges advocates face when working for health reform, and that foundations could be more effective in channeling their resources. The organizations offered concrete explanations for these criticisms and made suggestions for improvement.

Many respondents also expressed an appreciation for the challenges of distributing limited resources and monitoring and measuring successful projects. A strong thread of support emerged for collaborative efforts between funders and advocates, as both sectors strive to improve the health care system.

One caveat about the findings is that while some responding organizations are relatively small, most are fairly large and established. Sixty percent have annual budgets greater than \$500,000 (with 40% having budgets greater than one million dollars) and 65% have been in existence for more than ten years (with 40% in existence for more than twenty years). As a result, the voices of newer organizations and those with smaller budgets are under represented in our survey results. The experiences of newer, smaller organizations with foundation funding of health policy work are a topic ripe for further investigation.

Funding systemic change

“Fund advocacy to change systems that don’t work (like healthcare), or you will forever be funding projects that are like sticking fingers in the holes in the dike.”

Many survey respondents had a difficult time obtaining grants for systemic health sector change. While the majority of respondents had received funds to work for reform, 30% had not received such grants, despite seeking them. Even though many organizations had gotten dollars for policy and advocacy work, they expressed frustration at how hard it was to obtain such grants. Respondents told us that when it comes to staffing and operations to support policy work, their top needs are for advocacy and policy staff, with development and grants management staffing a close second.

Most of the respondents had been rejected for grants that they thought would advance reform. Respondents cited similar types of projects that had been declined: systemic policy and advocacy work around a specific issue (i.e. health care reform, medical debt, expanding children’s health insurance); grassroots organizing to help shape the health care debate; community education about health care reform; and creating coalitions to work on health reform.

The most oft-cited reasons for rejection of grants for systemic change work were: the foundation wanted to fund direct service or specific projects, rather than policy work; the foundation did not fund advocacy; scarce resources; and the project was not a foundation priority. A number of organizations often received no reason for declined funding or reasons they felt were boilerplate, such as “we had more applicants than dollars to go around.”

“Funding programs is easier to do – it’s safer, it’s non-political, and there are clear outcomes. Funding real policy change is much more difficult.”

“Some of the foundations don’t get it, at least at first. For one of the foundations that funded us, it was a big shift for them to think about advocacy as a form of change as opposed to direct service. They kept asking, ‘What do you call it? How do you measure that?’”

“The important things that many funders don’t seem to understand include: 1) how policy is actually made; 2) that consumer organizations are not financially interested in the outcome of the policy debates around health care reform; and 3) we are challenging the biggest for-profit industries in the health care system with relatively little to no resources especially in the areas of communications and lobbying.”

“There are only a few foundations willing to fund policy work and we’re running out of places to go.”

“Some foundations only want to fund polite, collaborative advocacy. Policy change without conflict is not always possible.”

“We are working to build our core capacities and create a strong system of advocacy that can push for health care reforms that will benefit all consumers, particularly the most vulnerable. Core operating support would give us the flexibility to respond to the changing environment without restriction of a project and build our staff capacities including organizing, media, policy and lobbying.”

“[Core support] would provide greater flexibility to be strategic and on the cutting edge in pursuing new opportunities. Currently, we often want to promote actions that are only coming into public view but we think are promising—and foundations are only themselves beginning to identify such opportunities and put resources into place to support them.”

“Program and administrative advocacy often does not have tangible “successes” that demonstrate effectiveness, yet it is critical to making programs work better for the people who rely on them to get their health care. Operating support allows you to work on issues that are not necessarily au courant or politically popular.”

“Core funding makes a lot more sense, based on the conditions we face and the type of work we do. The challenge is that organizations need to be responsible in updating funders about important changes in strategic direction and the policy environment, to provide assurances the money is still being spent toward the funders’ goals.”

Core operating support

“General support would give us the flexibility to respond to the changing environment without the restriction of a project and to build our staff and expand our capacities...”

The organizations surveyed were nearly unanimous in stating they wanted the opportunity to apply for unrestricted, core support not tied to individual projects (97%). Nearly all expressed the belief that this type of support, and the flexibility it provides, is critical to the success of their organizations and their ability to change policy. About 70% had received such grants.

Respondents’ feedback about core funding echoes other reports and data addressing general support.²⁷ Data gathered by the Foundation Center demonstrates the lack of general support dollars: for all grant dollars in the United States, general support accounts for 20% of overall grant dollars. In health funding, the proportion for general operating support is even less, only 11%.²⁸

“Flexibility” is the word that respondents used repeatedly in explaining the benefit of unrestricted grants for core operating support. We consistently heard that unrestricted grants give organizations the agility to respond to needs or opportunities as they arise. Health system reform is dynamic, and unrestricted grants allow organizations to respond to a rapidly changing external environment – or to be proactive and nimble in working on emerging issues. Respondents’ organizations use a variety of shifting strategies depending on the environment, and project-based funding can inhibit their ability to adjust their staffing and tactics. Respondents know there are times when project-based funding makes sense – for a report, a survey, or for a discrete event, for example. But they stated that this kind of funding is generally less helpful when engaging in policy work, which can be unpredictable.

According to respondents, core grants allow for continuity and capacity building. Core funding can help organizations retain experienced staff without worrying about gaps in funding. Respondents also said that core operating grants allow them to invest in and maintain a functioning infrastructure -- one respondent noted that it is difficult to fund a grant for the electricity bill.

Finally, core funding helps organizations stay true to their missions and priorities. Respondents expressed concern that project-based grants require “contortions” in program priorities to create projects that are fundable, the proverbial tail wagging the dog.

Long-term investment and multi-year grants

“It’s usually easier to see an immediate need – someone or some concern that is in desperate straits – and shell out dollars to alleviate a current pain. It’s much more difficult to look ahead and spot trouble down the road. We need to find more compelling ways to describe that trouble and make a case for what we do...I would hope that foundations will be willing to invest in the future.”

Time and again, respondents told us they wanted foundations to maintain a long-term perspective on health reform and make a sustained commitment to funding policy work and to the organizations working for change. Respondents sometimes find themselves in the middle of policy work on a specific issue when funding ends. When the funder doesn’t continue support, the effort likely will falter. In recounting an effort to change policy on a specific issue, one respondent said, “we fell off a cliff because they wouldn’t fund us again to continue the work beyond nine months. So the work ended and the policy change was never solidified.”

Respondents said that multi-year grants are critical for them to make headway in their efforts to change policy. The vast majority of organizations have received multi-year grants and value them tremendously. Multi-year projects allow organizations to leverage dollars, to plan for the future, and to dig deeper into policy work. Single-year grants are difficult because policy change often takes longer and many organizations do not want to hire staff for a one-year grant unless they have the possibility of keeping them on board. Furthermore, one-year grants require the continual expenditure of limited staff resources in writing proposals to ensure a constant stream of grant funding.

“When you have a longer time to do the work, it’s often better quality. We can build skills in staff, develop expertise, and do deep policy work.”

Some foundations disappear at the end of a grant “without recognizing that those of us who do policy work need to sustain ourselves between sexy projects.”

“Multi-year grants enable you to get your work done while still being responsive to the changing policy environment. You save energy chasing money so you can actually do the work.”

“When you’re dealing with major changes and powerful interest groups who are opposing that change, it’s not going to happen overnight.”

“To build strong, vibrant organizations, foundations need to make a longer-term commitment. You can’t build a consumer organization and make change in twelve months.”

“It’s good to know you have funding secured at a consistent level for several years, so you can implement the program, without scurrying around looking for more funding. We’re a small organization, so in our case the people who are doing the work are also the ones who have to write the proposals. We depend on our advocates for both advocacy and fundraising. So a multi-year grant can enable 1-2 people to spend the lion’s share of their time actually doing the work.”

“Public education and media strategies - supported over several years - must go hand in hand with health policy reform. This means adequate funding to gain broad understanding of the policy change supported. And, it means having sufficient funds to promote the education/campaign over a minimum of 3-5 years. Change takes time!”

“Boards and foundations think grassroots mobilization is lobbying, rather than educating the public about a problem and offering solutions.”

“If you call it grassroots mobilization, you won’t get any money.”

“It is not hard to get funding for specific research/policy analysis/model program development. It is difficult to get funding for anything that looks like advocacy.”

“Greater value is placed on policy work, but reports alone don’t make change—it’s the public pressure that we can generate.”

Funding high need activities for policy change

We asked respondents about the activities their organizations needed funding for as they worked for health system reform. We provided a list of activities and asked them to identify all for which they needed funding.

A large cluster of respondents listed communications-related needs at the top:

- Media strategy and outreach (64% of respondents rated this as a significant step to health care reform that needs funding);
- Public education and information campaigns (62%); and
- issue framing and messaging (52%).

