

GIH

HEALTH REFORM
FIVE YEARS LATER:

*Philanthropy Steps Up
to the Challenge*

MAY 2015

A SPECIAL
REPORT FROM
GRANTMAKERS
IN HEALTH

Despite the policy fluctuations, the headlines, and the ongoing political battle, health reform has already helped millions of people and will soon help millions more. We certainly have to work with our grantees to address the current and developing challenges, but we also have to keep a hopeful eye on the horizon... This is where our leadership is vital. This is where we reveal ourselves, to our grantees and to the public... This is our moment.

– Andy Hyman (1966-2015)
Robert Wood Johnson Foundation

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EXECUTIVE SUMMARY

HEALTH REFORM FIVE YEARS LATER:

Philanthropy Steps Up to the Challenge

Five years ago, the Patient Protection and Affordable Care Act (ACA) was signed into law, establishing a new framework for providing health insurance coverage to millions of Americans and catalyzing numerous efforts to reform the health care delivery system. Since then, foundations have been engaged in a wide range of activities as the federal and state governments implemented the multifaceted law.

PHILANTHROPY'S IMPACT ON HEALTH REFORM

Health foundations have been engaged in efforts to expand coverage and to reform the health care delivery system for decades. Over the last five years, foundations have stepped up those efforts and have had a significant impact on virtually all aspects of health reform, both related to and independent of the ACA.

- **Foundations elevated health reform as a critical issue and helped keep it on the national and state policy agendas over the course of many years.** Efforts by local, state, and national foundations over the last decade to develop data and policy research about different reform options, support public education and awareness campaigns, and implement pilot projects, among other activities, helped build the policy imperative for action.
- **Foundations invested significantly in outreach and enrollment activities.** Local, state, and national funders invested in outreach and enrollment activities through a number of different strategies, enabling many states to surpass their original projections.
- **Foundations provided long-standing support to advocacy organizations and coalitions.** Philanthropy has invested in a complementary set of strategies over the years, including building and strengthening various aspects of the advocacy infrastructure, such as policy research and analysis, grassroots organizing, and policymaker relationship capacity. However, a wide variation in advocacy funding and capacity remains across the country.
- **Foundations jump-started delivery system reform activities.** Philanthropy has long supported program innovation and pilot initiatives for improving the health care delivery system. With health reform, the imperative to improve quality and outcomes and reduce costs increased, and foundations supported a variety of efforts that capitalized on the momentum and resources being made available under the ACA.

Foundations recognized that, in order to maximize their impact, they needed to change the way they operate—adjusting existing strategies and undertaking new ways of doing business. Funders **modified grantmaking practices**, including increasing funding levels, streamlining processes and procedures, and becoming comfortable with a higher level of risk; **partnered with and funded state government**, such as increasing their level of engagement with and providing critical resources for government in ways that they had not done previously; **exerted leadership in the state** through convening, relationship building, and other activities; and **developed and deepened collaborations** with other foundations, focusing, in particular, on outreach and enrollment activities.

There were myriad challenges during the implementation process, most of which are well known: the significant start-up problems encountered by the federal, as well as many state, insurance marketplace websites; the low level of health insurance literacy of many of the applicants, necessitating lengthy assistor appointments; and the issue of integrating health insurance marketplaces and Medicaid systems, among others. Two challenges stood out, which funders sought to address:

- **Polarization:** The most challenging aspect of engaging in health reform-related activities over the last five years has been the depth of political polarization and resistance to the ACA in many parts of the country.

Nevertheless, funders brought evidence-based nonpartisan analysis and data to inform the debate.

- ▶ **Inadequate State Policy Capacity:** The lack of state government policy and operational capacity to implement the ACA and other health reform activities was an impediment in most states. To overcome this barrier, many funders partnered with and funded government in new ways and at new levels.

GOING FORWARD: REALIZING HEALTH REFORM'S POTENTIAL

Recognizing the many implementation-related issues that still warrant attention associated with the state and federal marketplaces and Medicaid, there are three overarching issues that funders will be addressing going forward:

- ▶ **Targeting Outreach, Enrollment, and Education Activities:** Although millions of Americans have gained access to insurance through both the marketplaces and Medicaid, many still remain uninsured. In particular, enrollment of Latinos has lagged behind, and investment in targeted outreach strategies is needed. The low level of health insurance literacy of many individuals who obtained insurance in the marketplaces during the first enrollment period also suggests the need for education activities.
- ▶ **Accelerating Service Delivery Reform:** Although the philanthropic community has long been involved in efforts related to reforming the health care delivery system and will continue to invest in a range of research and demonstrations, two issues have emerged in the wake of the ACA: health care costs, including payment reform, and the sufficiency of the workforce. In both of these areas, funders are exploring how they can best deploy resources and contribute given the long-term nature of these issues and the significant roles played by government.
- ▶ **Elevating and Advancing Health Equity:** Foundations identify health equity as one of the top issues on the horizon, although there are differences in how funders approach the issue, depending on whether the foundation is a national, state, or local funder and where the foundation operates. Many funders believe that health reform and the ACA, in particular, may provide a springboard to advance a broad-based strategy to achieve greater health equity.

RECOMMENDATIONS

- ▶ **Find the balance between staying the course and advancing new issues on the horizon.** One of the hallmarks of philanthropy is the ability to identify and elevate issues on the horizon. At the same time, many advocates, as well as funders, are concerned that the field may move on to other concerns, even though implementation of the law still faces significant challenges. Health philanthropy will need to find a balance between staying the course and continuing to support both health coverage and service delivery reform issues, with early investments to lay the ground for new issues, such as health equity.
- ▶ **Recognize that service delivery reform efforts will require advocacy organizations to develop new skills and expertise, and invest in their capacity building.** As both funders and advocates increasingly engage in efforts to reform the health care delivery system, consumer advocacy organizations will need to develop new capacities, relationships, and skills. Funders invested for years in coverage issues, and advocates believe a similar timeframe will be needed for service delivery reform efforts.
- ▶ **Build on successful models of collaboration.** Several of the issues on the horizon that funders identified—health equity and prevention-related issues—require cross-sector partnerships. Therefore, health funders will need to collaborate to a greater extent with colleagues from foundations in other fields, such as income security, education, housing, and criminal justice.
- ▶ **Capitalize on and leverage past investments in the advocacy infrastructure for health equity and other goals.** State and national advocates believe that philanthropy played a significant role in the passage of health reform through investments in a variety of activities, particularly the advocacy infrastructure, over the course of many years. Several funders and advocates believe that infrastructure could be a platform for addressing new issues, beginning with those closely related to health reform, such as health insurance literacy, and then moving to a broader range of health equity efforts.

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BACKGROUND AND CONTEXT

The Patient Protection and Affordable Care Act (ACA), signed into law in March 2010, was perhaps the most significant social policy enacted since Medicare and Medicaid, nearly 50 years earlier. The law set forth a new framework for providing health insurance coverage to more than 26 million Americans, instituted new rules governing the private health insurance market, offered an infusion of resources to help reform the health care delivery system and reduce costs, and provided new opportunities to promote prevention and public health.

The process of passing the legislation was difficult and controversial, and the implementation process has faced resistance on multiple fronts. Opponents to the law pursued efforts to repeal, defund, or otherwise block its implementation in Congress, state legislatures, and the courts. Ultimately, the Supreme Court upheld the major tenets of the law, including the individual mandate; at the same time, it weakened the Medicaid provisions by giving states the opportunity to opt out of the expansion. In general, operationalizing the law at both the federal and state levels—from the website and enrollment processes to outreach and education—has proven to be far more complicated than anyone anticipated.

Nevertheless, for many health foundations, the ACA represented a significant opportunity to achieve the long-standing goals of providing health insurance coverage to millions of uninsured Americans, and they stepped up efforts to support its implementation.

Five years ago, Grantmakers In Health (GIH) issued the report *Implementing Health Care Reform: Funders and Advocates Respond to the Challenge*, which identified key strategies under consideration by foundations and provided an overview of the plans, activities, and challenges of national and state-based consumer advocacy organizations. Since then, foundations have engaged in a wide range of activities as the federal and state governments implemented the multifaceted law. Beyond the ACA, health funders have also renewed efforts to help redesign the health care delivery system to improve quality and health outcomes and reduce costs.

With this new report, GIH seeks to capture the full spectrum of ways in which foundations have engaged in health reform-related efforts—both coverage expansion and health service delivery reform—since passage of the ACA (although not all activities are directly related to the ACA). The report also includes what foundations describe as the major issues on the horizon. Moreover, like the 2010 report, this report includes the perspectives of key state and national consumer advocacy organizations. Finally, the report concludes with recommendations for foundations to consider.

THE LAST FIVE YEARS: PHILANTHROPY'S CONTRIBUTIONS AND ROLES

OVERVIEW

To collect data from as many health funders as possible, a survey was sent to all GIH Funding Partners. A vast majority of respondents reported that they supported health reform activities, with three-fourths of them indicating that their activities were related to the ACA (Figure 1). That number, however, is likely even larger. For example, one survey respondent whose foundation's activities were described as not ACA-related, reported that the foundation focused its access-related funding on navigation and insurance enrollment. The foundation did not call it an "ACA" initiative, but, nevertheless, supported local partners that were providing enrollment assistance, and funded the creation of a formal network of health navigators.

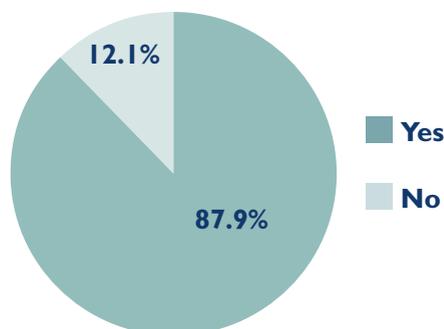
Over the last five years, funders prioritized a range of health reform issues, including a broad mix of health coverage and health delivery system reform issues. Out of a list of 19 issues included in the survey,¹ funders identified two issues, in particular, as their highest priorities: access and coverage options, including for individuals ineligible for the ACA, and care coordination. Outreach and enrollment, health disparities and equity, and public health and prevention rounded out the top five (Figure 2). Funders supported and carried out a broad range of strategies in support of these issues, with convening, program innovation and reform, and advocacy being the top three (Figure 3).²

SURVEY HIGHLIGHTS

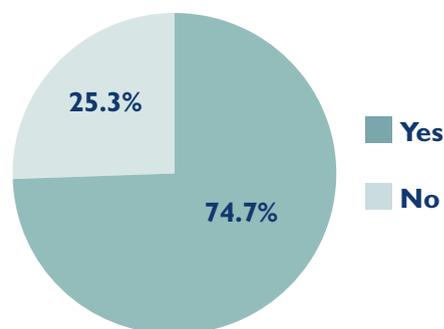
- Sent to 224 individuals from discrete foundations
- Forty-one percent response rate
- Respondents from a broad diversity of funders across geography, size, and funder type (local, statewide, regional, and national)
- Majority completed the survey

FIGURE 1

Over the last four years, has your foundation supported any health reform-related activities, which we define as either reforming the health care delivery system or expanding coverage? (n=91)



If your foundation supported health reform-related activities, were the majority of those activities related to or associated with the ACA? (n=76)



¹ See Appendix B for complete list of issues.

² In addition to the original list of six strategies from the 2010 report, Monitoring and Evaluation was added to the list for the survey.

FIGURE 2

Which of the following health reform-related issues are your foundation's highest priorities?
Top five choices shown. (n=83)

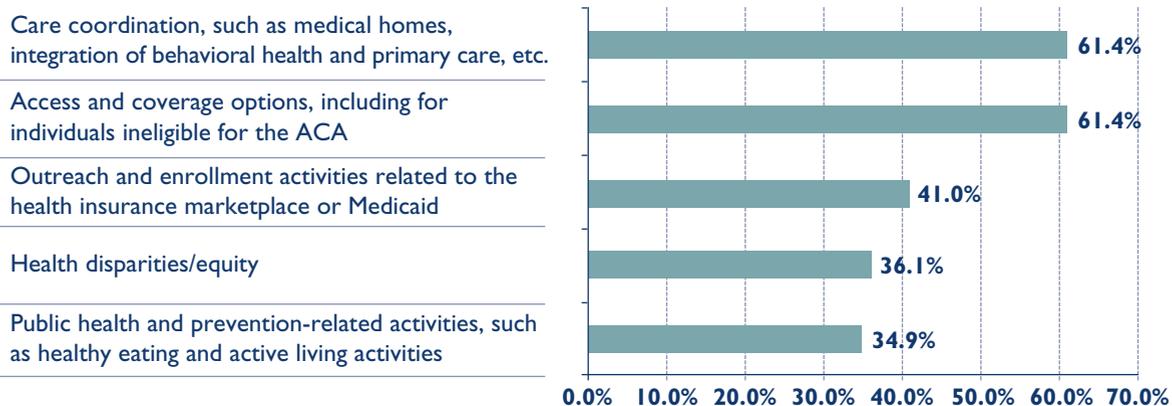
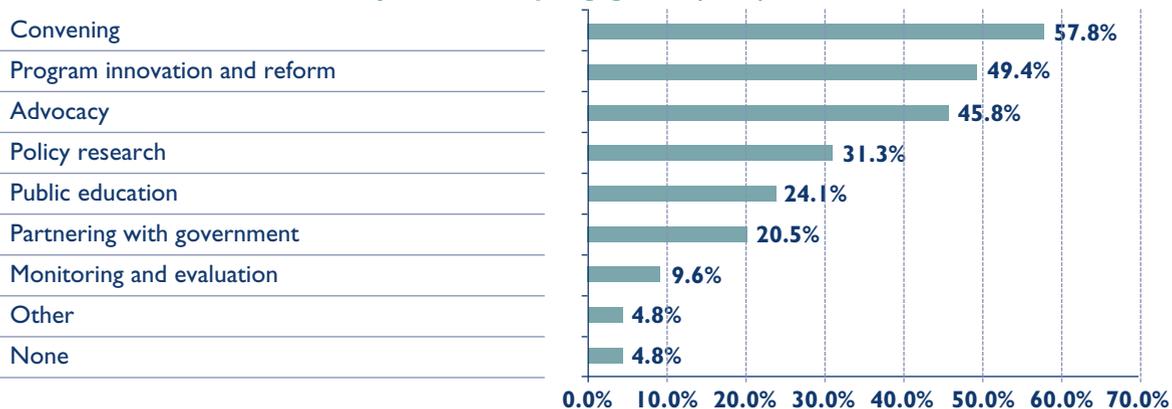


FIGURE 3

Looking back over the last four years, please indicate which activities your foundation has predominantly engaged in. (n=83)



PHILANTHROPY'S IMPACT

Foundations have had a significant impact on virtually all aspects of health reform. Foundation contributions in four areas, in particular, emerged through the survey and interviews as having been especially important.

- **Foundations elevated health reform as a critical issue and helped keep it on the national and state policy agendas over the course of many years.** Efforts by local, state, and national foundations over the last decade to develop data and policy research about different reform options, support public education and awareness campaigns, and implement pilot projects, among other activities, helped build the policy imperative for action. One leading national policy observer commented that philanthropy played a particularly important role in laying the groundwork for health reform by documenting the scope of the uninsured and why the lack of insurance is a strain on people and economies.

Moreover, within the ACA, several issues were included as a result of philanthropic support, at least in part. For example, advancing public health and prevention is an area that is heavily supported by philanthropy, and there are few institutional champions or resources to advocate for prevention. Inclusion

in the ACA of the Public Health and Prevention Fund, which provides a dedicated revenue stream for prevention activities for the first time, reflects the work of many foundations and their grantees.

- **Foundations invested significantly in outreach and enrollment activities.** Perhaps more than any other activity, funders and advocates alike commented on the critical role played by foundations in supporting outreach and enrollment activities. This support began in anticipation of, and through, the 2014 launch of the health insurance marketplaces. Funding and capacity were limited in all states, and there was generally insufficient attention to the needs of diverse, non-English speaking populations. Moreover, some states took steps to block recruitment, training, and funding for enrollment assistance.

Local, state, and national funders invested in outreach and enrollment activities through a number of different strategies, enabling many states to surpass their original enrollment projections. Key strategies include:

- *Supporting the Creation and Implementation of Enroll America:* National, state, and local funders, spearheaded by the Robert Wood Johnson Foundation, provided significant resources to create Enroll America, which assisted 11 states in conducting outreach and education activities. According to an evaluation conducted by Mathematica Policy Research (2014), Enroll America was successful in “yielding positive outcomes” in outreach and enrollment.
 - *Catalyzing Coalitions of Organizations to Coordinate Enrollment Activities:* The Missouri Foundation for Health, for example, convened a coalition of organizations, called Cover Missouri, to increase the number and capacity of enrollment counselors and build awareness. Hundreds of organizations are participating in the coalition, which, by many accounts, has been very successful. The coalition, as well as the foundation’s direct funding of other enrollment activities, enabled the state to exceed its enrollment projections.
 - *Providing the “State Match” to Draw Down Federal Funding for Outreach and Enrollment:* The California Endowment assisted the state, which was still experiencing budget difficulties, to more fully fund outreach and enrollment activities.
 - *Underwriting Various Navigator and Outreach Positions at the Local and State Levels:* Funders of all sizes were able to contribute in very concrete ways by supporting one or more positions.
 - *Targeting Support to Assist Diverse Populations:* Although efforts were made to translate materials, many populations, such as the Asian American and Pacific Islander (AAPI) community, were left out. The Walter H. Coulter Foundation, joined by other national funders, provided significant resources to 70 organizations in 22 states that reached 200,000 AAPI individuals. In Washington State, the Empire Health Foundation created a subsidiary called Better Health Together, which was the In-Person Assistor network administrator for a 14-county region targeting hard-to-reach populations. The network enrolled 50,000 people, far exceeding its goal of enrolling 10,000 people.
 - *Celebrating and Motivating Outreach Workers:* Believing that the second enrollment period would be at least as challenging as the first one, The Colorado Health Foundation sought to renew enthusiasm and momentum by hosting an enrollment conference in partnership with the Colorado Division of Insurance, the state health insurance marketplace, and Medicaid. Beyond providing navigators and assistors with necessary information, the main purpose of the two-day conference was to inspire them. The foundation recognized the challenging nature of the work and wanted to celebrate past successes and motivate the one thousand or so enrollment assistors who attended the conference.
- **Foundations provided long-standing support to advocacy organizations and coalitions.** The 2010 report identified supporting advocacy as one of the six key strategies funders were undertaking with regard to health reform. Survey respondents ranked advocacy third among their most-used strategies (Figure 3). Foundations have long funded advocacy, supporting the development of a robust advocacy infrastructure in many, but not all, parts of the country. In fact, more than half of survey respondents (57 percent) reported that they fund consumer or other types of advocacy.

FIGURE 4

Do you currently fund consumer or other types of advocacy to work on health reform-related issues? (n=68)

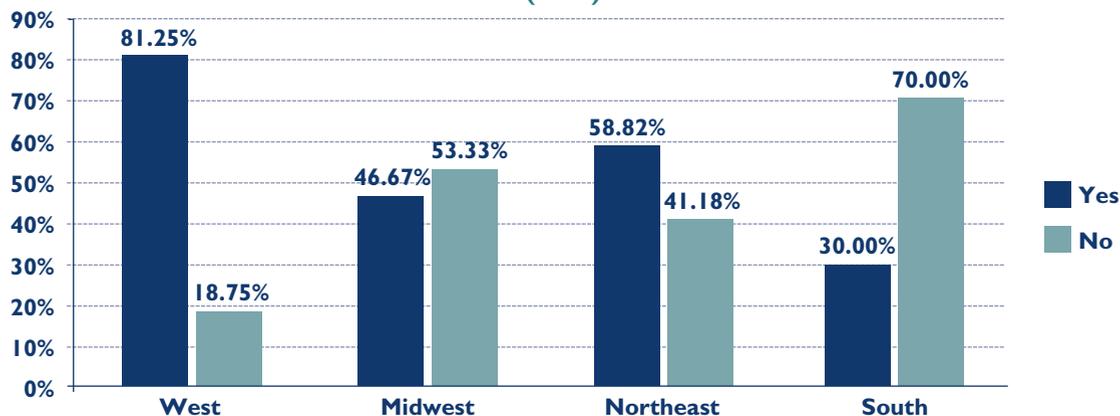
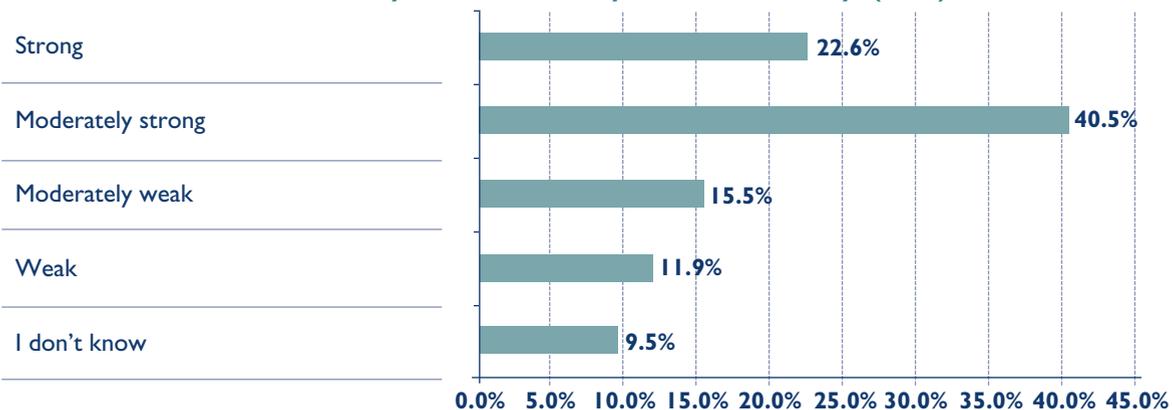


FIGURE 5

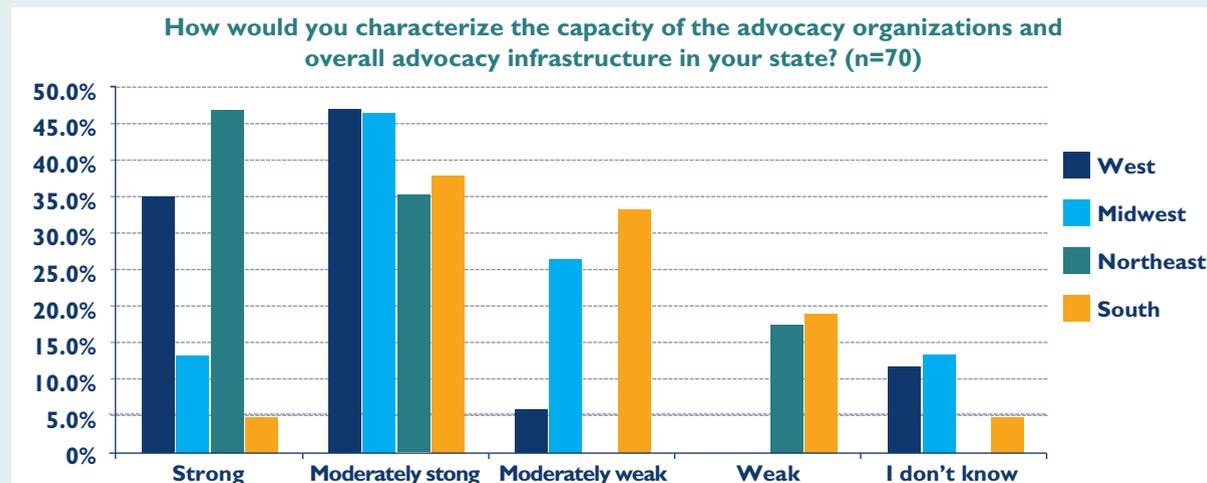
How would you characterize the capacity of the advocacy organizations and overall advocacy infrastructure in your state/nationally? (n=83)



At the same time, there is wide variation in advocacy funding and capacity across the country. For example, only 30 percent of funders in Southern states reported that they support advocacy, compared with more than 80 percent of funders from the West (Figure 4). Similarly, foundations' perceptions of the strength of the advocacy capacity in their states varied by region. Overall, 63 percent of funders that participated in the survey characterized their states as having a strong or moderately strong advocacy infrastructure (Figure 5). Although over 80 percent of funders in the West and the Northeast describe the capacity of advocacy organizations in their states as strong or moderately strong, less than half of funders from the South (only 43 percent) characterized the advocacy infrastructure in their states in that way (Figure 6).

National funders and advocates have sought to address this situation for years, but it remains a challenge. Advocates report that, first and foremost, it is a matter of having more resources to hire more people. For some advocates in low-capacity states, solutions come with their own set of challenges. One advocate noted that greater funder collaboration to support coalition building would be helpful, but was also concerned that such an effort would result in multiple reporting requirements, adding to their burden.

FIGURE 6



Overall, advocates believed that philanthropy played a critical role in health reform. A national advocate observed, “I would say philanthropy has understood the importance of the ACA as a generational event and has come together to support the efforts of state advocacy to implement it.” Advocates noted, in particular, that foundations have invested in a complementary set of strategies over the years, including building and strengthening various aspects of the advocacy infrastructure, such as policy research and analysis, grassroots organizing, and policymaker relationship capacity. At the same time, funders have supported specific advocacy efforts in response to windows of opportunity.

Advocacy-related strategies reported by funders include³:

- *Supporting Advocacy with a Health Equity Lens:* The W. K. Kellogg Foundation has maintained a long-standing commitment to enhancing racial, ethnic, and cultural equity. It funded a network of national policy and advocacy organizations that work on behalf of various communities of color and that are connected to state and local networks of organizations. The network included: Advancement Project, Asian and Pacific Islander American Health Forum, Demos, National Association for the Advancement of Colored People, National Congress of American Indians, National Council of La Raza, National Urban League, PICO National Network, Poverty and Race Research Action Council, and Race Forward.
- *Directly Engaging in Advocacy Efforts:* Some foundations indicated that they were seeking to be a part of advocacy efforts. The Mt. Sinai Health Care Foundation believes that directly engaging in the policy arena keeps the foundation better informed; moreover, by being “at the table,” the foundation is able to add value to its grantmaking, such as raising key issues that may be difficult for grantees in sensitive situations.
- *Creating a New 501(c)(4) Health Advocacy Organization:* The Colorado Health Foundation has been classified as a public charity, although it will be transitioning to a private foundation in 2015. To take advantage of being a public charity, the foundation created a new 501(c)(4) organization, Healthier Colorado. The foundation is providing an endowment large enough that its interest earnings can support the operations of the new organization; however, the organization cannot use the interest for campaigns, so it will need other funding to support advocacy work going forward.

► **Foundations jump-started delivery system reform activities.** Philanthropy has long supported program innovation and pilot initiatives for improving the health care delivery system. As Figure 3 shows,

³ See also Coen, S., and S. Cotsoradis, “Reflections on Building the Advocacy Capacity of Nonprofit Organizations,” *GIH Bulletin*, Views from the Field, July 21, 2014, for an in-depth description of efforts to strengthen advocacy organizations in Kansas.

fundes ranked program innovation and reform as the second-most utilized strategy undertaken on health reform.