Coalition building, policymaker education, and policy analysis also emerged as areas of high need (54%, 53% and 50% respectively).

Funding needs also included:

- Convening interested organizations;
- Community organizing;
- Lobbying legislative bodies;
- Report writing and dissemination;
- Research;
- Using a web site and/or the Internet for organizing and action;
- Administrative advocacy;
- Polling and focus groups.

Respondents said that a combination of strategies is necessary for success. For example, good policy analysis along with community mobilization and an ability to build coalitions across interests can be effective. Advocates also linked organizing and messaging. One interviewee said “in order to move people, you need to figure out the message that works to reach them.”

Respondents told us that for many foundations, some activities seem to be “off-limits.” For example, many respondents stated that raising money for community organizing is very difficult. Some advocates are concerned that foundations may not even know about the organizations that do organizing and that these types of groups often do not have the capacity to develop relationships with foundations.

It is understandable that foundations steer clear of activities they believe IRS rules prohibit or limit them from funding, such as for lobbying. Most of the strategies respondents told us they needed funding for to achieve health system reform, however, are allowable under IRS rules. (See box on page 24).

Funder/grantee relationship

“Our most positive experiences have been when foundations have regarded us as a learning partner and we have helped in the design and further development of initiatives rather than treating us as simply a grantee. This is very dependent upon the orientation of program officers and the direction they receive.”

Many respondents talked about the importance of positive relationships with accessible program officers who are willing to listen. Some respondents describe the desire for foundation staff to be active partners and collaborators. They appreciate advice on their proposals and sometimes want an opportunity to discuss and resubmit a grant. Other respondents said they appreciate the benefits of a partnership, but expressed concern about micromanagement by foundation staff.

Respondents have had good experiences with program officers who trust them and their expertise. They especially appreciate foundation staff well-versed in leveraging the foundation's dollars. They want foundation staff to trust that organizations understand the needs and priorities of communities. Respondents also urge the involvement of the community and grantees in designing initiatives and priorities.

Respondents want foundations to help them look ahead to the future for the opportunities and challenges. While funding for specific “hot topics” can make sense, it should not happen, respondents told us, at the expense of other issues that may seem intractable, but need ongoing attention and effort. Foundations should strive for a balanced portfolio that allows them the flexibility to respond to urgent funding needs (such as Hurricane Katrina, for example), while not compromising attention to long-term systemic reform.

Some respondents expressed frustration at the perceived “preferred list” of grantees, a “small pool” from which some funders may solicit proposals. Many urged encouraging new candidates, including organizations representing people of color, to apply.

Many respondents appreciate when funders sponsor convenings to support organizations and foster shared learning. They like the networking opportunities and possibilities for learning from other organizations. At the same time, some groups expressed discomfort with “forced collaborations,” when funders require or request that groups collaborate in order to receive funding. But most of the reaction on this topic was positive: people expressed appreciation for working with groups with which they might not have otherwise collaborated.

“It’s been most helpful when there is collaboration in proposal development and ongoing communication and refinement of project direction...also assistance in leveraging additional funding for funded projects.”

“Really comprehensive knowledge of our goals by foundation project managers can be outstandingly helpful. When there is collaboration, the outcome is decidedly stronger and provides everyone with greater benefits.”

We appreciate “funders who appreciate the value of the non-tangibles of health policy advocacy - the coalition-building, the working with policy-makers to establish relationships - which is not project-specific, but is essential in translating research into policy change.”

What has been most helpful with funders is “active partnership, flexibility, provision of additional resources when needed, and open, honest communication.”

Some foundations “fund research, conferences, and media campaigns coupled with a refusal to fund the advocacy work that actually proposes concrete solutions and asks policymakers to act. It seems it’s easy to fund talk about issues, but when it comes to advocacy and action based on that talk, many foundations would like ‘someone else’ to do the work without the foundation having to pay for it.”

“Be more specific as to why applications were not funded, and what can be done to [improve] the applicant for the next period without fear of repercussions for being honest....”

“System reform takes time and its course is unpredictable. A funder should expect results - at least in a process sense, but should understand that such an initiative may not lend itself to neat little descriptions or 100% success, in terms of completed tasks or deliverables.”

“Find strong organizations at the state level with a proven track record of actually getting changes made in the state regarding health reform. Fund these organizations with multi-year general operating support grants. Ask for comprehensive reports detailing the work and success of these organizations.”

Application, grant reporting and evaluation

“We had an experience where the funder ... made us go through several revisions to fit our ideas into a programmatic framework; we had reports due every six months; we didn’t get feedback after the reports were sent in and had little sense of what the foundation thought of our progress...[We] later learned they were not happy, yet no one communicated that with us and it created friction...”

From a logistical standpoint, respondents value the availability of a simple, online application process and uncomplicated, straightforward grant reports. They also appreciate setting clear expectations from the outset of a grant to avoid misunderstandings and disappointment at the evaluation end of the process. A number of respondents complained about the length of time between the submission of a proposal and approval (or rejection) – time lags that impeded them from making a policy impact because of lack of funds for staffing.

Some respondents stated that they want specific, honest answers to why their proposals were declined. Armed with that information, respondents felt they could at least revise their proposals for success the next time.

Respondents understand the need for accountability, but raised concerns about overly detailed, cumbersome reporting requirements. They also told us that it is challenging to evaluate the success of policy work.²⁹ A number of respondents worry about some foundations’ over-reliance on data “without recognizing that people on the ground have a real time understanding of needs and priorities that is almost obsolete by the time there is statistically significant data to support action.” Others felt that “more subjective and process-oriented goals...are often more relevant to system change.”

Reaffirming and Rethinking Foundation Funding of Health Reform: The Time is Now

The stakes involved with fundamentally reforming the health care system are high. The forces resisting change are entrenched, extraordinarily well-resourced, and using increasingly sophisticated and costly strategies in opposition. Paid advertising, other communications tactics, funding “astroturf” groups, and extreme lobbying expenditures have created an ever-greater challenge for nonprofit health advocacy groups. For example, in 2005, the pharmaceutical industry spent \$80 million on competing California ballot initiatives that would have established a discount drug program in the state. Consumer and labor groups, in contrast, had approximately \$1 million to promote their position. In 2007, tobacco companies spent nearly \$12 million to defeat an Oregon ballot initiative to raise tobacco taxes to finance health care for uninsured children. Supporters of the initiative spent \$3.4 million, making the fight the most expensive ballot initiative in state history.

Building broad public understanding and a groundswell of pressure will be essential to move reform in a consumer-friendly direction. To accomplish that requires savvy messaging, polling and focus group expertise; coalition and alliance building; and capacity for sophisticated analysis and financial modeling – all resource-intensive activities. More than ever, policy organizations need the support, expertise, and resources of the philanthropic sector to achieve reform.

Our survey results confirmed what other reports have documented: many foundations (and their boards) that fund health work are reluctant to support policy and advocacy work. Some foundations equate this work with lobbying. Others state that they should be “neutral” and do not want to get involved in partisan battles. Still others believe they are prevented by law from supporting policy work.

This report does not offer legal advice about permissible activities for foundations. Other reports address the wide latitude private foundations have to fund the spectrum and component pieces of advocacy.³⁰ But organizations that responded to our survey engage in a variety of activities that promote policy change – and many of these strategies are

clearly fundable: coalition building, convening interested organizations, issue framing and messaging, policy analysis, public education and information campaigns, and media strategy and outreach. (See box below.) Foundations can earmark dollars for specific strategies, and they also can provide core operating support that organizations can use for a variety of activities.

The groups we surveyed want comprehensive reform now and are working hard to achieve it, primarily at the state level. With the prevalence of state health reform activity in so many states around the country, targeted foundation resources could create unprecedented opportunities for change. If foundations work with policy and advocacy organizations to improve relationships and dialogues, precious philanthropic dollars could be used more effectively.

Foundations May Fund Charities That Lobby

Some foundations and their boards are concerned that they cannot legally fund advocacy. As more foundations have considered supporting this type of work, a number of organizations have issued reports outlining the legal parameters of funding advocacy efforts.³¹ While foundations should seek legal advice when funding advocacy activities, philanthropies have more leeway to support advocacy than they may realize.

Distinguishing between advocacy and lobbying is key – advocacy is much broader than lobbying and involves a multitude of strategies, of which lobbying may be one.³² And, in fact, while most private foundations may not lobby, the law permits them to support charities that lobby and even provides some opportunity for foundation support of lobbying efforts.

In addition, many foundations believe they cannot fund 501(c)(4) organizations. Private foundations can make grants to these types of entities, but can only fund activities that could have been legally conducted by a 501(c)(3). Grants by private foundations to non-501(c)(3) grantees cannot be made for general support, but must be earmarked for a specific program or activity and those activities cannot involve lobbying.³³

To clarify the guidelines foundations and their boards should consult sources such as The Alliance for Justice for general guidance and rely on sound legal advice for specific questions.³⁴ In doing so, foundations can realize their maximum impact on improving the health system.

Recommendations

Foundations vary in philosophy, priorities, culture, and size, yet advocates expressed consistent messages about their experiences seeking foundation funding from a spectrum of foundations to work on health policy change. And many of our survey findings are consistent with conclusions reached by other analyses and research.³⁵ As we analyzed the input from survey respondents and interviewees, we sought to identify recommendations for increasing and improving the dialogue among and between nonprofits and foundations working to improve the health system, with the ultimate goal of realizing sustainable and effective health care reform. Below we outline potential next steps to continue and enhance the conversation that is happening among and between foundations and nonprofits.

I. Recommendations For Foundations

Foundations should recognize that they have a critical role to play in health care reform. They can commit to funding many of the activities that lead to policy change without running afoul of IRS requirements.

Funders should consider earmarking a substantial portion of their portfolios for supporting state and local efforts for policy change work, especially efforts to improve the health of our most vulnerable populations. Respondents to the survey and interviews expressed frustration that many foundations will not fund policy work because they equate it with lobbying. In fact, much – probably most – work leading to policy change happens outside of the legislative process. The overwhelming majority of respondents engage in policy change work that is clearly permissible under IRS rules, e.g. 88% engage in coalition building, 86% in policymaker education, and 86% in policy analysis. While foundations and advocacy nonprofits have real constraints on lobbying, there is a vast area in which both may operate to influence public policy.

Foundations should increase the amount of core support they provide.

Core support is critical for the success and survival of organizations that work for health system change. Respondents to our survey sent a clear, unanimous message that core support would improve the viability, capability, and long-term success of groups working for health policy change. While organizations understand the challenges foundations face in providing general support, they view this kind of support as an essential and effective grantmaking strategy.³⁶

Foundations should fund for the long-term with multi-year grants.

Significant change in the health system necessitates a long-term investment by philanthropy. Nonprofits need ongoing, steady support to build capacity and expertise. Foundations should continue to work hand-in-hand with nonprofit groups to create and maintain a long-term investment in health care system change. Funders need to see and understand progress – the nonprofits they fund can help them identify successes, as well as understand the challenges in making change.

Foundations that fund advocacy and reform efforts should continue to share their successes and encourage other funders to join them.

Many foundations, as well as Grantmakers in Health, have offered information about the successes and concrete strategies in funding policy work. Foundations that support health policy change should amplify their role as champions for supporting consumer advocacy to move health reform. They can do so by communicating with their foundation peers about the full range of their experiences funding advocacy so that those foundations that embark on funding policy work have information about what is allowable, what has worked, and how to avoid potential pitfalls.

Foundation boards should reflect the communities they serve and have greater representation by individuals with an advocacy background.

While foundations need leaders with demonstrated skills in finance, management and fundraising, community representatives can provide unique connections, perspectives, and experience. In turn, foundation boards can provide a venue for developing community capacity and leadership for groups generally unrepresented on foundation boards.³⁷

“There’s a long, intense education of trustees about advocacy projects that has to happen.”

“I don’t think board members and foundation staff routinely seek out contact with people and organizations that are affected by their program guidelines and restrictions. If they consult with grantees at all, they may ask a narrow range of informants, maybe the five people they lunch with and trust. We’d like to see foundations step back and ask the communities they serve – where are the needs of this community really going?”

“Do funders think about fostering new voices, new ways of working, creative tactics as ways of enriching their grantmaking portfolio?”

“Funders want a sure thing. They seem to have little recognition that many things fall outside the narrow agenda they’ve adopted, or the ‘hot issue’ of the day.”

“Ask funders how they believe that policy is made. Ask funders what level of resources they believe that the medical and insurance industries are putting into fighting universal health coverage. Ask funders whether they truly understand what is... permissible and impermissible advocacy under the tax code.”

“Most foundations are completely unaware of how policy gets made and do not want to fund advocacy or anything ‘controversial.’ So, for example, reports that would expose documented insurance industry practices of retroactively denying coverage or removing benefits without government review – which hurt people and cost the health system millions of dollars – are too controversial.”

“Some of the large funders should spend time ‘walking in our shoes’ to see how policy really gets made. After seeing the 27 lobbyists (no kidding) that our organization faces in the insurance committee everyday and after seeing the huge sums of money that the medical, pharmaceutical, and insurance industries are putting into state-based ‘spin tanks’ that advocate ‘free market’ solutions to health insurance and health care issues, then maybe they will begin to understand what it will take to win true reforms.”

Board members with on-the-ground policy and advocacy experience can provide valuable input about how systemic health reform can happen. Community listening tours and community advisory structures can help broaden board perspectives, as well, but there is no substitute for “enfranchising” those who have worked for policy change to also to have a say in the allocation of philanthropic assets -- what the National Committee for Responsive Philanthropy has called “democratizing foundation governance.”

Foundations should acknowledge and address the power imbalance between their organizations and those they fund.

Foundations and nonprofits should seek to create and sustain partnerships built on mutual respect and understanding. Many funders and nonprofits maintain positive and ongoing relationships. However, many of those surveyed believe the ever-present power differential between the funder and the grantee can negatively affect the relationship if not carefully managed by both parties. Foundation staff and board can begin to address the power differential by working collaboratively with nonprofits as much as possible.

Foundations should create opportunities for community input in setting priorities and engage nonprofits that work for health reform in an ongoing dialogue.

The survey results and interviews with nonprofit advocacy leaders engaged in health reform surfaced several common themes, such as the need for multi-year funding, more core operating support, and funding for coalition building, communications and policy analysis. Yet there are not always avenues for potential grantees to express their opinions and needs to foundations, outside a survey like the one we administered or a foundation-sponsored customer feedback tool. The findings of this survey could form the basis for ongoing dialogues between funders and grantees.

Obvious structural barriers impair open, honest conversation between grantees and foundation staff or boards. As one respondent told us, “There’s always some self-censoring that may be going on. When I submit proposals, I make a passionate pitch for them, and if they are turned down I begin work on a program of ‘self-improvement’ and ‘rehabilitation.’ I wouldn’t think to sit down with the program officer and say, ‘Honey, you are really missing the boat.’ It might be an honest and forthright thing to say. But it also might compromise and prejudice my position as a grant-seeker looking to recover the ground I’ve lost...”

Nonetheless, some foundations are trying to open the door to conversation. In a 2006 survey of the foundations formed from the charitable assets of nonprofit health care conversions, Grantmakers in Health found that a majority of conversion foundations report a moderate to high level of systematic community involvement in program planning and priority setting.³⁸ Some conversion foundations report engaging communities by seeking input on programs and planning. They also share information with the community about foundation activities, gather feedback in different forums, and help support key community

coalitions. Some conversion foundations use Community Advisory Committees to institutionalize community engagement, increase community participation and foster inclusive planning and decisionmaking. These permanent committees report directly to a foundation's board.

Even foundations without this sort of history of engagement can begin the dialogue by taking some small steps. For example, those surveyed repeatedly said that the timing of grantmaking decisions often does not meet the demands of the policymaking arena. A conversation about this issue could result in shared understanding and changes – such as expedited turnaround on smaller discretionary grants – that would help foundations meet their missions and that would help health advocacy organizations effectively build toward system change. Grantees express deep appreciation for funders that help them leverage dollars from other foundations. Funders and grantees could benefit from a concrete dialogue about the possibilities and challenges of leveraging foundation dollars. Establishing an ongoing dialogue – adding to those that already occur – to facilitate and improve the relationship between funders and grantees and make grantmaking more grantee-friendly could also make a real difference in changing the health system.

Foundations should especially consider seeking out the feedback and input of smaller organizations that engage in health policy work, whether funded by the foundation or not. As noted above, many of the respondents to our survey are from larger, more established organizations. Getting the perspective of groups that may not even be on the philanthropic radar screen for health policy work would enlarge and round out the nonprofit perspective.

II. Recommendation for Nonprofit Advocacy Groups

Nonprofit grantee organizations should continue to engage in dialogue about ways to help each other build a powerful movement for health system reform.