In many states, especially those that implemented their own health insurance marketplaces and/or the Medicaid expansion, most of the attention and energy of foundations was dedicated to coverage-related issues. Nevertheless, foundations are increasingly recognizing that it is the readiness of the health care system to absorb newly insured people that will determine the success of health reform. In states that did not implement their own marketplaces or the Medicaid expansion, delivery system issues provided opportunities for philanthropy to engage in health reform-related activities. Advocates similarly identified the imperative of addressing the dysfunctions of the health care system before the increasing demands exacerbate them. A wide variety of on-the-ground system reform and practice improvement efforts have been supported by fundes across the country.

- The Health Foundation for Western and Central New York focused its health reform-related work on practice transformation and local implementation strategies by helping prepare the safety net system and ancillary community services to serve the increasing number of people who are newly insured. In particular, as the health system begins to shift from fee-for-service to pay-for-performance under Medicaid, the foundation supported a multistep initiative to help the safety net system develop appropriate new competencies.
- The Sierra Health Foundation in California focused on developing a regional strategic plan for bolstering the capacity of community health clinics. Because the ACA was going to make new resources available to community health centers, the foundation assisted clinics interested in pursuing federally qualified health center status and expanding their service capacity in anticipation of meeting the needs of newly insured individuals. It also assisted them with integrating access to specialty care and encouraged them to all use the same electronic health records. The foundation was then able to leverage its support to engage other fundes to further strengthen the operational, financial, and clinical capacity of these centers.
- The SCAN Foundation helped California successfully apply to be a national Medicaid-Medicare dual-integration pilot site. The foundation partnered with The Commonwealth Fund to provide national technical assistance to state leaders responsible for creating and implementing Medicare-Medicaid integration pilots as its most successful health reform-related collaboration.
- The Jewish Healthcare Foundation in Pennsylvania has engaged in a series of demonstrations to test new models of care for complex patients, including physical and behavioral health integration, primary care transformations, and readmissions reduction. In each case, it identified policy, payment, workforce, and other barriers to achieving optimal systems of care and the best outcomes for patients. The ACA catalyzed new partnerships and projects, and the foundation has been able to leverage resources provided by the Center for Medicare and Medicaid Innovation to accelerate health systems reform, such as transitions in care and readmission-reduction efforts.

NOT BUSINESS AS USUAL

The philanthropic community recognized that the ACA represented an opportunity to significantly expand health coverage and access for the uninsured. Consequently, many also recognized the need to respond in new ways to meet the various challenges associated with implementing the ACA, including the enormous complexity of the law, the limited capacity of many state governments, the tight timeframes and deadlines, and the political environment. Nearly 60 percent of survey respondents reported that they changed their funding priorities as a result of increased health reform activities, half said they changed their grantmaking approach, and 30 percent reported changing grantees.

- **Modified Grantmaking Practices:** Many foundations changed their grantmaking practices, including increasing funding levels, streamlining processes and procedures, and becoming comfortable with a higher level of risk. The California Endowment, for example, sought and received approval from its board of

directors to take a “very aggressive stance” with regard to implementation. Several hundred million dollars over four years—above and beyond the foundation’s regular grantmaking budget—was allocated to support an overall plan that focused on outreach and enrollment, workforce, and health homes. In addition:

- The Commonwealth Fund put special procedures in place to be able to fund requests, when necessary, more quickly than is possible with its traditional schedule.
- The Colorado Trust supported the establishment of the Strategic Advocacy Fund, a quick-turn-around, project-specific fund to respond to emerging issues. Although the trust no longer supports the fund, The Colorado Health Foundation’s new consumer advocacy strategy is designed to be similarly nimble.
- The REACH Healthcare Foundation in Kansas roughly doubled its budget—from 10 percent to 20 percent—for discretionary grants (as opposed to requests for proposals) to enable the foundation to be more nimble and responsive. Enactment of the ACA also affected the foundation’s funding and policy priorities. When the foundation developed its five-year strategic plan in 2010, ACA implementation was on the bottom of the list. Now it is a significant part of the foundation’s work. Moreover, the ACA prompted the foundation to change the way it approaches its work—investing, for example, in policy work and capacity building for advocates.
- The Kate B. Reynolds Charitable Trust in North Carolina moved quickly to fund a range of outreach and enrollment activities. The trust recognized that organizations were venturing into new territory, and it had only a few months to get money into the field. Understanding that everyone was scrambling and making educated predictions about the first open enrollment, the trust sent a flexible message to applicants: “Give us your best guess about what’s needed to get people enrolled, and we’ll do our best to review and invest quickly in the most promising ideas.”

► **Partnered with and Funded State Government:** Although only 21 percent of survey respondents indicated that they partnered with government during the last four years (Figure 3), many foundations also indicated that they increased their level of engagement with government and provided critical resources for government in ways that they had not done previously. Several foundations acknowledged that funding the state directly represented a departure from past practices. However, the combination of state governments’ limited capacity and the opportunity presented by the ACA prompted them to revisit previous policies about not “backfilling” government.

Examples of how foundations partnered with government include⁴:

- The Paso del Norte Health Foundation funded the strategic plan for the Texas health insurance marketplace and hired a grant writer to enable the state to submit a grant for federal funding to implement the plan.
- Three California health foundations supported a series of stakeholder-engagement processes associated with the development of California’s State Innovation Model grant proposal.
- Foundations in Colorado long supported a health policy advisor in the Governor’s Office, and the California HealthCare Foundation funded a position in the first year to develop an implementation plan for the ACA.
- The Connecticut Health Foundation funded the development of the state’s All-Payer Claims Database.
- The New York State Health Foundation took a behind-the-scenes role with the state by acting as a sounding board and producing policy analyses on key issues and decisions facing the state.
- The California Endowment is providing the state share for the 2703 Medicaid health home initiative and provided logistical support for stakeholder meetings.

⁴ See also Zepeda, S., and J. Lee, “‘Acting Bigger’ by Partnering with Government.” *GIH Bulletin*, Views from the Field. August 18, 2014, for an in-depth description of Kentucky’s efforts.

- The Con Alma Health Foundation supported a comprehensive, multisector process to develop a work plan for implementing the ACA in New Mexico. Subsequently, by supporting the state's grant application process, Con Alma helped bring over \$34 million to the state to help plan the state health insurance marketplace.

Foundations in several states described various ways in which they supported the development and upgrade of state information technology (IT) systems and infrastructure, as states realized that their IT systems were woefully out of date and inadequate to meet the demands of ACA implementation. Major issues included interoperability of data from multiple departments, as well as the capacity to create a health insurance marketplace website that was designed to meet consumer needs.

The New York State Health Foundation provided funding that helped the state get a federal match to upgrade its IT systems. Enroll UX 2014, a project spearheaded by the California HealthCare Foundation in collaboration with other state and national funders, worked with 17 states and the federal government to create a state-of-the-art online tool that marketplaces could use to assist consumers with identifying eligibility, selecting a plan, and enrolling in health insurance. The final design was made available for every health insurance marketplace to use as its front-end design (the part that consumers would see and use). At least seven states (California, Colorado, Maryland, Minnesota, New York, Oregon, and Washington) and the federal government have leveraged the Enroll UX 2014 design in their marketplace development.

- **Exerted Leadership in the State:** One of philanthropy's most important leadership roles comes from its ability to build relationships and bring people together. In fact, nearly 60 percent of foundations reported using convening as a strategy for health reform. For example, the Sunflower Foundation in Kansas described how its image as a neutral player enabled it to convene payers and providers even when tensions exist.

Beyond convening, many foundations reported that, as a result of the ACA, they sought out additional ways to provide leadership and shape the debate:

- The Connecticut Health Foundation built a history of good relationships with state leaders. The foundation's longtime investment in "thought capital" allowed it to leverage its influence and provide input to state leaders. Moreover, the CEO of the foundation was appointed vice chair of the Governor's Health Care Cabinet to advise on health reform implementation.
- The REACH Healthcare Foundation hired a health care advocate to advise the board and weigh in on specific issues; these activities complemented education efforts supported by other foundations.

FIGURE 7

What types of funders did your foundation collaborate with on health reform-related activities?

(n=85)

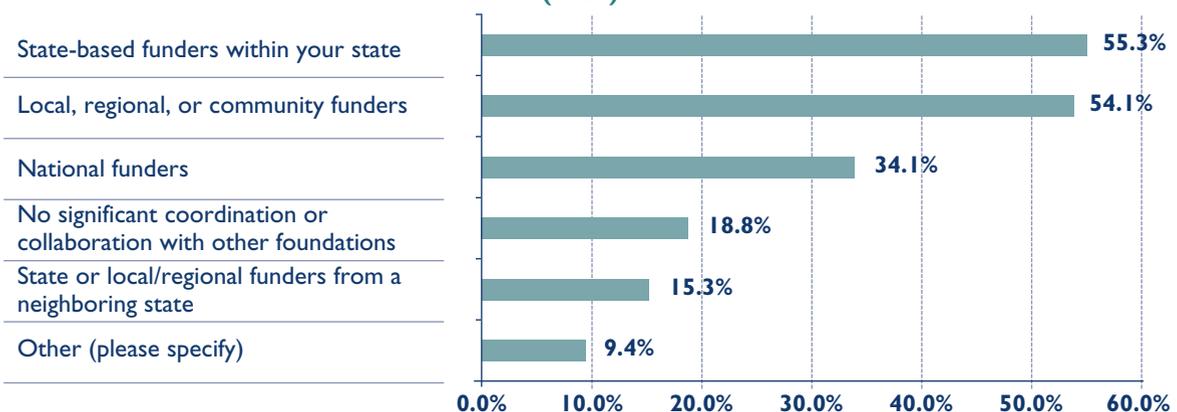
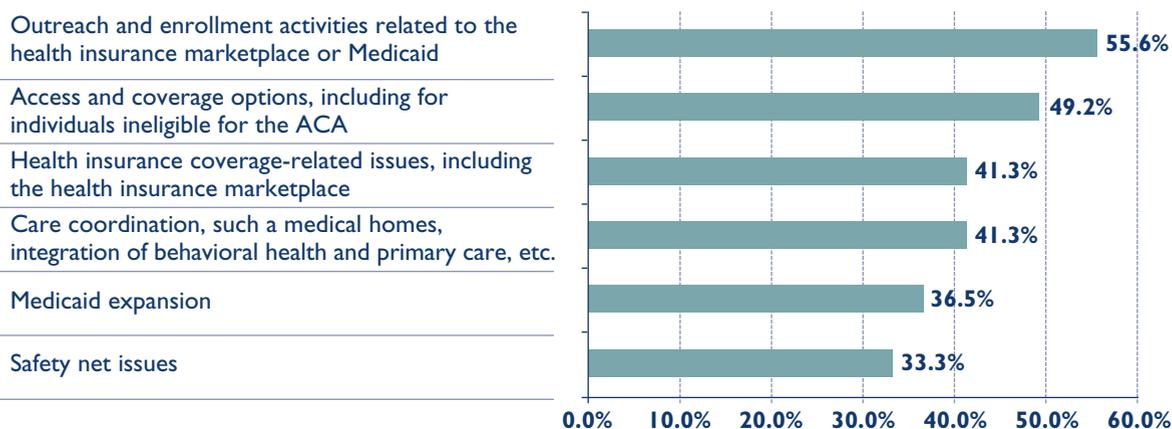


FIGURE 8

Which issues did you collaborate on with other foundations? Top six choices shown. (n=63)

- Several foundations exerted leadership by taking a variety of actions—funding coalitions, commissioning policy research, undertaking communications activities, and educating policymakers—to inform their states’ leadership about the importance of implementing the Medicaid expansion. For example, St. Luke’s Health Initiative in Arizona supported polling and story-banking (collecting and publicizing consumer stories) related to the need for Medicaid. In Ohio, the Mt. Sinai Health Foundation provided testimony to various state legislative committees about a commissioned study on Medicaid.

► **Developed and Deepened Collaborations with other Foundations:** The 2010 report identified greater funder coordination and collaboration as a critical strategy for stretching scarce resources and enhancing the effectiveness of philanthropic efforts in health reform. In the 2014 survey, over half of respondents reported that they collaborated with local, regional, or state funders, and a third reported collaborating with national foundations. Only 19 percent indicated that they did not collaborate at all (Figure 7). More than half of foundations that collaborated did so on activities related to outreach and enrollment (Figure 8). Funders also reported significant collaboration on access to coverage, health insurance coverage-related issues, and care coordination. For example:

- Because northern Virginia had only two official navigators, the Northern Virginia Health Foundation funded a 50-group coalition that trained staff and volunteers to become certified assistors. The foundation encouraged other funders to contribute, and eventually funding was matched one-to-one by three other area funders.
- Kansas is home to six health conversion foundations, which meet regularly. The ACA provided their first major opportunity to develop a joint project, which became the Health Reform Resource Project (HRRP). What made this collaboration unique—and successful—is that the funders agreed to hire someone to represent it. Deeply knowledgeable, this person has become the “go to” person on health reform in the state. The HRRP provides education, convening, and funding opportunities to assist organizations, communities, and the legislature in understanding the ACA.
- In Texas, the Hogg Foundation for Mental Health reported that as a result of both the ACA and the state’s pursuit of a Medicaid 1115 waiver, Texas foundations accelerated efforts to work together, from networking to pooled funding opportunities. Specifically, the Texas Network of Behavioral Health Grantmakers grew out of a meeting of the Rockwell Fund, The Houston Endowment, the Meadows Foundation, and the Hogg Foundation. The network educates foundation staff on key behavioral health issues and tracks trends in the policy environment. Participants vary greatly in their expertise on behavioral health issues, and the network provides a safe space to share strategies and raise questions.

- Several funders identified the ACA Implementation Fund, a collaboration of nine national foundations hosted by Community Catalyst, as a very successful effort. The fund enabled a significant number of foundations that might not otherwise have had the expertise or capacity to identify and fund projects to participate in grantmaking related to health reform. For smaller national foundations without deep expertise in health reform, such as the Jacob and Valeria Langeloth Foundation, it provided a way to contribute and feel confident that the states with the greatest need were being identified and funded.

Although some successful collaborations between national and state foundations were identified, several funders reported challenges in establishing such relationships, in part because each funder is accountable to and measured by goals established by independent boards and leadership. Moreover, national and state funders expressed difficulty in identifying potential partners on the particular issues in which they were interested.

OVERCOMING CHALLENGES

Funders and advocates alike confronted myriad challenges during the implementation process, most of which are well known: the significant start-up problems encountered by the federal, as well as many state, insurance marketplace websites; the low level of health insurance literacy of many of the applicants, necessitating lengthy assistor appointments; and the issue of integrating health insurance marketplaces and Medicaid systems, among others. Two challenges stood out:

- **Polarization:** By far the most challenging aspect of engaging in health reform-related activities over the last four years has been the depth of political polarization and resistance to the ACA in many parts of the country. The Supreme Court ruling that allowed states to choose whether to implement the Medicaid expansion was another unanticipated challenge, resulting in many states foregoing billions of dollars in federal Medicaid funding. Many states' implementation efforts were further complicated by the elections of 2010 and 2012 and resulting changes in state leadership; after months of intense planning and preparation, some states reversed course on implementing a state-based marketplace and the Medicaid expansion.

Nevertheless, funders sought ways to continue to inform the debate. Some foundations, such as The Commonwealth Fund, stressed the importance of taking a long view and the need to speak to all sides. Key strategies used by foundations to tackle polarization include:

- the production of evidence-based nonpartisan analysis and data,
 - outreach and relationship building with legislators of both parties, and
 - communications and framing to depoliticize the issues.
- **Inadequate State Policy Capacity:** The second major challenge experienced by funders was a lack of state government policy and operational capacity to implement the ACA and all of its complexities. Although capacity is weakest in the South, states in all regions of the country faced inadequate staffing and expertise as a result of the severe recession post-passage of the ACA and years of state budget cuts. To support state policy capacity, many funders partnered with and funded government in new ways and at new levels. One of the most successful efforts cited by funders has been the Robert Wood Johnson Foundation's State Health Reform Assistance Network, which provided technical assistance to 11 states (Alabama, Colorado, Illinois, Maryland, Michigan, Minnesota, New Mexico, New York, Oregon, Rhode Island, and Virginia) to help them with a variety of coverage-related implementation activities.

GOING FORWARD: REALIZING HEALTH REFORM'S POTENTIAL

The survey asked foundations to rank which issues they believed are going to be the most critical over the next two years (Figure 9). Out of a list of 12 issues, the top two were:

- Care coordination
- Controlling health care costs

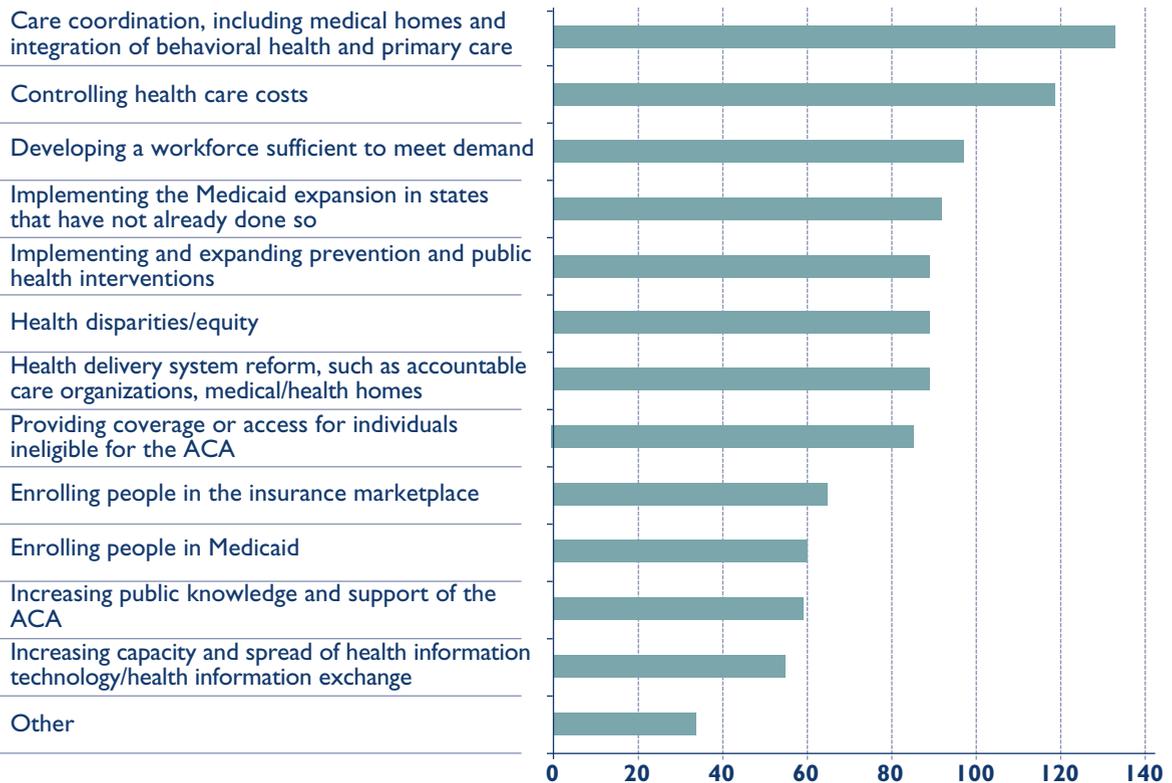
The next six issues were closely ranked:

- Workforce sufficiency
- Medicaid expansion in states that have not yet expanded
- Prevention and public health
- Health disparities/equity
- Health delivery system reform
- Providing coverage or access for individuals ineligible for the ACA

Although enrolling people in the health insurance marketplaces and in Medicaid were ranked near the bottom, many interviewees emphasized the myriad implementation-related issues associated with the state

FIGURE 9

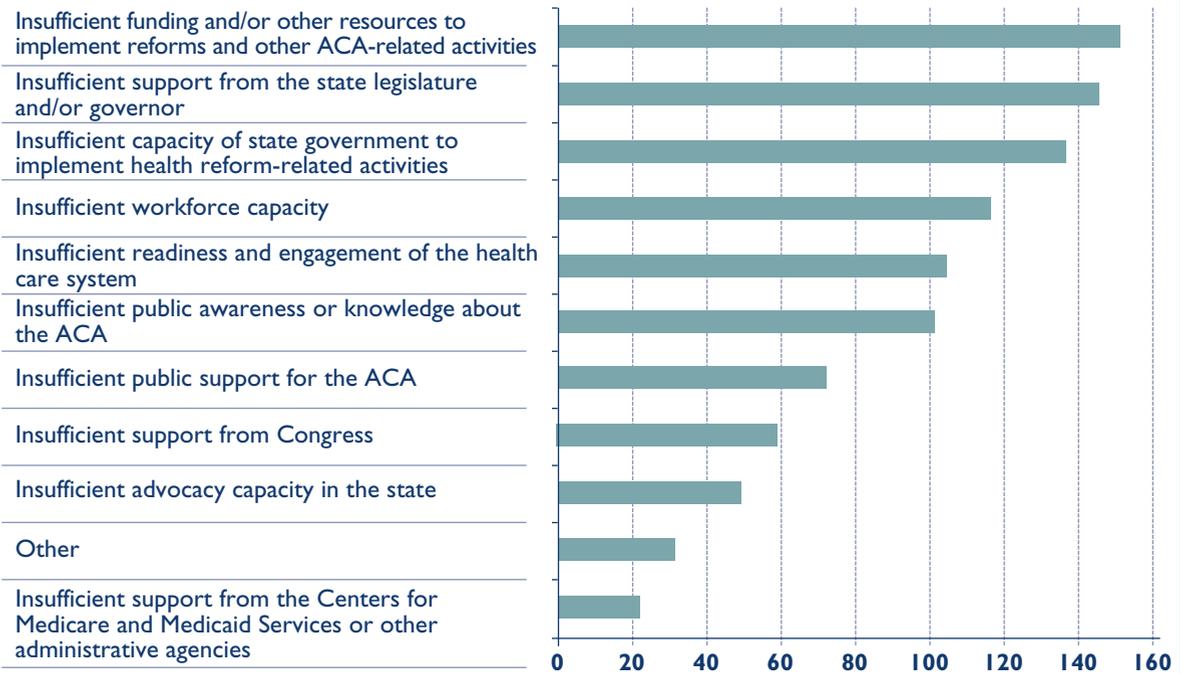
What do you think are the most critical issues related to health reform that need to be addressed in your state (or nationally, if you are a national funder) over the next two years? Please rank from one to five where one is the most critical. (n=78)



Note: raw count based on weighted ranking values.

FIGURE 10

What do you think are the biggest challenges to addressing the most critical health reform-related issues? Please rank from one to five where one is the biggest challenge. (n=75)



Note: raw count based on weighted ranking values.

and federal marketplaces, as well as Medicaid, that still need attention. Specifically, they identified four significant policy issues that will need to be addressed during the next couple of years: 1) tax-related issues, as the individual mandate is implemented and enforced, 2) State Children’s Health Insurance Program reauthorization, 3) the relationship between Medicaid and the marketplaces, and 4) retention of individuals who have already enrolled.

For example, one national advocate described the inherent complexity of using a tax-based system to deliver a monthly subsidy and the broader challenge of how to bring tax concepts to the health policy arena. This is both a federal and a state issue as state marketplaces perform the tax filings. Another complication of the subsidy system—the so-called “family glitch”—relates to people whose incomes are between 138 and 400 percent of the federal poverty level and have workplace coverage. They may be locked out of the subsidy system because the higher cost of a family plan offered by their workplaces is not factored into affordability calculations. Finally, the forthcoming Supreme Court decision regarding subsidies for people enrolled in the federally facilitated marketplaces presents a potential new challenge to the entire system, which could require both federal and state policy fixes.

The survey also asked foundations what they thought the major challenges were to addressing critical health reform issues on the horizon (Figure 10). Resources, support from state government, and capacity of state government continue to be major concerns going forward.

Informed by both the survey and the interviews, the following three major categories of issues emerged that foundations believe warrant attention.

TARGETING OUTREACH, ENROLLMENT, AND EDUCATION ACTIVITIES

Many funders and advocates expressed concern that during the second enrollment period, which just concluded, there would be fewer resources available for outreach and enrollment, even though the eligible-

but-unenrolled population would likely be harder to reach and the time period for enrollment was shorter than during the first enrollment.⁵ Moreover, ensuring that individuals who initially enrolled were aware that they need to renew was a separate but equally important focus of this enrollment period, which would be further challenged by waning public and media attention.

Two additional issues were raised:

- **Latino Outreach:** In many states, enrollment of Latinos lagged significantly below expectations during the first enrollment period. This was a particular problem in states with large Latino populations. For example, Texas funders noted that the state has not communicated to Latino populations very well. Gaps in knowledge about how to effectively market to Spanish speakers made outreach particularly difficult for funders. Even ACA-supportive states such as California and New York were slow to get materials translated. Moreover, enrollment of Latinos is complicated by immigration issues. Some families with mixed immigration status are reluctant to enroll members who may be eligible.

The Kate B. Reynolds Charitable Trust believes that one of its most successful health reform activities was to provide support for on-the-ground navigation assistance for Spanish-speaking communities. The trust continues to invest in such assistance, but it also believes that an overarching vision for how to address the state's emerging Latino communities is needed.

For many funders, ensuring enrollment of Latinos in health care is integrally related to their health equity goals, so addressing this issue was a high priority for the second enrollment period.

- **Health Insurance Literacy and Consumer Engagement:** Funders and advocates expressed surprise at the low level of health insurance literacy of many individuals who obtained insurance in the marketplaces during the first enrollment period.⁶ Many people applying for coverage with assistors reportedly took far longer than expected to understand their options and enroll. Terms such as “deductible” and “premium” can be alien concepts. Helping enroll people required extensive consumer education.

Once enrolled in insurance, consumers confronted the next level of health insurance literacy—how to use the insurance benefits and access the health care system. Many people were acquiring insurance for the first time, and they were unfamiliar with managed care. For instance, the issue of narrow networks—restricted options for consumers for physicians and hospitals under managed care—has emerged in California and other states, raising concerns that consumers will not understand what they have signed up for. One national advocate described the challenge of helping people figure out what is most important to them—things like premiums, copayments, how a deductible works, and how to use the coverage—as one of the major gaps that will need to be addressed.

Funders and advocates alike identified the need for greater education of consumers at multiple stages and by multiple entities throughout the process. Two examples of strategies being undertaken by funders at the state and local level are:

- The Missouri Foundation for Health has made health literacy a major strategy by funding Health Literacy Missouri, one of the leading organizations of its kind in the country.
- The Highmark Foundation in Pennsylvania funded a health literacy consumer survey in Allegheny County to inform the work of a health literacy coalition supported by the foundation and other regional health care providers.

⁵ Interviews for this report were conducted just as the second enrollment period was beginning.

⁶ See also Long, S., et al., “[Low ACA Knowledge and Health Literacy Hinder Young Adult Marketplace Enrollment.](#)” *Health Affairs* blog, February 12, 2014; and Parragh, Z., and D. Okrent, “[Health Literacy and Health Insurance Literacy: Do Consumers Know What They Are Buying?](#)” Alliance for Health Reform, January 6, 2015.