Nonprofits often work together to make change. But nonprofit social justice work is demanding, and often focuses on near-term achievable goals that do not necessarily facilitate common and unified action in times of opportunity or crisis. Further, nonprofits can be limited in practical terms by their missions and the constant pressure to seek grants, contracts or service income. They may feel constrained to shape aspirations, strategies and tactics to fit foundation initiatives. And they also are often in competition for scant resources. For all these reasons, developing joint movement-building efforts may be difficult to achieve.

We, nonetheless, urge that nonprofit advocacy groups make time for discussions about long-term shared strategies for creating a fairer health care system. Questions for dialogue could include:

- How can we join forces with other nonprofits, as well as other allies, to create a louder voice for change?
- How can we directly help each other?
- How do we ensure that the voices of those most in need of health care reform will be heard? How can we directly empower organizing and representation of those communities?
- How can we most effectively advocate for increased philanthropic resources to assist in the development of grassroots movements for health care reform?

Conclusion

Without support for fundamental, system-wide change, the U.S. health system will continue to fail to meet the needs of many Americans, especially the most vulnerable. Advances and progress in improving health status and the quality of care are not distributed equally. The cost of delivering care continues to rise, and there is ongoing concern about the quality of care Americans receive.

While many in government and business have joined the voices of consumer advocates calling for systemic change, reform has continued to be elusive. Experts and stakeholders agree that our current health care system is fragmented, often ineffective, and unsustainable in the long term.

Funders can lead the way to real change through a concerted, targeted effort to fund systemic health reform shaped by joint vision with those dedicating themselves to that cause.

Endnotes

1 Consumers Union receives foundation funding for health related work, including resources from the Ford Foundation for this philanthropy project.

2 Josefina Atienza, Algernon Austin and Reina Mukai, *Foundation Giving Trends: Update on Funding Priorities* (New York: Foundation Center, 2007), 14.

3 The Foundation Center defines program support as “grants to support specific projects or programs as opposed to general purpose grants.” Foundation Center Online Librarian, e-mail message to author, January 22, 2008.

4 According to the Foundation Center, the 2% figure cited for “policy and management” in the 2005 report captures only a portion of health policy-related grantmaking by foundations. “Policy and management” includes a range of supporting activities or organizations identified by 18 different codes. For example, one code identifies organizations or programs that conduct research and analysis on public policy within a major field area, in this case health. For more information about the way the Foundation Center classifies grantmaking, see http://foundationcenter.org/gainknowledge/grantsclass/ntee_gcs.html#RTCC. Foundation Center Online Librarian, e-mail message to author, January 22, 2008.

5 Steven Lawrence, *Update on Foundation Health Policy Grantmaking* (New York: The Foundation Center, 2004), 2.

6 According to the Foundation Center, 12.5% in the 2004 report more fully reflects health policy-related grantmaking by foundations than the 2% in its 2005 report due to differing categorizations used in the two reports. The Center also points out that some foundations conduct their own health policy research and engage in other forms of related direct charitable activities, and those activities would not be counted in the Foundation Center’s figures for health policy-related grantmaking. Steven Lawrence, e-mail message to author, December 2, 2007.

7 Lawrence, *Update on Foundation Health Policy Grantmaking*, 2.

8 A recent report by Grantmakers in Health (GIH) highlighted the important role of conversion foundations in funding health. According to GIH, there are 185 foundations that were either newly formed with assets from a health care conversion or received assets generated by a conversion. Together, these foundations have a combined total of approximately \$21.5 billion in assets. See, Brent Ewig, *Connecting to Community and Building Accountability*, (Washington, DC: Grantmakers in Health, 2007).

9 Lawrence, *Update on Foundation Health Policy Grantmaking*, 5.

10 A recent initiative by the Robert Wood Johnson Foundation, Consumer Voices for Coverage, exemplifies the type of philanthropic effort that could significantly shore up the ability of advocacy organizations to make a difference in their states. The initiative will provide resources to state-based consumer health advocacy collaborations with the goal of building an integrated and robust advocacy network. For more information, see www.voicesforcoverage.org.

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13 American College of Physicians, *The Impending Collapse of Primary Care Medicine and its Implications for the State of the Nation's Care* (Washington DC: American College of Physicians, 2006), <http://www.acponline.org/hpp/statehc06.htm?hp/> (accessed January 7, 2008); Sara Rosenbaum, Peter Shin, Ramona Perez Trevino Whittington, *Laying the Foundation: Health System Reform in New York State and the Primary Care Imperative* (New York: The Primary Care Campaign, 2006), http://www.nyprimarycarehome.org/media/Rosenbaum_Study.pdf/ (accessed January 7, 2008).

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15 Centers for Disease Control and Prevention, *Racial and Ethnic Approaches to Community Health (REACH) 2010: Addressing Disparities in Health* (Atlanta: Centers for Disease Control, 2005), <http://www.allhealth.org/BriefingMaterials/RacialandEthnicApproachestoCommunityHealthREACH2010-50.pdf/> (accessed January

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17 Steven Lawrence, ed., *Social Justice Grantmaking: A Report on Foundation Trends*, (New York: Independent Sector & The Foundation Center, 2005). In this report, social justice philanthropy is defined as "the granting of philanthropic contributions to nonprofit organizations based in the United States and other countries that work for structural change in order to increase the opportunity of those who are the least well off politically, economically, and socially."

18 National Committee for Responsive Philanthropy, *Social Justice Philanthropy: The Latest Trend or a Lasting Lens for Grantmaking?* (Washington, DC: National Committee for Responsive Philanthropy, 2005). The report defines social justice philanthropy as "the practice of making contributions to nonprofit organizations that work for structural change and increase the opportunity of those who are less well off politically, economically and socially."

19 Foundations in the western United States allocate more dollars to health than their counterparts in the Northeast, Midwest and South. Also, large conversion foundations in California – the California Endowment and the California Wellness Foundation -- are among the top ten health philanthropies in the country, while in many other states there are fewer state or regional funders with programs to sustain ongoing advocacy and coalition work. Josefina Atienza, Algernon Austin and Reina Mukai, *Foundation Giving Trends: Update on Funding Priorities* (New York: Foundation Center, 2007), 15. A recent report by the Alliance for Justice highlights the "traditionally under-recognized" needs of the Gulf Coast States hit so severely by Hurricanes Katrina and Rita. Alliance for Justice, *Power Amidst Chaos: Foundation Support for Advocacy Related to Disasters* (Washington DC: Alliance for Justice, 2007).

20 Lester Salamon, *America's Nonprofit Sector: A Primer*, (New York: The Foundation Center, 1999), 135.

21 Grantmakers in Health, *Funding Health Advocacy*, (Washington, DC: Grantmakers in Health, 2005), 2. Adapted from remarks by Ruth Holton of The California Wellness Foundation, at Grantmakers in Health Issue Dialogue, *Funding Health Advocacy*, November 3, 2004.

22 *Ibid.*

23 Several California philanthropies collectively supported advocacy related to health reform in California recently, including the California Wellness Foundation and The California Endowment. Consumers Union was the fiscal sponsor for one such grant from The California Endowment for the It's Our Healthcare! Coalition.

24 See, Ruth Holton, *Reflections On Public Policy Grantmaking* (Woodland Hills: The California Wellness Foundation, 2002); National Committee for Responsive Philanthropy, *Social Justice Philanthropy: The Latest Trend or a Lasting Lens for Grantmaking?* (Washington, DC: National Committee for Responsive Philanthropy, 2005); Steven Lawrence, ed., *Social Justice Grantmaking: A Report on Foundation Trends*, (New York: Independent Sector & The Foundation Center, 2005).

25 The organizations we surveyed were derived from two lists: Consumers Union's database of organizations and individuals we have worked with on health issues around the country over the past decade, and the attendees at the 2006 Families USA conference. We culled the combined list by focusing on state-based organizations that engage in policy work around health system reform. We also solicited survey responses from some national organizations that do intensive work in states, as well as some local branches of national groups.

26 We received an especially large response from California groups. This is likely due to the number of health advocacy groups in California on our mailing list, the size of the state, Consumer Union's long presence in California, and a well-developed health funding community.

27 Rick Cohen, *A Call to Action: Organizing to Increase the Effectiveness and Impact of Foundation Grantmaking* (Washington, DC: National Committee for Responsive Philanthropy, 2007); Judy Huang, Phil Buchanan & Ellie Buteau, *In Search of Impact: Practices and Perceptions in Foundations' Provision of Program and Operating Grants to Nonprofits* (Cambridge: Center for Effective Philanthropy, 2006); Grantmakers for Effective Organizations, *General Operating Support Action Guide* (Washington, DC: Grantmakers for Effective Organizations, 2007).

28 Josefina Atienza, Algernon Austin and Reina Mukai, *Foundation Giving Trends: Update on Funding Priorities* (New York: Foundation Center, 2007), 15.