ACCELERATING SERVICE DELIVERY REFORM

A variety of efforts are underway to reform the health delivery system. Federal funding for health information technology has enabled many hospitals and physician practices to implement electronic health records and promoted interoperability through health information exchanges. These developments are critical for changing incentives and improving quality. As new models of care, such as person-centered medical homes, integrated behavioral health, and accountable care organizations, are accelerating, many funders are paying close attention to helping safety net providers keep pace with transformation. Although purchasers, payers, and providers are in the driver's seat on these issues, funders can play a critical role, from research and analysis, to demonstrations, to evaluating and monitoring the impact of local and state-level reforms.

In particular, funders identified two critical issues on the horizon. It is important to note that the path forward with regard to both of these issues is still being charted.

- ▶ **Health Care Costs and Payment Reforms:** Health care costs drive policy and practice more than any other factor. As coverage expands because of the ACA, the pressure to keep costs down will increase. The challenge is to restrain costs by improving quality and outcomes and, ultimately, by preventing disease. Advocates and funders remain concerned that efforts to control costs do not result in reductions of benefits or eligibility.

It is not clear how philanthropy can best deploy its resources and contribute to this issue. With major payment reform demonstrations being funded by the federal government, no significant need for additional foundation-funded demonstrations was identified. Moreover, most foundations do not have the depth of expertise or access to the data to engage with provider systems. Finally, state leadership is needed to take any payment reform to scale, and not all states have taken steps to do so. Nevertheless, foundations can make contributions to the field. Ideas and options include:

- *Investing in Transparency:* The Connecticut Health Foundation supported the state in launching its All-Payer Claims Database—a tool for transparency and tracking costs, as well as for identifying racial and ethnic disparities.
 - *Researching, Innovating, and Evaluating Models:* The Health Foundation for Western and Central New York provided critical evaluation funding for a Center for Medicare and Medicaid Innovation (CMMI) grant received by the Erie County Medical Center. The CMMI grant tested the use of community health workers to reduce emergency room costs, but funding to evaluate the effort was insufficient, so the foundation filled that gap.
 - *Demystifying Cost Issues:* Because ultimately policymakers and system leaders must lead the way to change how care is delivered and paid for, The Commonwealth Fund believes that philanthropy can help ensure that they have access to the best information when making those decisions. One of the foundation's contributions is to demystify what drives health care costs and uncover options. Likewise, the New York State Health Foundation sees public policy as a key lever for change. In order to support fact-based public policy analysis, it has synthesized existing data and information by, among other things, publishing a chart book. Before the chart book, the state had no go-to source on costs. The foundation is also supporting new information resources, such as a statewide payment-reform scorecard.
 - *Supporting State Cost Commission and Other Policy-Related Supports:* In Colorado, the Rose Community Foundation is contributing resources to a legislative commission that is examining ways to constrain health care costs. In addition, the former chair of the foundation board's health committee is serving as the interim chair of the commission, so the foundation will be able to stay abreast of, and involved in, the effort.
- ▶ **Workforce:** Many funders identified adequacy of the workforce as a critically important issue to meet the health needs of millions of newly insured Americans. Because workforce is tightly tied to care

coordination and care transitions, experts believe that the redesign of the delivery system will also require redesigning the workforce. However, the long timeframe involved in many training programs, the expense associated with training health care professionals, the critical role that state governments play in workforce development, and the influence of various professions in defining scope of practice make it difficult for foundations to identify the best entry point or focus. In addition, as several foundations commented, the traditional strategy of supporting physician scholarships does not address the needs of the new models of care.

Concurrent with innovations in health care, many foundations are exploring strategies to support the development of new types of health care workers; expand the use of community-based or lower-level practitioners, such as community health workers; and support team-based care.

- New York has very stringent scope-of-practice laws, and the Health Foundation for Western and Central New York is exploring alternatives. For example, it is working on a new certification that would let lower-level workers called “medication aides” place pills into seven-day trays; currently, only family members and nurses are allowed to do that.
- The Foundation for Community Health, which focuses on access to care and serves a rural part of Connecticut with many older residents, is concerned about the growing need for a competent home care workforce. Low wages, long distances, and poor road conditions are among the factors the foundation is examining as it considers how to address significant transportation barriers for this workforce.
- The California HealthCare Foundation is investigating community paramedicine and how to deploy paramedics in new ways that could help reduce the use of emergency departments.
- The Foundation for a Healthy Kentucky is exploring the support of a certification process and reimbursement approaches for community health workers.

ELEVATING AND ADVANCING HEALTH EQUITY

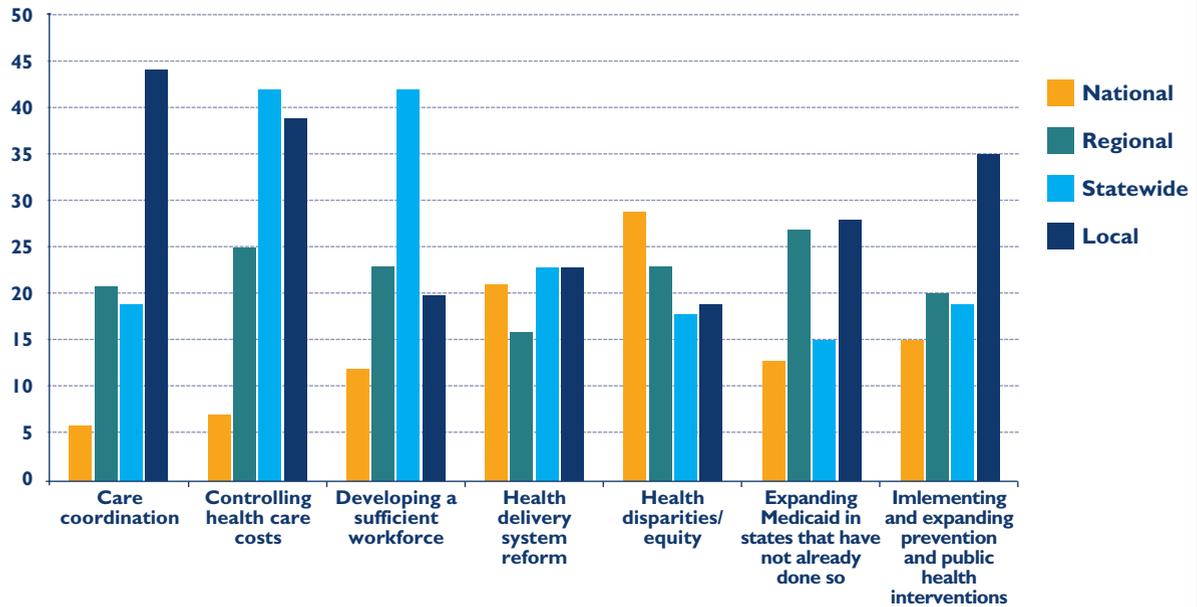
In both the survey and the interviews, foundations identified health equity as one of the top issues on the horizon. Likewise, a recent survey by Community Catalyst of advocates around the country found that the vast majority identified some aspect of health equity as a priority (Sherry 2014). However, there was significant variation among national, state, and local funders. Although national funders ranked health equity highest, local, regional, and statewide foundations considered it a much lower priority (Figure 11). As a national funder, the W. K. Kellogg Foundation explicitly uses a health equity frame for its health reform work, which it believes is critical to responding to demographic trends. However, at the local level there is no clear consensus or guidance on what strategies can best address health equity or what foundations should support.

Major differences were evident in how funders at the state and local levels and in different parts of the country are approaching the issue. Foundations from the Northeast and West are directly tackling health equity. In fact, several foundations—Connecticut Health Foundation, The Colorado Trust, and The California Wellness Foundation, among others—have recently moved to make health equity the guiding framework for their work.

However, foundations and advocates in the South and the Midwest, while expressing strong support for addressing health equity, also noted that they have to take into consideration the framing and messaging of the issue. For example, one foundation in the South observed that, in many cases, local and state funders are doing health equity work but they are not using that language; rather, they will say they are working on homelessness or other specific issues. An advocate from the Midwest raised a similar concern. She believes that although health equity, per se, may have difficulty gaining traction, framing issues in terms of the social determinants of health can garner interest.

FIGURE 11

What do you think are the most critical issues related to health reform that need to be addressed in your state (or nationally, if you are a national funder) over the next two years?
Please rank from one to five where one is the most critical. (n=78)



Note: raw count based on weighted ranking values.

Beyond bringing an overall health equity lens to their work and focusing on issues where there are significant disparities, foundations identified three specific health equity-related issues and strategies that they are pursuing:

- **Data to Drive Policy:** Data are the foundation for policy and financing reforms to address inequities in health. Without data that can demonstrate differences in health outcomes by race and ethnicity, sexual orientation, and other measures of vulnerability, it is difficult to address health equity and identify potential solutions. One national consumer advocate repeated a common refrain about data: “If you don’t measure it, it doesn’t exist.”

Health data systems are often not designed to collect data by race and ethnicity; moreover, there is little attention to subpopulations, which can experience very different health outcomes.

The Connecticut Health Foundation, whose leader participated on the Lieutenant Governor’s Health Reform Cabinet, successfully advocated for the state exchange to explicitly address racial and ethnic disparities among its enrollees, with the first step being the collection of data by race and ethnicity. Beyond documentation, data will be needed for policy and financing reforms to address inequities in health. A consumer advocate from the Northeast noted that equity must ultimately be tied to delivery system performance and reimbursement for it to take hold. Recognizing that financial incentives drive practice, he said, “We need to pay people to eliminate disparities.”

- **Health Insurance Coverage for the Remaining Uninsured, Including Immigrants:** In the survey, funders identified “access and coverage options, including for individuals ineligible for the ACA” as their highest priority (along with care coordination) (Figure 2). Although this topic includes a wide range of issues, local, state, and national funders identified the remaining uninsured as an ongoing area of focus. For example, the Grant Healthcare Foundation, a local foundation in Illinois, reported that it is mostly interested in individuals who continually “fall through the cracks” and live without health insurance and access to quality health care services. For many foundations, this is a major health equity issue, because a

large proportion of individuals who do not qualify for Medicaid or the marketplace are Latino. The California Endowment, for example, is seeking to build on the platform created by the ACA to cover all Californians, with advocacy and policy activities related to care and services for the uninsured.

- **Leveraging Health Reform:** Recognizing the enormous amount of work that still remains to be done to ensure successful implementation of health reform, many funders and advocates also believe that it is an opportune time to initiate a broad-based strategy to achieve greater health equity. Various policies, programs, and activities associated with the ACA provide a springboard to advance such a strategy.

Population strategies have already begun under the ACA's Prevention Fund. Now that individuals can no longer be denied health insurance because of pre-existing conditions, health systems have a greater stake in improving community health, and payment reforms are beginning to incentivize health outcomes. Moreover, recognizing that improving population health—and achieving greater health equity—depends on addressing the social determinants of health, policymakers and health systems are exploring how to better connect health care with various human services systems.

For example, some states are streamlining Medicaid eligibility processes for people already eligible for food stamps. Research is also beginning to demonstrate the connections between poverty, high stress, and child health outcomes and identifying the combined role of anti-poverty supports (Center on Budget and Policy Priorities 2013). Another issue that is growing out of the ACA is access to banking. If a low-income individual is “unbanked,” that can be a barrier to paying the monthly premium. One advocate recommended that health reform could be a springboard to a whole range of financial literacy and asset-building efforts.

Still another issue along the spectrum is the relationship between mental health, substance use, and the criminal justice system. Greater coverage of these conditions by Medicaid and the insurance marketplaces has implications for criminal justice reform and how to help this population gain access to needed services.

Finally, at the leading edge of equity-related issues, a national advocacy organization believes that there is potential for leveraging health reform to increase voter registration. A national voter registration law requires federal entitlement programs to ask enrollees whether they are eligible and registered to vote. To implement the requirement, the advocacy organization trained affiliates and partners to help applicants for health coverage learn about the law and how to register people to vote.

ADVOCATES' PERSPECTIVES

The last four years have been a time of excitement for advocates as they worked to implement the ACA, of frustration as multiple challenges and obstacles arose, and of exhaustion as they ramped up health reform-related activity on top of other health policy and advocacy work. Both state and national advocates acknowledged that implementation turned out to be far more complex than they originally thought it would be, with their efforts made more complicated by a highly polarized political environment.

The following themes were consistently raised by advocates, whether they worked at the state or national level, and across all four regions.

CONTINUED FOCUS ON OUTREACH, ENROLLMENT, AND OVERALL IMPLEMENTATION

At the time of the interviews, advocates were very focused on the second enrollment period and the significant amount of work still to be done to ensure that coverage-expansion aspects of the ACA are effectively implemented. Having anticipated that the second enrollment period would be more challenging than the first, advocates across the country described successful outreach and enrollment efforts and noted that foundations played an important role in their states being able to meet, and even surpass, expectations for enrollment in the new insurance marketplaces. This held for states that were supportive of the ACA, as well as those that were not. As one state-based advocate in an “unsupportive” state observed, “The foundations propped up that entire world, and even though [enrollment] was at a low level, the success is due to their funding.”

State and national advocates expressed concerns that philanthropic support for outreach and enrollment, as well as other implementation activities, might be waning, even though new policy issues are arising and challenges to the law persist. One state advocate emphasized that enrollment is a “three- to five-year disciplined implementation effort” and was concerned about the field, including philanthropy, being able to maintain the energy and momentum needed over this time period.

MEDICAID EXPANSION IS PRIORITY ONE

Advocates identified Medicaid expansion as their top priority, with national advocates and those in states that have not yet implemented expansion generally feeling the strongest about the issue. As of March 2014, more than half of the states (29) had implemented the expansion—with another six states actively discussing it—providing coverage to as many as 10.5 million people. Yet many of the states with the highest rates of poverty and the largest communities of color had not agreed to Medicaid expansion (KFF 2014a; Families USA 2014). Some states that moved forward with the expansion have done so through a Section 1115 waiver, adopting a private-sector approach and imposing new requirements. Advocates are concerned that some of the waivers have the potential to erode important consumer protections. They believe it is critical to continue to monitor these programs closely and that closer coordination between state and national advocates and funders could be beneficial.

It is important to note that foundations have also placed a high priority on continuing efforts to support Medicaid expansion. Foundations ranked Medicaid expansion fourth overall in terms of issues on the horizon, with funders from the South reporting it to be the highest priority. For example, the Healthcare Georgia Foundation supported an economic impact analysis about Medicaid expansion and created a platform for widespread advocacy efforts, media coverage, and stakeholder engagement.

Achieving universal expansion of Medicaid is a long-term endeavor—one that was not anticipated before the Supreme Court ruling in 2012. One national advocate compared the current situation with Medicaid expansion to marriage equality for gays and lesbians. Several years ago, grantmakers funding lesbian, gay, bisexual, and transgender issues set out to reverse the state bans on marriage through a concerted, nationally coordinated, state-by-state campaign to build public will. That campaign has helped produce one of the

largest—and quickest—shifts in public opinion on a major policy issue. Although there are major differences between marriage equality and Medicaid, the strategy may serve as a model for consideration.

NEW SKILLS AND CAPACITIES FOR ENGAGEMENT IN SERVICE DELIVERY REFORM

Advocates recognize that engaging in the range of service delivery reform issues will be critical to making health reform a reality for low-income people and communities of color. However, they are challenged by both resources and staffing, since coverage-related issues still warrant ongoing vigilance. Moreover, although some advocates have been involved in access issues, most have not developed the depth of expertise to engage in discussions about care coordination, quality, and payment reform. One state-based consumer advocate described the challenge associated with being a lay person participating on a panel regarding evidence-based medicine. The level of technical knowledge needed to participate was significant, and attaining such knowledge was difficult, particularly without the resources to access proprietary journals or other source documents. Ensuring that patients and consumer advocates have a voice in this and other issues, such as the development of accountable care organizations or other models of integrated care, requires a new level of expertise.

Another challenge for advocates is that working on delivery system issues requires new relationships and coalitions with health provider organizations and other entities. Some of these may strain long-standing alliances that advocates have built with managed care organizations and hospitals during the years of advocacy for health coverage expansion. For example, advocates and managed care plans, hospitals, and health systems may find themselves on opposite sides of consumer protection issues. Ensuring quality of care under Medicaid managed care was raised by several advocates, specifically the need for policy research related to metrics and key consumer protections.

Looking down the road, several advocates believe that consumer groups will need to “pivot,” and ultimately transform, along with the health delivery system to take a more significant leadership role on issues related to quality and cost. Doing so will require different activities and skill sets. Delivery reform issues involve policy implementation and systems change, rather than policy generation and advocacy with state legislatures. Advocates need new tools to help understand how to assess these issues, as well as training and capacity building. Community Catalyst’s recently released report, *The Path to a People-Centered Health System: Next Generation Consumer Health Advocacy*, identifies the opportunities, challenges, and needs, along with recommendations for moving forward⁷.

Both advocates and funders talked about the need to engage consumers more actively in their own health care and advocacy. The Sunflower Foundation, for example, believes that the biggest ongoing challenge is building a stronger consumer advocacy voice in Kansas—not just for vulnerable populations, but a broad consumer voice that represents everyone, from the uninsured to business owners. As a potential part of that type of effort, one advocate suggested that new communications tools are needed because terms such as “delivery system reform” are difficult for people to understand. He suggested more direct language such as “making sure that health care works for people.”

⁷ <http://www.communitycatalyst.org/resources/publications/document/Next-Generation-HST-Report.pdf>

REGIONAL SNAPSHOTS

Funders who responded to the survey were evenly distributed across the four regions of the United States, as shown in Figures 12 and 13. For many of the survey questions, funders' perspectives exhibited significant regional variation. To better understand these regional differences, interviewees for this report were selected by region (see Appendix C for more information about the methodology). Two states from each region were targeted (three, in the case of the Midwest), and two foundations and one advocate were interviewed for each state. The following state and regional snapshots were created using data from the survey and interviews. Figures 14, 15, and 16 display data from the survey for three questions (top priorities, most critical issues on the horizon, greatest challenges) by region. Refer to Figures 4 and 6 for questions regarding foundation funding of advocacy and perceptions of advocacy capacity by region. Although every state is unique and made decisions based on its own history with health care and health reform, trends did emerge across states within each region.

THE NORTHEAST: CONNECTICUT AND NEW YORK

The Northeast has largely been supportive of ACA implementation and boasts the three states with the highest percentage enrollment of eligible enrollees: Vermont, Rhode Island, and Connecticut. Five out of nine Northeast states have state-based marketplaces; three use federally facilitated marketplaces; and one state, New Hampshire, has a partnership model. All states except Maine have implemented the Medicaid expansion.

Key findings about the region from the survey include:

- *Top Priorities.* The highest proportion of funders in the Northeast ranked care coordination as their top-priority health reform-related issue; they were also the only group of funders that ranked program innovation and reform as the top strategy.

FIGURE 12

The Four Main U.S. Census Regional Designations

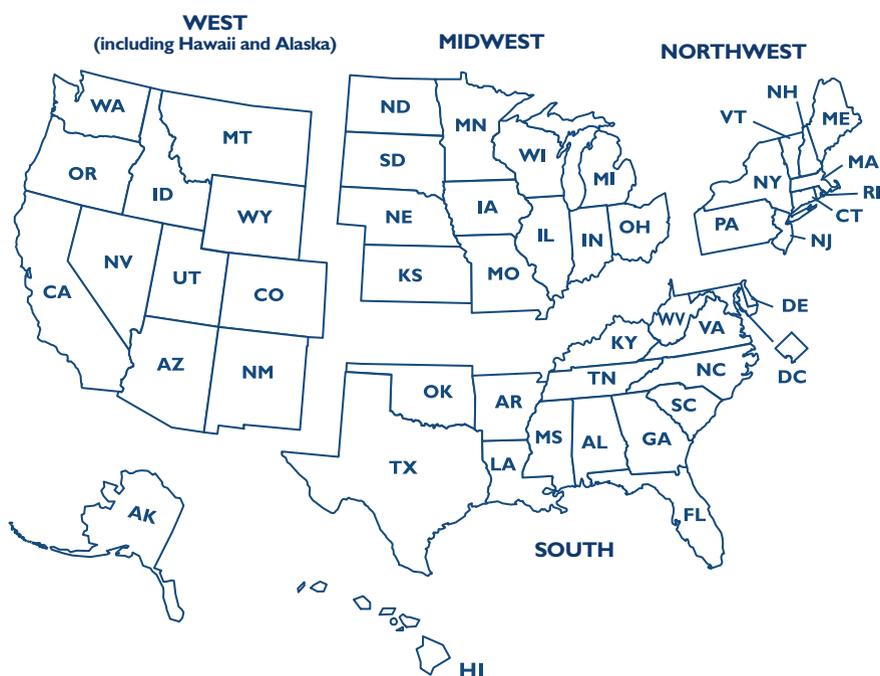


FIGURE 13

Regional Distribution of Survey Respondents* (n=76)



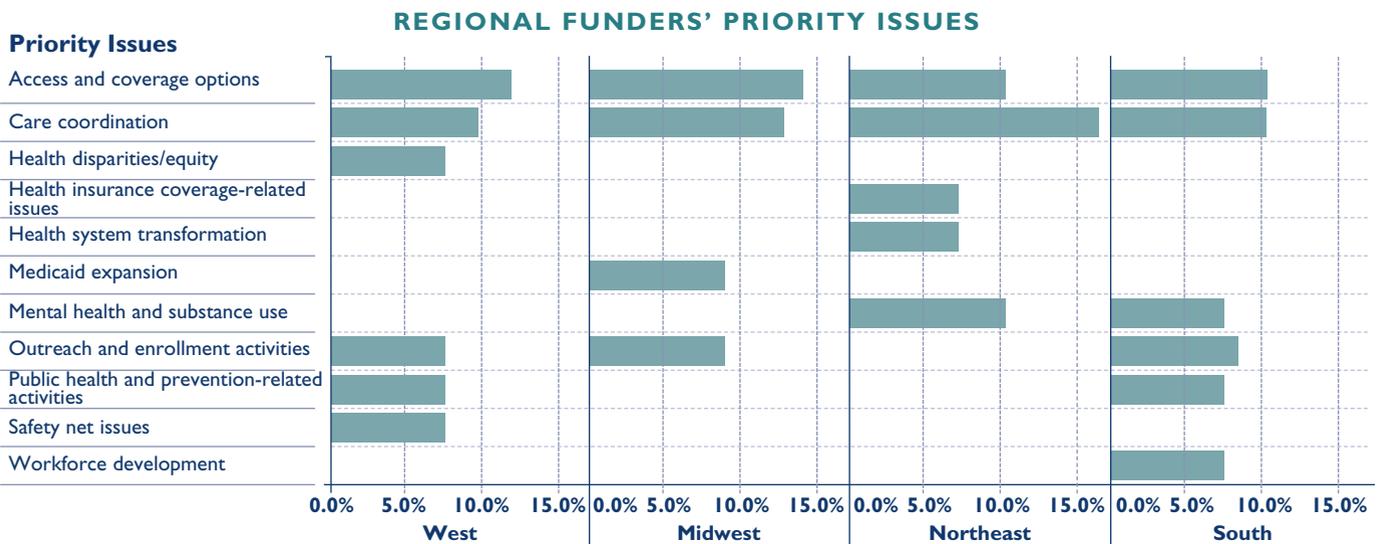
*national funders excluded

- *Advocacy Funding and Capacity*: Northeastern funders rated their region's advocacy capacity and advocacy infrastructure as the strongest, compared to other regions.
 - *Most Critical Issues on the Horizon*: Funders in the Northeast ranked implementing and expanding prevention and public health interventions higher than funders in any other region (second, as compared to fifth overall).
 - *Greatest Challenges*: Along with the West, the Northeast ranked insufficient readiness and engagement of the health care system as the top challenge. The Northeast also ranked insufficient public awareness or knowledge of the ACA higher than other regions, though only slightly higher than the Midwest.
- **Connecticut** – Connecticut embraced health reform, implementing all market reforms, expanding Medicaid, and establishing a state-based marketplace whose website has become a national model. The state enrolled double its initial enrollment target during the first enrollment period. According to the Foundation for Community Health, part of the state's success was that the effort to enroll individuals was not restricted to only those who typically serve the Medicaid population. Anybody could write a grant and become an assistor, and newly educated assistors spread information to their networks, both personal and professional. In terms of advocacy capacity, pre-ACA work funded by the Universal Health Care Foundation of Connecticut and others created a robust advocacy infrastructure for funders to build on. This capacity proved critical during the debate on the ACA, when new players were needed at the table. Advocates credit funders for taking a proactive role by supporting and creating reliable policy and other research for advocates to use, such as the *Connecticut Health Care Survey*, which was the result of a collaboration among six foundations. The survey gathered information on the experiences and perspectives of Connecticut residents regarding their health and the health care system.

The Connecticut Health Foundation saw the ACA as a major opportunity to advance health equity principles through participation in state policymaking processes and supporting leadership development for advocates of color. Funders also took advantage of the opportunity provided by the ACA to advance delivery system reform issues. The Children's Fund of Connecticut worked with the state's Medicaid Administrative Services Organization and the Department of Public Health's Maternal and Child Health Block Grant program to expand the implementation of medical homes for children. It also funded research through its subsidiary and primary beneficiary, the Child Health and Development Institute of Connecticut, on improving care coordination and on integrating primary care and behavioral health to improve children's health outcomes.

FIGURE 14

Which of the following health reform-related issues are your foundation's highest priorities?
Please choose up to six. (n=69)



- **New York** – Soon after the ACA passed, the New York State Health Foundation created a roadmap for the state. The foundation then provided funding for different activities in response to the roadmap and the state's needs. The foundation assessed the state's information technology systems and supported critical upgrades that could help garner federal matching funds. It also supported policy research, including analyzing the costs and benefits of developing a Basic Health Plan (BHP), and collaborated with the state to identify gaps in knowledge and capacity. The report on the BHP is cited as critical to New York becoming one of only two states moving forward with a BHP. The foundation supported consumer outreach and enrollment activities by funding a statewide network, as well as individual organizations, and bolstered the effort with support from local funders.

The New York State Health Foundation and others were already supporting a strong network of enrollers, along with policy analysis and evaluations of that work, so the Health Foundation for Western and Central New York looked for a complementary way to add value. It focused on bolstering the state's safety net system through a series of initiatives, starting with "Ready or Not," which subsequently transitioned into "Get Set." These initiatives were designed to help the safety net acquire competencies to participate in pay-for-performance programs, including the Delivery System Reform Incentive Payment Program under the state's 1115 waiver. The combination of the ACA and the 1115 waiver continues to drive delivery system reforms in New York. The foundation's programs provided grantees with consulting and other capacity building support, including a learning community to share best practices. The foundation is also engaging other foundations to sponsor organizations to participate in this effort.