29 A number of foundations and other organizations have addressed the challenges of evaluating advocacy. See, for example, The Alliance for Justice, *Advocacy Capacity Assessment Tool and Advocacy Evaluation Tool*, www.advocacyevaluation.org, (accessed on September 14, 2007); The California Endowment, *The Challenge of Assessing Policy and Advocacy Activities: Strategies for a Prospective Evaluation Approach* (Part I) and *The Challenge of Assessing Policy and Advocacy Activities: Moving from Theory to Practice* (Part II), (Los Angeles: The California Endowment, 2005, 2006); Grantmakers in Health, *Funding Health Advocacy*, 31.

30 See, e.g., Grantmakers in Health, *The Path to Policy Change: Practical Steps and Lessons from Health Funders* (Washington, DC, Grantmakers in Health, 2006).

31 See, e.g., Grantmakers in Health, *Funding Health Advocacy*; Northern California Grantmakers, *Public Policy Grantmaking Toolkit*, www.ncg.org/toolkit/html/gettingstarted/legalparam; (accessed on September 14, 2007); Alliance for Justice, *Investing in Change: A Funder's Guide to Supporting Advocacy* (Washington, DC: Alliance for Justice, 2004).

32 Grantmakers in Health, *Funding Health Advocacy*, 2.

33 Northern California Grantmakers, *Public Policy Grantmaking Toolkit*.

34 See, e.g., Alliance for Justice, *Investing in Change: A Funder's Guide to Supporting Advocacy* (Washington, DC: Alliance for Justice, 2004).

35 See, e.g., Holton, *Reflections on Public Policy Grantmaking*; Grantmakers in Health, *Funding Health Advocacy*; Cohen, *A Call to Action*.

36 As recently noted in a *New York Times* article, project-based funding can force grantees "to sacrifice long-term effectiveness for short-term efficiency...." Caruso, Denise, "Can Foundations Take the Long View Again?", *New York Times*, Jan. 6, 2008, Business section. See also Grantmakers for Effective Organizations, *General Operating Support Action Guide* (Washington, DC: Grantmakers for Effective Organizations, 2007).

37 Consumers Union and Community Catalyst, *Building and Maintaining Strong Foundations: Creating Community Responsive Philanthropy in Nonprofit Conversions* (San Francisco/Boston: Consumers Union & Community Catalyst, 2004), 14.

38 Brent Ewig, *Connecting to Community and Building Accountability* (Washington, DC: Grantmakers in Health, 2007), 4.

Appendix A

Survey on Foundation Funding for Health Reform

Thank you for agreeing to take Consumers Union's Survey on Foundation Funding for Health Reform. We are asking you, as someone who has worked on health reform, to tell us about your organization's experiences raising money from foundations.

You should complete this survey if your organization solicits funds from foundations and works for policy change in the health care arena. For purposes of this survey, we define policy change as a decision or action by a government official or body (e.g. a budget decision or administrative rule) or by an organization (e.g. a private or nonprofit organization's decision to change the way it does business) that directly affects people's lives—getting from "what is" to "what should be."

In appreciation for your time, the first 300 responders will receive a free subscription to Consumer Reports onHealth, Consumers Union's monthly newsletter to help you get healthy, get informed and stay well. We also will send every responder a copy of our final report. If you are interested in receiving the newsletter and the report, be sure to include your name and address in the appropriate fields.

Helpful Hints

-The survey should take approximately 10-15 minutes to complete.

-Questions with an asterisk are required. You will not be able to move to the next page before fully answering.

-As you proceed through the survey, your answers will be saved. This allows you to come back and complete the survey at a later time if you are unable to finish in one sitting. The only limitation is that you must come back to the same computer from which you began the survey.

-Your responses are completely confidential. No individual results will be reported.

Survey on Foundation Funding for Health Reform

Organizational Profile

*** 1. Name of organization**

Organization
Address
City
State
Zip
Phone

*** 2. Name of person responding to survey**

First
Last
Title
Phone
Email

*** 3. Is your organization dedicated solely to health issues? (If you check yes, skip to question #5.)**

☐ Yes ☐ No

4. If your organization works in other areas, what percentage of your work is spent on health issues?

☐ 5% - 20%
☐ 20% - 50%
☐ 50% - 90%

*** 5. What types of work does your organization do to accomplish its goals? (Check all that apply.)**

- ☐ Coalition building
- ☐ Community organizing
- ☐ Direct service
- ☐ Education
- ☐ Legal
- ☐ Lobbying
- ☐ Policy
- ☐ Research
- ☐ Other (please specify)

Survey on Foundation Funding for Health Reform

* 6. Is your organization's work focused on a segment of the population?

- ☐ No, we focus on the general population. (If checked, skip to question #8.)
- ☐ Yes, we focus on a specific segment of the population.
- ☐ The organization focuses on both the general population and specific segments of the population.

7. If your organization focuses on specific segments of the population, please specify:

- ☐ Children
- ☐ Disease group
- ☐ Disabled
- ☐ Low-income
- ☐ Racial/ethnic group(s)
- ☐ Seniors
- ☐ Uninsured
- ☐ Other (please specify)

* 8. Which health issues does your organization work on? (Check all that apply.)

- ☐ Comprehensive health reform
- ☐ Conversions and mergers (health plans/hospitals)
- ☐ Environmental health
- ☐ Health quality/patient safety
- ☐ Hospital closings/services
- ☐ Increasing access to health insurance coverage
- ☐ Long-term care
- ☐ Medicaid
- ☐ Medical debt
- ☐ Medicare
- ☐ Mental health
- ☐ Nutrition/obesity
- ☐ Prescription drugs
- ☐ Private insurance reform
- ☐ Racial/ethnic/gender health disparities
- ☐ Specific disease/Other

Survey on Foundation Funding for Health Reform

*** 9. Does your organization work for changes in public policy or corporate practice on one or more of the issues listed in Question 8?**

☐ Yes

☐ No

10. If you answered yes to Question 9, on which level is your organization working for policy change? (Check all that apply.)

☐ Federal

☐ State

☐ Local

☐ Corporate campaign (e.g. pressuring health plan or hospital)

*** 11. Which strategies for policy change has your organization utilized? (Check all that apply.)**

☐ Advocating before administrative agencies

☐ Coalition building

☐ Community organizing

☐ Convening interested organizations

☐ Issue framing and messaging

☐ Litigation

☐ Lobbying legislative bodies

☐ Media strategy and outreach

☐ Policy analysis

☐ Policymaker education

☐ Polling/focus groups

☐ Public education and information campaigns

☐ Report writing and dissemination

☐ Research

☐ Web site and/or the Internet for organizing and action

12. Please describe an example of your organization's work for health policy change that you consider successful.

Survey on Foundation Funding for Health Reform

Foundation Experience

*** 13. Approximately how many different foundations has your organization received grants from over the past 5 years (or since your organization's inception, if it is less than 5 years old?)**

- ☐ 0
- ☐ 1
- ☐ 2-5
- ☐ 5-10
- ☐ 10-15
- ☐ 15-20
- ☐ Greater than 20

*** 14. What is the approximate total amount of funding your organization has from foundations over the past 5 years?**

- ☐ Less than \$50,000
- ☐ \$50,000-100,000
- ☐ Greater than \$100,000
- ☐ Greater than \$250,000
- ☐ Greater than \$500,000
- ☐ Greater than \$1,000,000

*** 15. From which kind of foundations has your organization received grants? (Check all that apply.)**

- ☐ National (e.g. Kellogg , Robert Wood Johnson Foundation, Gates Foundation)
- ☐ Regional
- ☐ State
- ☐ Local (e.g. community foundations)
- ☐ Family
- ☐ Corporate

*** 16. Has your organization received foundation grant support from any "conversion foundations" (foundations formed when a nonprofit health insurer or hospital converted to a for-profit entity?)**

- ☐ Yes
- ☐ No
- ☐ Don't know

Survey on Foundation Funding for Health Reform

*** 17. Has your organization ever received multi-year grants from foundations?**

☐ Yes

☐ No

18. If your organization has received multi-year grants, what was the longest grant period?

☐ 2 years

☐ 3 years

☐ 5 years

☐ Greater than 5 years

*** 19. Has your organization received unrestricted grants/core operating support (i.e. grants that are not tied to a specific program or project?)**

☐ Yes

☐ No

*** 20. Would your organization like to have the opportunity to apply for unrestricted grants/core operating support?**

☐ Yes

☐ No

21. If you answered yes to Question 20, how would unrestricted grants/core operating support be helpful to your organization?

*** 22. Has your organization received one or more grants in the last five years that has enabled the organization to work for specific structural changes or systemic reforms in the health care system?**

☐ Yes

☐ No

*** 23. Are there grants your organization has applied for that you thought would advance systemic change that were not funded?**

☐ Yes

☐ No

24. If you answered yes to Question 23, what was your organization proposing to do and what was the reason given for declining to fund?

Survey on Foundation Funding for Health Reform

* 25. What are the most significant steps to health care reform your organization needs funding for at this time?

- ☐ Advocating before administrative agencies
- ☐ Coalition building
- ☐ Community organizing
- ☐ Convening interested organizations
- ☐ Issue framing and messaging
- ☐ Litigation
- ☐ Lobbying legislative bodies
- ☐ Media strategy and outreach
- ☐ Policy analysis
- ☐ Policymaker education
- ☐ Polling/focus groups
- ☐ Public education and information campaigns
- ☐ Report writing and dissemination
- ☐ Research
- ☐ Web site and/or the Internet for organizing and action
- ☐ Other (please specify)

Survey on Foundation Funding for Health Reform

* 26. Which of these areas have been hardest to fund through foundation dollars?

- ☐ Advocating before administrative agencies
- ☐ Coalition building
- ☐ Community organizing
- ☐ Convening interested organizations
- ☐ Issue framing and messaging
- ☐ Litigation
- ☐ Lobbying legislative bodies
- ☐ Media strategy and outreach
- ☐ Policy analysis
- ☐ Policymaker education
- ☐ Polling/focus groups
- ☐ Public education and information campaigns
- ☐ Report writing and dissemination
- ☐ Research
- ☐ Web site and/or the Internet for organizing and action
- ☐ Other (please specify)

* 27. What are your organization's greatest unfunded staffing and operations needs that would support your organization's policy work? (You must rank all choices listed. Please choose n/a if the choice is not applicable to your work.)

Administrative support staff	<input type="text"/>
Development/grants management	<input type="text"/>
Financial management staff	<input type="text"/>
Lobbying staff	<input type="text"/>
Management staff	<input type="text"/>
Policy and advocacy staff	<input type="text"/>
Rent/office equipment	<input type="text"/>
Research staff	<input type="text"/>
Staff training and development	<input type="text"/>
Other	<input type="text"/>

Survey on Foundation Funding for Health Reform

*** 28. What foundation practices do you associate with your most positive foundation grant experiences?**

*** 29. What foundation practices do you associate with your least favorable foundation grant receipt experience?**

*** 30. If you could be a "confidential advisor" to foundations who fund health-related programs and projects, what advice would you give them?**

*** 31. On a scale of 1 to 5, how well do you think the foundations with which you work understand the challenges your organization faces in working towards health reform?**

- ☐ 1-Don't understand the organization's challenges at all
- ☐ 2-Understand the organization's challenges to a limited extent
- ☐ 3-Understand the organization's challenges
- ☐ 4-Understand the organization's challenges well
- ☐ 5-Have an exceptional understanding of the organization's challenges

*** 32. On a scale of 1 to 5, how effective are foundations with which you work in channeling funding to health system reform?**

- ☐ 1-Not Effective
- ☐ 2-Somewhat Effective
- ☐ 3-Effective
- ☐ 4-Very Effective
- ☐ 5-Exceptionally Effective

33. Is there anything additional you think the foundation community should know about supporting health system change?

Survey on Foundation Funding for Health Reform

More Organizational Profile Details

* 34. Organizational budget

- ☐ Less than \$50,000
- ☐ \$50,000-100,000
- ☐ \$100,000-200,000
- ☐ \$200,000-400,000
- ☐ \$500,000-1,000,000
- ☐ Greater than \$1,000,000

* 35. What are your organization's sources of funding? (Your answers must add up to 100% for the question to register as completed.)

Service fees	<input type="text"/>
Individual donations/bequests	<input type="text"/>
Government contracts/grants	<input type="text"/>
Foundation grants	<input type="text"/>
Endowment	<input type="text"/>
Product sales/related business	<input type="text"/>
Other	<input type="text"/>

* 36. How many full-time staff does your organization employ?

* 37. How old is your organization?

- ☐ 1-5 years old
- ☐ 5-10
- ☐ 10-20
- ☐ Greater than 20 years old

* 38. Are you willing to be contacted for a phone interview about how foundations could be effective in funding health care system change?

- ☐ Yes ☐ No

* 39. Would you be interested in participating in focus groups on how foundations could be effective in funding health system change or in a funders/grantees dialogue about it?

- ☐ Yes ☐ No

Survey on Foundation Funding for Health Reform

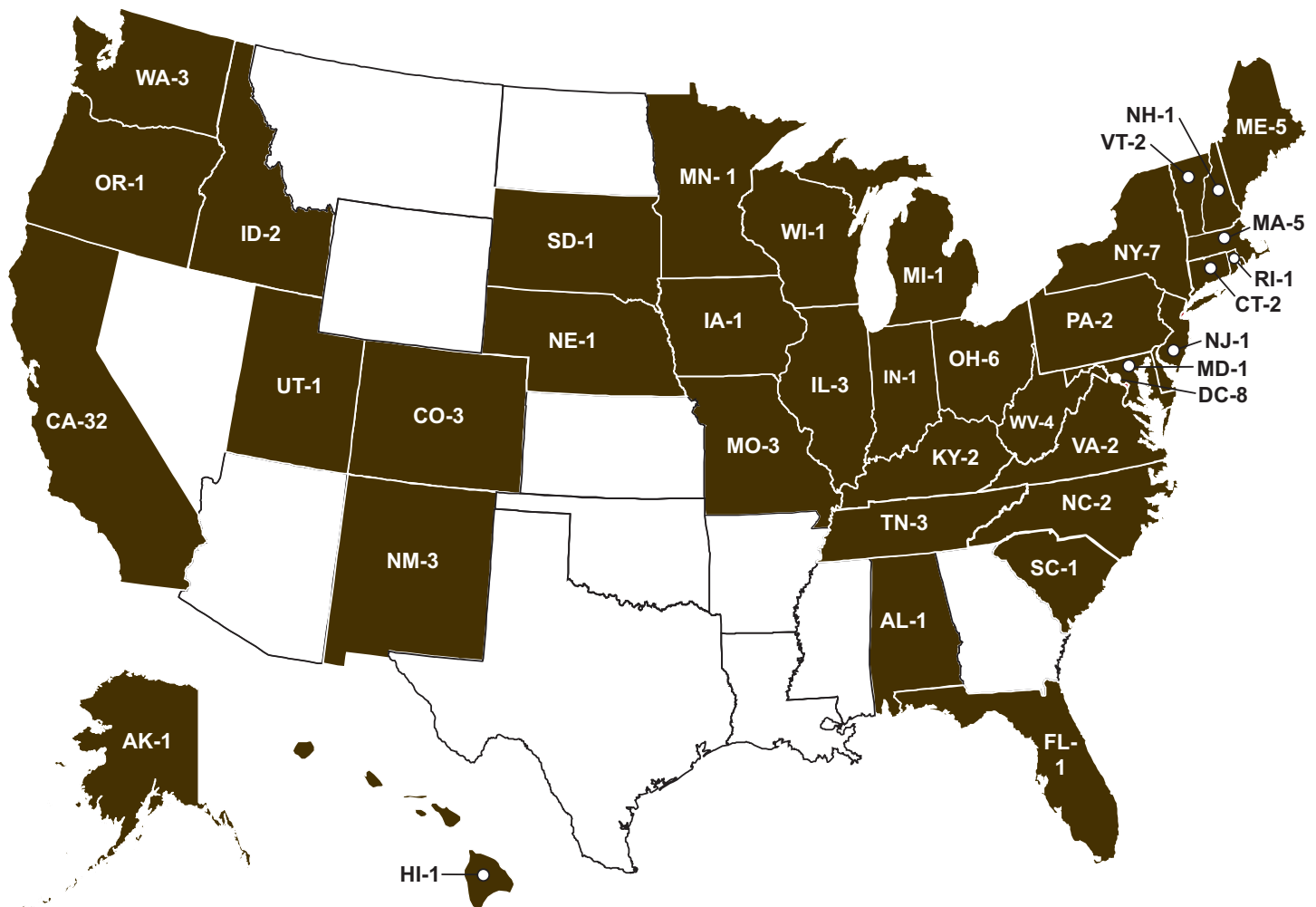
Thank you for taking the survey.

Thank you for taking the survey.

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Appendix B

Those Who Responded to the Survey By State



Appendix C

Our survey asked a number of open-ended questions about respondents' experiences with foundations when seeking grants for health policy and advocacy work. Their answers were well-considered and informative. One question that yielded especially thoughtful answers was the following: If you could be a "confidential advisor" to foundations who fund health-related programs and projects, what advice would you give them?