THE MIDWEST: KANSAS, MISSOURI, AND OHIO

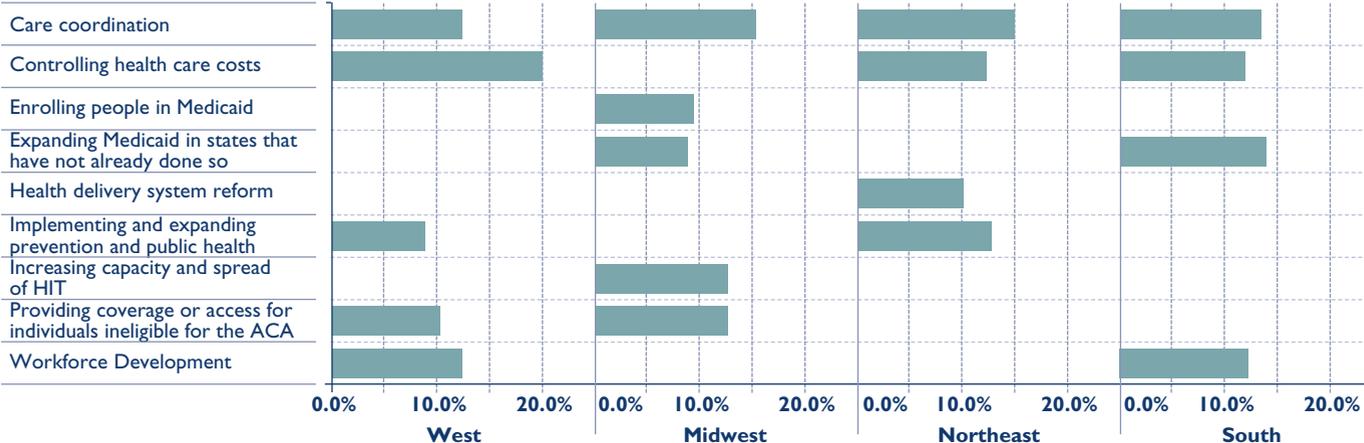
The Midwest is characterized by mixed political support for health care reform, resulting in a variety of approaches to implementation. Eight out of 12 states (North Dakota, South Dakota, Nebraska, Kansas, Missouri, Wisconsin, Indiana, and Ohio) are using the federally facilitated marketplace; three adopted a partnership model (Indiana, Illinois, and Michigan); and only one, Minnesota, implemented its own marketplace (KFF 2014b). Many Midwest governors and/or legislatures remained opposed to the marketplace and, like their counterparts in many of the Southern states, sought to limit assistance for enrollment. As of March 2014—the end of the first enrollment period—only 12.2 percent of Midwesterners eligible for

FIGURE 15

What do you think are the most critical issues related to health reform that need to be addressed in your state over the next two years? Please rank from one to five where one is the most critical. (n=64)

REGIONAL FUNDERS' MOST CRITICAL ISSUES GOING FORWARD

Most Critical Issues



coverage through the new marketplaces had enrolled, the lowest of any region (KFF 2014c). In terms of Medicaid expansion, the Midwest also has a mixed record—half of the region’s states implemented the expansion (with Iowa and Michigan using 1115 waivers to do so); five did not; and one state, Indiana, has a waiver application pending approval by the Centers for Medicare and Medicaid Services.

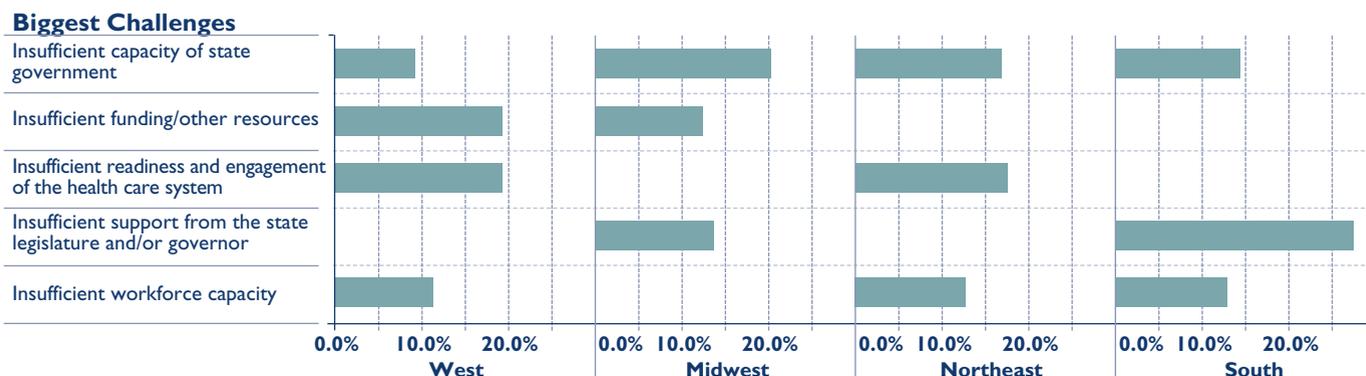
Key findings about the region from the survey include:

- *Top Priorities:* The Midwest was the only region to rank Medicaid expansion in its top five priority issues, behind access to care and care coordination. The Midwest and the West were the only two regions to rank health disparities/equity in their top five.
 - *Advocacy Funding and Capacity:* A slim majority of Midwest funders—53 percent—reported that they do not currently fund consumer or other types of advocacy work on health reform-related issues. At the same time, 21 percent of the region’s funders reported that they planned to increase their advocacy funding—the highest percentage for any region in the survey.
 - *Most Critical Issues on the Horizon:* Compared with their counterparts in other regions, a higher percentage of funders from the Midwest chose increasing the capacity and spread of health information technology as a critical issue on the horizon.
 - *Greatest Challenges:* The Midwest was the only region to rank insufficient capacity of state government to implement health reform-related activities as the greatest challenge.
- **Kansas** – Kansas was one of the first states to receive a federal marketplace Early Innovator grant. However, following a change in the governorship in 2010, the state sent those dollars back, and the state’s political leadership has remained staunchly opposed to ACA implementation. Kansas has a strong community of health funders with a history of collaboration. Several funders pooled resources to bolster outreach, enrollment, and education efforts in two key ways. First, in a collaborative effort, funders contracted with Enroll America on digital campaigning when it was clear that there would be no dollars coming into the state to support public education. For the REACH Healthcare Foundation, funding a marketing strategy was a new approach: there was no guarantee that they would be able to link enrollment to investment in a public education grant, which was a departure from funding that typically

FIGURE 16

What do you think are the biggest challenges to addressing the most critical health reform-related issues?
Please rank from one to five where one is the biggest challenge. (n=62)

REGIONAL FUNDERS' BIGGEST CHALLENGES



had clearly defined evaluation goals. Second, a large group of funders collaborated to create the Health Reform Research Project (HRRP). The project's goals were to assist in public education and stakeholder engagement related to health reform, to provide technical assistance to advocacy organizations and other stakeholders, and to assist Kansas entities in securing grants and programs available under the ACA. Pooled funding for the HRRP's ACA Opportunity Fund provided tremendous return on investment, with \$450,000 of local grants converted into approximately \$20 million in federal funding. The success of this effort has led to establishing another joint grant fund, managed by HRRP, to support other health reform activities in the state.

- **Missouri** – Like Kansas, Missouri faced strong opposition to ACA implementation, primarily from the state legislature. The governor has expressed support for Medicaid expansion, but the legislature has not reached an agreement to pass it (Kansas Health Institute 2014; Statereform.org 2014). With both convening and funding support from the Missouri Foundation for Health and other funders, Missouri's strong advocacy community formed Cover Missouri, a coalition that includes hundreds of organizations in a flexible "network of networks" with the ability to adapt and respond to new challenges. The coalition is credited by both advocates and funders as a key factor in the state's ability to exceed enrollment projections. The Missouri Foundation for Health also made staying connected to policymakers part of its staff's responsibility. Having the ability to scan the environment for opportunities led to a partnership with the state government to update its computer systems so that the state could move forward technologically. Locally, the Health Care Foundation of Greater Kansas City, which took a strong position in support of the Medicaid expansion, "field tested" outreach efforts in order to be prepared should the state implement the expansion.
- **Ohio** – In 2011 Ohio's governor proposed expanding Medicaid and created the Office of Health Transformation to spearhead health delivery system reform. The legislature did not agree to the proposal in 2013, and the governor turned to the state's Controlling Board, which has the authority to authorize spending of federal funds between the state's two-year budget periods. The Controlling Board approved the expansion through 2015, a decision that has since survived several legal challenges (KFF 2014d). To help make the case for Medicaid expansion, and recognizing the need for comprehensive data analysis, a group of Ohio funders—Interact for Health, The George Gund Foundation, and Mt. Sinai Health Care Foundation—funded the Health Policy Institute of Ohio to conduct an Ohio Medicaid Expansion Study. The study played a significant role in state government discussions and was critical in advocacy campaigns by regional and statewide coalitions. In addition, Mt. Sinai Health Care Foundation played an active role by providing testimony on the study's findings to various state legislative committees.

Other funders worked collaboratively through the state's grantmaking association, Philanthropy Ohio, to launch a health initiative to coordinate the Ohio Network for Health Coverage and Enrollment (ONCE). ONCE is a statewide collaborative of navigators, certified assistance counselors, and others engaged in outreach and enrollment efforts. Philanthropy Ohio eventually spun off regional coalitions in Cincinnati, Dayton, and Akron.

One innovation with regard to delivery system reform was supported by the HealthPath Foundation of Ohio, which seeded funding for a Community Loan Fund to provide favorable-term loans to community health centers and other safety net providers. These loans are intended to help the clinics better meet the needs of people obtaining coverage through Medicaid and the marketplace.

THE SOUTH: NORTH CAROLINA AND TEXAS

The South can be generally characterized as opposing the ACA. With a few exceptions, states in this region did not implement a state-based marketplace or adopt Medicaid expansion. Kentucky, Maryland, and the District of Columbia were the only jurisdictions that implemented their own marketplaces, while Kentucky, West Virginia, Maryland, Delaware, and the District of Columbia implemented the Medicaid expansion. Arkansas obtained a 1115 waiver to implement its own version of the program, and Tennessee and Virginia are in discussions regarding possible Medicaid expansions (The Commonwealth Fund 2014). The population of the South is diverse, with people of color making up 41 percent of the region (KFF 2014c). The South is also home to the largest share of the nation's uninsured adults in the coverage gap (79 percent), with a majority of the nonelderly uninsured population in the South being people of color (KFF 2013; KFF 2014c).

Key findings about the region from the survey include:

- *Top Priorities.* The South was the only region to rank workforce development in its top five priority issues, and, along with the Northeast, the South ranked mental health and substance abuse as a top priority.
- *Advocacy Funding and Capacity.* Seventy percent of funders from the South said they did not fund consumer or other types of advocacy, a much higher percentage than all other regions.
- *Most Critical Issues on the Horizon.* The South was the only region whose funders ranked expanding Medicaid in states that have not already done so as the most critical issue on the horizon.
- *Greatest Challenges.* The South was the only region whose funders ranked insufficient support from the state legislature or the governor as the greatest challenge to addressing critical health reform-related issues.

In addition, while most funders surveyed from the South supported health reform-related activities, 33 percent reported that they did not—a much higher percentage than in other regions. However, 33 percent of funders in the South said that they were planning to increase their funding for health reform-related activities, which was also a higher percentage than in other regions.

- **North Carolina** – Early on, North Carolina moved forward with ACA implementation by expanding Medicaid, planning a partnership model for the state-based marketplace, and bringing in federal dollars for outreach and enrollment and upgrades in health information technology. Funders in the state supported an implementation plan based on the state's direction. However, in 2010, Republicans won a majority in both houses of the legislature, and in 2013, less than a year before the beginning of open enrollment, the governorship switched from Democratic to Republican. The state reversed its stance on the Medicaid expansion, sent back all federal dollars, and funders and advocates needed to reevaluate their plans in response to the shift in state policy direction.

Led by the Kate B. Reynolds Charitable Trust, funders pooled dollars to obtain a matching grant from the Robert Wood Johnson Foundation in order to engage Enroll America in supporting outreach and

enrollment for low-income, rural, and Latino communities.⁸ Because North Carolina has a history of collaboration among health advocates, policy researchers, and the state's Medicaid system, there was an infrastructure to help support enrollment. Working with the North Carolina Institute of Medicine, legal aid groups, and the state, advocates began looking at navigator grants for available funding. To bolster those efforts, funders supported a statewide navigator consortium, which included a centralized navigator scheduler that now serves as a model for other states and is credited with North Carolina's enrollment success—350,000 residents obtained health insurance. Funders also continued to support policy research and nonpartisan education through the North Carolina Institute of Medicine, which catalyzed education activities around the state on the ACA. The institute disseminated reliable information about the ACA down to the community level.

On the local level, the Cone Health Foundation funded a coalition that met twice monthly. As a result of Cone's advocacy funding, a symbolic Medicaid Expansion Resolution was passed at the city council level in Greensboro, which may help keep the issue on the policy agenda. Statewide advocates have also started shifting to local advocacy work in support of implementation activities.

- **Texas** – As in many states where the Medicaid expansion did not move forward because of a challenging political environment, Texas funders and advocates still made progress on health reform by focusing on health delivery systems reform. In 2013 the 83rd legislature passed the state's largest-ever public mental health budget, along with a law that directed the Health and Human Services Commission to integrate physical health services and behavioral health services into managed care. For the Hogg Foundation for Mental Health, which had been funding integrated behavioral care since 2006, this legislation presented an opportunity to accelerate that work. The foundation participated directly in various state-level rule-making and policy education initiatives, offered resource information, and provided technical assistance on mental health policy.

Advocates have worked on bolstering consumer support for the state's under-resourced Medicaid managed care program, while balancing other issues. Methodist Healthcare Ministries of South Texas, Inc. determined that it needed to be more responsive to challenges faced by federally qualified health centers, which, without the Medicaid expansion, had to meet increased performance requirements with the same or fewer dollars. The foundation saw an opportunity to position itself to be at the table to leverage investments that supported or aligned with the ACA's delivery system reforms. Methodist also funded the redesign of delivery systems and networks through a collective impact process and regional expansion strategies. It was recently awarded a \$10 million federal Social Innovation Fund grant to bolster regional strategies for establishing integrated behavioral and primary care health models.