This is the full set of responses we received. (Some comments have been edited slightly to protect the anonymity of respondents.)

- They [foundations] have been so directed toward provider groups and the number of people served, they haven't looked at structural issues where they could make a bigger difference.
- The new "advocacy" is giving money to organizations to get more kids into CHIP - rather than pushing for strategic solutions. The program has structural problems and barriers -- private insurers won't offer the product -- and I have a proposal to address that but I don't know who to present it to who would be interested in funding this.
- Don't be afraid to fund advocacy and coalition-building. Coalitions require resources if they are to be sustained and effective; all-volunteer coalitions fail in the long run.
- Fund advocacy and organizing!
- Funding for local community-based health care and coverage organizing and policy work with a grassroots element is an essential component of achieving change in the health care system. University-led research and publishing projects that lack a connection to community-based research and mobilization are not enough.
- Don't be afraid of the politics of health care.
- Put higher value on written work products that are actually entered into the policy-making process: comments on regulations, draft legislation, legal briefs. Background reports are fine, but if anything is to flow from them, some more specific work often must be done. We do it.

- Find strong organizations at the state level with a proven track record of actually getting changes made in the state regarding health reform. Fund these organizations with multi-year general operating support grants. Ask for comprehensive reports detailing the work and success of these organizations.
- System reform takes time and its course is unpredictable. A funder should expect results - at least in a process sense, but should understand that such an initiative may not lend itself to neat little descriptions or 100% success, in terms of completed tasks or deliverables.
- Support advocacy that is geared towards improved public policy and systemic reforms and employs lobbying as a significant strategy.
- Identify grantees who have been doing consumer health advocacy for at least 5 years; Provide them with multiple year, significant funding (relative to the size of the organization); Provide the funding in the form of general operating support so long as the mission of the grantee is in line with the funder's goals. Ask funders how they believe that policy is made. Ask funders what level of resources they believe that the medical and insurance industries are putting into fighting universal health coverage. Ask funders whether they truly understand what is the line between permissible and impermissible advocacy under the tax code.
- To support small to medium size agencies that are working on health issues at a grassroots community level. To provide funding support for administrative overhead. To provide agencies with multiyear funding opportunities.
- I'd like the health-related funders not to be afraid of reproductive health; and conversely, I'd like to encourage the reproductive rights and health funders to recognize health care for all as a reproductive rights issue.
- Pay more attention to work being done at the community and state levels, as opposed to funding the "big bang" national solutions to fixing the health care system.
- First, don't rely so much on the formal proposal writing, with its goals and measurements for success. Look instead to fund those with a proven record for positive change. Who is at the switchboard is much more important than the issue de jour. Second, don't fund stop-gap, individual service delivery projects (although they are very important) without funding a corresponding project to address systemic problems with access and quality
- Identify the broad range of healthcare best practices in your region (and nationally) and determine what can be done to expand and improve on them. Even if that means specifically soliciting applications from organizations that might not come to you. Similarly, identify the projects that the foundation has funded that have been the most successful and determine ways to expand them and replicate them.

- The impact of policy change can be significant. Help groups increase their development capacity with other funders, so groups have a broader base of support. While politically it is easier to distribute small grants to many, it might be more effective to do fewer, larger grants.
- Spend some time getting to know the groups that are doing the frontline work on health systems change. Talk to the corporate sector in this industry and ask them who they consider to be a pest. That pest is almost always your catalyst for change in that community.
- Support projects with specificity in terms of issue work and capacity building potential for organizations; do not fund vague capacity building work. Fund projects with support for all components necessary for policy change: community organizing, policy analysis, research, dissemination (media/messaging), coalition building, policymaker education, and policy advocacy.
- Decrease substantially funding for policy and research and sit down with a handful of us and let's talk about what is needed to truly build a health care coalition, and how long it will take.
- Fund a broad range of groups so they can work on this issue. Though we are a disease specific group, we are known in the environmental health field as a being a group that takes a very broad social justice policy perspective on the work we do.... We want quality universal health care for all. We are funded well by environmental health funders because they recognize the value we bring to the coalitions we serve on, but I don't think health care reform funders understand that about us yet.
- Have focus groups or direct conversations with past or current grantees to ask them this question and explore the answers in depth. This survey is a preliminary and perhaps overly simplistic step toward what should be a richer and more direct exchange of information, perspectives, and ideas between people/organizations who presumably share many of the same goals.
- Look to expand the organizations that you fund - smaller, creative and results-driven groups who operate on a shoestring, but are extremely effective.
- Please find ways to help build relationships among advocates and "grass tops" leaders in the business and corporate community.
- More funding is always needed in the smaller organizations to do work.
- Health care reform is both an immediate need and a long-term project. Yes, please keep funding organizations that work within the current system to care for people. But please also fund organizations that work for justice. Pope John XXIII said justice before charity. We've put charity first. A more just system would not need so much charity.
- Be more specific as to why applications were not funded, and what can be done to better the application for the next period, without fear of repercussions for being

honest, that is without fear that if an application is denied and the actual reasons given that a lawsuit would not be filed to ask the court if project A was better than project B. For example, in hiring practices, you can not only tell the person not hired that there were other people more qualified. You can assist them by saying things like your communication skills were lacking without fear of legal action.

- Look for conveners; aggressive, and effective advocacy organizations with visible policy staff; avoid jumping on current bandwagons; and take time to assess what's not being covered or funded.
- Be willing to take risks and invest in major systemic change - which will involve advocacy at a state or national level. The current health care system - which is based on a private insurance paradigm - is failing. To establish a different one - whether it is single payer, a coop or a 24 hour workers compensation model (Wisconsin) requires massive organizing, education and outreach not only to health care advocates and unions, but to businesses and the agricultural and ranching communities as well.
- People tell you what you want to hear and are too intimidated to tell the truth. Foundations (and staff) are treated like the wealthy uncle that no one wants to upset. Some non-profit hospitals have false halos and get large grants despite ugly collection practices
- 1. Ask current/former/potential grantees for input on reporting requirements (frequency, format), RFP structure etc. 2. Revisit funding priorities (particularly for those who only fund through large initiatives) on a more frequent basis and make the priority setting process more transparent. 3. For national foundations, consider more carefully the future of projects begun with large initiatives. Often a state/local foundation is reluctant to meet match requirements and/or pick up where the national foundation left off when the grant period expires.
- Think boldly about policy -- and about affecting the policy process.
- I would advise them to have more direct discussions on what they are doing that is helpful to providers and to changing and improving the delivery of care to uninsured and working poor communities with specific issues such as cultural and linguistic needs. I would advise them to recognize that their newsletters and internal research efforts are often times irrelevant in terms of providing vital information to making real changes and identifying issues that need serious attention. I would inform them that there is a tendency for them to operate with a "politically correct" mentality themselves and that they also make funding decisions based on this attitude and value. I would advise them to set aside funds to assist non-profits with stop-gap measures that require immediate turn around otherwise vital providers of care will be lost financially and programmatically. I would require them to speak to actual patients in forums that allow for real exchange and discussion with the patient population that they are always saying is of major concern to them.

- Fund passion; let the program happen sign the check, walk away, come back in six months and see what's been done with the money.
- Look for partnerships/collaborations/coalitions where partners essential to reform have a commitment to a clear and distinct role within a collaboratively defined strategic plan for how to get to broad based system reform. Provide seed money to jump-start those partnerships/collaborations/coalitions where none exist.
- Be generous and don't expect change overnight!
- Fund services for longer periods of time; don't change priorities frequently; don't require new programming as a requirement.
- I think one major new opportunity in child health is to go beyond "covering kids" to "covering kids with the services needed to ensure healthy development." This involves health prevention and promotion, developmental surveillance and follow-up services, and taking a broad definition of child health that includes medical and social services. It includes addressing issues of social and emotional health and such lifestyle issues that can begin to address child obesity and other health behaviors. There are exemplary practices within pediatrics that need to become routine practice, and this will require some policy and funding incentives and supports to occur. I think there are a lot of possibilities for foundations to promote and diffuse such practices and the policies needed to support them.
- Give more funding to consumer assistance programs that also do policy work.
- Give unrestricted funding and allow real policy advocacy, don't just fund the research.
- 1. Provide general support 2. Fund national organizations to mentor state organizations in building capacities 3. Bring grantee organizations together.
- Think long-term. Think about what messages/understanding we need to advance and what policies advance toward the long-term goal. Consider how the community [is] involved in the organizations. Access alone isn't enough; we need to address the disparities within the system as well.
- Limit the number of objectives that you ask an organization to achieve. Don't manipulate objectives so that an organization feels that they need to promise to achieve something in order to be funded, but are "secretly" concerned that it doesn't fit into their mission and capacity at the time.
- 1. Bring grantees together more often to strategize about the long-term vision of health care reform enabling organizations to identify gaps and then determine their niche. 2. Develop grant reports that allow grantees to see what they have accomplished while encouraging them to think long-term as well. 3. Encourage more organizations of color to apply and award them grants. The demographics of the nation are changing and organizations need to represent, at the leadership levels, the needs of their communities.

- Fund more core support; fund advocacy.
- Fund advocacy to change systems that don't work (like health care), or you will forever be funding projects that are like sticking fingers in the holes in the dike. Give multi-year grants for operating support to effective organizations so they don't have to expend so much time and energy every year trying to raise funds and can plan ahead more.
- Continue to move towards funding policy and media work in broad terms. Recognize policy changes will be incremental and take time over the grant cycle. Find synergies between organizations to fund or fund true collaborations (vs. just paying groups to bring people together in fluffy convenings). Start developing ways to fund health and non-health groups to work together on related issues (e.g., environmental health) rather than having them compete for funding on a very narrow topic.
- Take risks; invest in longer-term projects since reform is multi-year and complex.
- Be open to a wide range of ideas that can support your ultimate funding priorities. Specifically be open to considering proposals that involve limited lobbying as a small component of the overall public policy initiative. Also, consider funding media campaign[s] that include enough funding for adequate message development strategies such as polling and focus groups and also enough funding to run paid media messaging.
- Foundations that would like to have an impact on public policy need to be able to make decisions and get grants out faster.
- Fund grassroots organizing which will lead to policy changes.
- In order to effectively fund health policy work, in addition to multi-year core operating support, foundations need to be more flexible and timely in their grantmaking.
- Fund core operating grants that allow for flexibility.
- Although seniors have many government-sponsored programs to assist them as they get older, there are many gaps in the system and many low-income seniors suffer despite the government "safety nets." And when the government cannot explain its complicated federal programs such as Medicare Part D to the average citizen... nonprofit[s] fill a very apparent need.
- Encourage them to fund policy research and analysis, including public dissemination and advocacy efforts.
- Fund health care access advocacy work!! Reforming the health care delivery system will take several years. Be patient with efforts by the state advocacy groups. Each state has a different set of circumstances and political climate. Treat each state differently. Understand smaller and poorer states do not have as much access to family and private foundations as bigger states.
- Systemic change - the only answer to the health care crisis - will not occur without your support.

- Commit to a long-term process for building buy-in among the many-faceted health-care stakeholders for sustainable systems. Right now reform is sweeping the nation, but much of the reform is overly compromised and doesn't get at fixing the funding mechanisms in health care, and making the tough choices in health care that are really necessary. This requires real nitty-gritty negotiation, education, and deep policy shifts.
- 1. Trust the grantees to identify the needs of their communities; 2. Keep it simple for everyone; 3. Make the process commensurate with amount of the grant; 4. Make the process transparent and merit based.
- Experiment. Don't give all the research, policy money to a small handful of DC and NY organizations at the expense of smaller policy shops, who are more connected with grass-roots or coalition activity at the state level.
- Trust folks working in the field. Fund core support. Support more statewide work. Fund multi-year grants.
- Give responsible non-profits an opportunity to use the funding in a little less structured manner.
- Check in with people in the field before making grants to organizations; see what their colleagues have to say.
- Set the rules, require project outcomes and minimize detailed requirements.
- 1. Multi year funding is crucial. 2. Setting up technical support in the form of media and/or political strategizing will improve the outcomes of the organization.
- Focus on wellness, education and prevention programs.
- Fund consumer health advocacy organizations based on track record of effectiveness. Contact legislators, policymakers, health care organizations and community-based organizations to ask them about the effectiveness of the applicant. Look for projects that "push the envelope" toward health system changes that benefit individuals. Look for organizations that pay attention not just to broad policies but also to the effective implementation of those policies. Provide general support to organizations that have a proven track record.
- Stop funding picky projects that expend more human energy on creating a new infrastructure than on outcomes. Stop funding projects that have more paperwork and accounting steps than has been paid for by the grant! Fund advocacy! Even if it is the educational steps toward it - education, organizing, mobilization, change will not occur through studies alone. Fund STATE level programs that can include local allies instead of funding tiny projects that lack knowledge or capacity to carry them out. If you really want change - look to the larger change agents, not just the small players.
- Be willing to look at dull, existing programs that have a successful track record - rather than always looking for latest, new thing

- Trust and fund creative, clear talent and dedication. Encourage advocacy and work that builds on needs of individuals into effective efforts for systemic change. Provide funding for on-going needs and operations of organizations that are doing a good job - so they can keep doing it. Provide funding for leadership development.
- Fund projects that focus on policy change. The only way to create long-term, sustainable change is by focusing on policy and systems modifications.
- Fund more efforts for massive system change that are centered on community organizing and leadership development.
- Develop long-term relationships with grantees and support project and core support issues with commitment to funding for multiple years (of course with periodic review and potential cessation if not making good progress). This commitment allows grantee to focus on project outcome, develop high quality in-house staff, and not always be gaming to cover necessary expenses. In turn, the grantee should be expected to commit to the long-term nature of the project without running off in new directions.
- Think about what you think can be accomplished – what is the plausible end result – and how a particular grant may end up moving towards that goal.
- Think about health in a more holistic way. Health includes having an adequate place to live and enough money to afford food, housing and peace of mind. Low-income communities need to be connected to the vast amount of research and policy analysis that is being done. Invest in helping communities organize and learn so that they can speak for themselves.
- Look to models that work, think outside the ‘box’: i.e. insurance reform to ‘cover the uninsured’ will be sloooooow at best...look to other models of caring for vulnerable populations and the uninsured, support ‘volunteer’ based organizations: you get a bigger ‘bang for the buck’, assist on standards of care and policies and procedures, and website development of national organizations helping grass roots organizations.
- Oral health care is underfunded and yet vitally important to general, overall health. Public policy development in oral health is even more woefully underfunded.
- As the policy environment is ever changing, I would recommend that they check in with their grantees to be kept informed and to discuss potential changes in focus.
- Teach your Board about how funding coalition/policy change groups can lead to larger sustainable victories. Teach them about how funding needs to be somewhat sustained since policy education takes a long time. Teach them that the bang is worth the bucks.
- Recognize the unfunded niche areas that are critical to an overall goal such as healthcare; many foundations express similar funding requirements and organizations meeting these requirements tend to be large and well funded. A variety of organizations serve targeted populations, however, and that work is also critical in meeting the overall goal.

- We need larger national and multi-year funders to get behind state-level initiatives because it is clear that that's where real progress is being made. Multi-year funding is critical because of the complexity of this systemic problem. Successful strategies are those that build a base of support and build policy support and momentum over a period of 3-5 years.
- Make a long term commitment to your key grantees.
- Look at what the group you are about to fund does best and fund that. We often are doing things that are our core business and foundations need to invest some of their funding into the core business and not always be looking for "new" and "different". Even if a percent of every grant would be for core funding, that would be great.
- Take a risk - help unlikely organizations build their capacity to advocate for health and other issues - it pays off to have non-health organizations involved actively in lobbying for health care reform. Yet know that health care might not be only issue organization is advocating for. Very few are willingly to fund public policy advocacy work yet our advocacy work is incredibly effective.
- Fund civil rights strategies for health care reform
- 1. Look for the most experienced (20-25+ years) professionals in positions to know how to make health policy change happen, and fund their work. 2. Look for strong local and state level collaborations on the projects funded. 3. Fund policy work for a 5 year stretch. It takes that long. 4. Require fiscal accountability but don't have a fiscal advisor that just nickel and a dime a grantee's every move.
- [V]isit the target areas.
- It is very important to provide core support and long term funding to organizations that provide a value to health care reform. A few organizations that are well liked is not enough, there needs to be a wide diversity of groups and expectations of how to measure success/progress need to be explicit from the beginning. Some organizations work on several health issues and there should be a better way to provide core support to those organizations rather than piecing together program funding
- Know your area and learn about grantees
- Treat organizations with respect, listen, try to be helpful.
- [Some] foundations are doing a terrific job of funding a diverse group of organizations working in this area. Their support is additive, but has never been duplicative.
- Be open to understanding that more than one organization should be funded to work on an issue; be clear that national organizations who claim to do national work usually only work on the east coast.
- Keep in mind that the small offices run larger organizations and are normally the "keepers" of statistical data. Data is typically the "guts" of the Foundation application process.



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