Despite an emphasis on delivery systems reform, Medicaid expansion remains a priority for advocates and funders, especially locally. The Texas legislature meets every two years, and advocates are working to maintain support for implementation, including reaching out to city and county officials in urban areas, and most chambers of commerce. In its local border region, the Paso del Norte Health Foundation funded a strategic plan for ACA implementation. It went on to support and help develop a local outreach and enrollment coalition and hire a grant writer to secure a federal implementation grant.

THE WEST: CALIFORNIA AND COLORADO

Most of the Western states—8 out of 13—have implemented their own state-based marketplaces or have federally supported state-based marketplaces (KFF 2015a). In terms of Medicaid expansion, Idaho is the only state that has not yet adopted the expansion and is not in discussions to do so. It is important to note that three states with Republican governors—Arizona, Nevada, and New Mexico—implemented the Medicaid expansion, while two—Utah and Wyoming—are currently in discussions (KFF 2015b).

⁸ North Carolina health funders that pooled funds to secure matching grants from the Robert Wood Johnson Foundation included the Kate B. Reynolds Charitable Trust, the Cone Health Foundation, and the Reidsville Area Foundation. <http://kbr.org/news/trust-brings-together-state-national-funders-invest-610000-help-north-carolinians-obtain-health>.

Key findings about the region from the survey include:

- *Top Priorities:* The West ranked safety net issues and health disparities/equity much higher as priorities than all other regions did.
- *Advocacy Funding and Capacity:* Over 80 percent of funders in the West reported that they currently fund consumer or other types of advocacy, a much higher percentage than in other regions.
- *Most Critical Issues on the Horizon:* The West ranked controlling health care costs and developing a sufficient workforce higher as critical upcoming issues than other regions did.
- *Greatest Challenges:* The West was the only region to rank insufficient funding and/or other resources to implement reforms and other ACA-related activities as the greatest challenge.

In addition, funders in the West reported the highest levels of collaboration with others, with more than 80 percent saying they collaborated with other state-based funders in their state, as well as with local or regional funders. Compared to other regions, a higher percentage of funders also partnered with government and supported program innovation and reform. Eighty percent of funders also said that they made significant changes to their funding priorities as a result of increased health reform activity, a much higher percentage than in other regions.

- **California** – California had the seventh-highest number of uninsured people before the ACA passed, and implementing health reform had strong political and stakeholder support from the beginning. Nevertheless, the scale and broad diversity of the state’s population posed significant challenges. California’s bevy of health funders drew from their individual strengths and went beyond their regular grantmaking practices to support the state government, as well as advocates and other stakeholders. The California HealthCare Foundation spearheaded a national public-private partnership on user design and experience for the marketplace websites. It also leveraged its strong history in policy analysis to research specific policy choices about the marketplace’s design, benchmark benefits, eligibility rules, state insurance regulatory oversight, and monitoring and reporting on both implementation steps and outcomes. The foundation built on its long history of working with state government. For example, early on, it supported a state position to develop an ACA implementation plan, even though it had not taken that kind of step before.

The Blue Shield of California Foundation supported the planning and implementation of the Low Income Health Program (LIHP) element of California’s 2010 Section 1115 Medicaid waiver. The LIHPs were designed as a precursor to the Medicaid expansion and enabled the state to transition over 650,000 LIHP enrollees to Medicaid in 2014, about one-third of California’s total enrollment.

As a regional funder, the Sierra Health Foundation focused on supporting the safety net in Sacramento and in the San Joaquin Valley. The foundation convened health care stakeholders and commissioned a market analysis of the region’s safety net system, which led to a multimillion-dollar initiative to build safety net capacity—much larger than the foundation’s typical investments.

California’s largest-scale investment came from The California Endowment, which called the ACA “a once-in-a-lifetime opportunity” and dipped into its corpus in order to dedicate several hundred million dollars for a variety of activities to support implementation. The endowment funded the state directly and provided opportunities to support research and training to help overcome the state’s limited bandwidth and funding availability. The endowment also funded a large-scale outreach and enrollment effort, specifically targeting the state’s Latino populations, and is providing \$50 million as a state match to support the federal health homes Medicaid initiative.

- **Colorado** – Colorado largely used health reform to accelerate and build on state reforms that were already in progress, and both funders and advocates engaged with the state government to implement efforts. The Rose Community Foundation continued to fund a health policy analyst in state government, which it had done for several years in collaboration with The Colorado Trust and The Colorado Health Foundation.

The Colorado Health Foundation engaged the business community in analyzing the economic impact of Medicaid expansion. The partnership with a group of business members to produce the report was important to the legislature and helped them have a constructive, fact-based discussion about the pros and cons of expanding Medicaid. The foundation is also piloting a collective-impact effort to align a set of health delivery system infrastructure organizations, such as the health information exchange, an employer group, and a practice transformation organization, to facilitate a process for aligning them around a common goal, such as integrated care or emergency department transitions. If successful, this process could accelerate progress on key health system transformation efforts.

The Rose Community Foundation bolstered its own opportunities for information gathering in the state capitol by hiring a lobbyist to monitor the state's fast-moving policy environment. The foundation also increased access for harder-to-reach populations by providing a marketplace portal in Spanish; language services; and convenient walk-in sites and enrollment events across the state in libraries, grocery stores, churches, and other community sites.

The Colorado Trust created a learning series to raise awareness, interest in, and dialogue about health equity among the nonprofit, foundation, health care, government, and other sectors. The trust also created a successful rapid-response grant program for advocacy related to emergent health reform issues that provided advocates with a turnaround decision time of three weeks or less on funding. After the 2012 Supreme Court decision that made Medicaid expansion optional, the rapid-response funds helped advocates develop a Medicaid strategy, which they had not anticipated would be needed.

RECOMMENDATIONS

FIND THE BALANCE BETWEEN STAYING THE COURSE AND ADVANCING NEW ISSUES ON THE HORIZON

One of the hallmarks of philanthropy is the ability to identify and elevate issues on the horizon and bring them to the attention of opinion leaders and decisionmakers. Among other activities, foundations fund research and seed innovation, which can define issues and identify solutions. Many foundations, in fact, had been involved in these types of activities for years before the enactment of the ACA. For example, The Commonwealth Fund believes that one of the reasons its work was so timely during the health reform debate was that 10 years before, it had identified key issues and developed projects around the key issues. Even though there was not a policy window open at the time, the information it had produced was ready when the debate began.

Funders and advocates have now begun working on the next big issues on the horizon, three to five, or even 10, years out, including identifying key questions and developing solutions. At the same time, many advocates are concerned that funders may move on to other issues, even though implementation of the law still faces significant challenges. They feel that health reform is not yet secure as a matter of policy, public opinion, or operations.

Health philanthropy as a field will need to find a balance between staying the course and continuing to support both health coverage and service delivery reform issues, with early investments to lay the groundwork for new issues and fields, such as health equity.

RECOGNIZE THAT SERVICE DELIVERY REFORM EFFORTS WILL REQUIRE ADVOCACY ORGANIZATIONS TO DEVELOP NEW SKILLS AND EXPERTISE, AND INVEST IN THEIR CAPACITY BUILDING

As both funders and advocates increasingly engage in efforts to reform the health care delivery system, consumer advocacy organizations will need to develop new capacities, relationships, and skills. Beyond funding advocacy organizations to build that expertise, one approach is for foundations to support health economists to work with advocates and help them analyze policy proposals addressing health care cost.

Several advocates described the importance of participating on consumer boards and commissions, noting that this work is very labor-intensive and often unfunded. Moreover, advocates will need to develop expertise in health care financing and service delivery arrangements in order to be effective in advancing consumer protections. One state-based advocate noted the long-term nature of advocacy, relationship building, and systems change work. Funders have invested for years in coverage issues, and advocates believe a similar timeframe will be needed for service delivery reform efforts.

BUILD ON SUCCESSFUL MODELS OF COLLABORATION

In the survey, foundations identified a number of successful local, state, and regional collaborations related to health reform. Although funders also reported challenges in developing these collaborations, the relationships could be particularly important because of the interplay between federal and state policy-making on health reform. Both the health insurance marketplace and Medicaid involve a complicated mix of policy and implementation choices; moreover, these programs interact with each other, as well as with the State Children's Health Insurance Program. One national advocate recommended that funders, and their funding, work at the intersection of federal and state policy in order to operate at both levels. Greater collaboration could be an effective strategy to facilitate that effort.

In addition, as funders begin to explore health equity and prevention-related issues, which require cross-sector partnerships, they will need to collaborate with colleagues from foundations in other fields, such as income security, education, housing, and criminal justice. For example, the inclusion in the ACA of

provisions related to mental health parity is resulting in an expansion of private insurance and Medicaid coverage for behavioral health services, including substance use. Enabling more people to obtain treatment could have a significant impact on criminal justice issues, and a cross-sector collaboration of funders could help advance the intersection of those policies.

CAPITALIZE ON AND LEVERAGE PAST INVESTMENTS IN THE ADVOCACY INFRASTRUCTURE FOR HEALTH EQUITY AND OTHER GOALS

State and national advocates believe that philanthropy played a significant role in the passage of health reform through investments in a variety of activities, particularly the advocacy infrastructure, over the course of many years. That infrastructure, which foundations consider moderately strong (although there is significant variation among the different regions), is now being mobilized for outreach and enrollment activities. Several funders and advocates believe it could be a platform for new issues, beginning with those related to health reform, such as health insurance literacy and, ultimately, a broader range of health equity efforts. One state-based advocate suggested that funders approach health in a more holistic way, so that systems transformation connects with education, housing, and immigration. Funders can encourage collaboration among advocacy groups that are currently siloed in different areas to enable them to take a broader view.

CONCLUSION

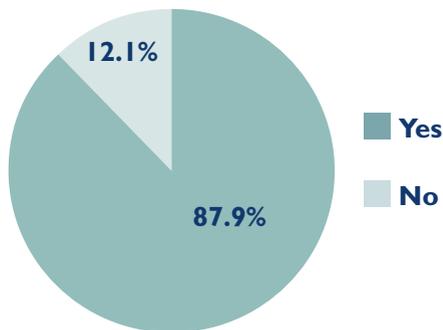
Five years after enactment of the Affordable Care Act, the rate of uninsured Americans has dropped to 13.2 percent—a 35 percent reduction from 2013 levels (ASPE 2015). Moreover, significant reforms of the health care delivery system are well underway. National, state, and local foundations across the country responded to the opportunities presented by the ACA and invested in a wide range of health reform activities consistent with their priorities, as well as the needs of and approaches taken by their states. Although the ACA is a federal law, in practice, “there are 50 different ACAs that vary across virtually every dimension the law touches” (Altman 2015).

The ACA is clearly helping lay a foundation for expanded coverage and health system reform. Nevertheless, gaps still exist. Both funders and advocates believe that those gaps must be addressed. At the same time, they are looking ahead to accelerate efforts to transform the delivery system, reduce costs, elevate prevention, and make meaningful progress toward greater health equity. Health reform will be an ongoing process that requires both continuing investment in the core components of the ACA, as well as seeding new innovations.

APPENDIX A: FIGURES

FIGURE 1

Over the last four years, has your foundation supported any health reform-related activities, which we define as either reforming the health care delivery system or expanding coverage? (n=91)



If your foundation supported health reform-related activities, were the majority of those activities related to or associated with the ACA? (n=76)

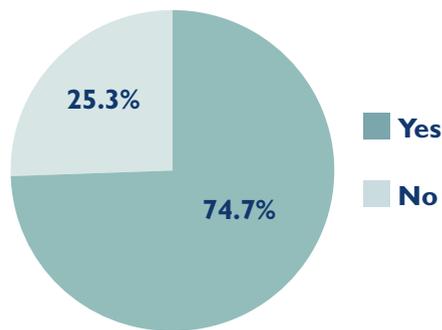


FIGURE 2

Which of the following health reform-related issues are your foundation's highest priorities? Top five choices shown. (n=83)

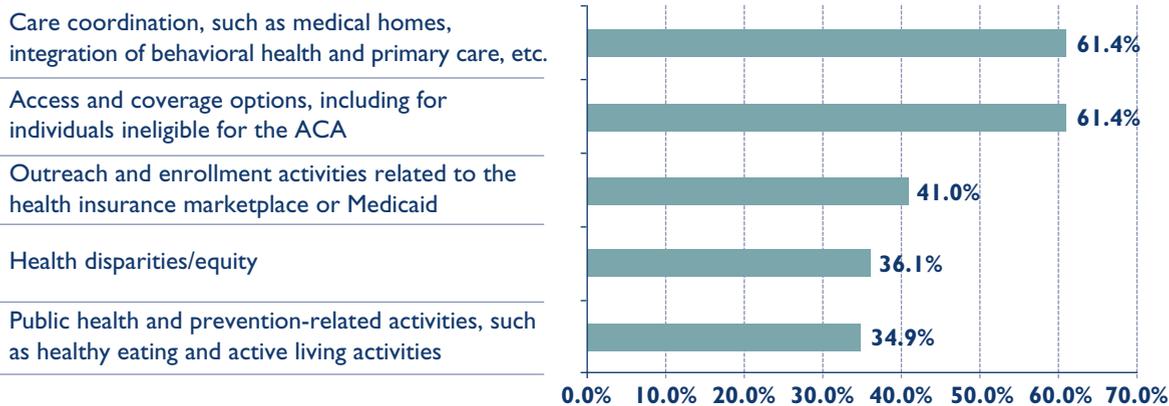


FIGURE 3

Looking back over the last four years, please indicate which activities your foundation has predominantly engaged in. (n=83)

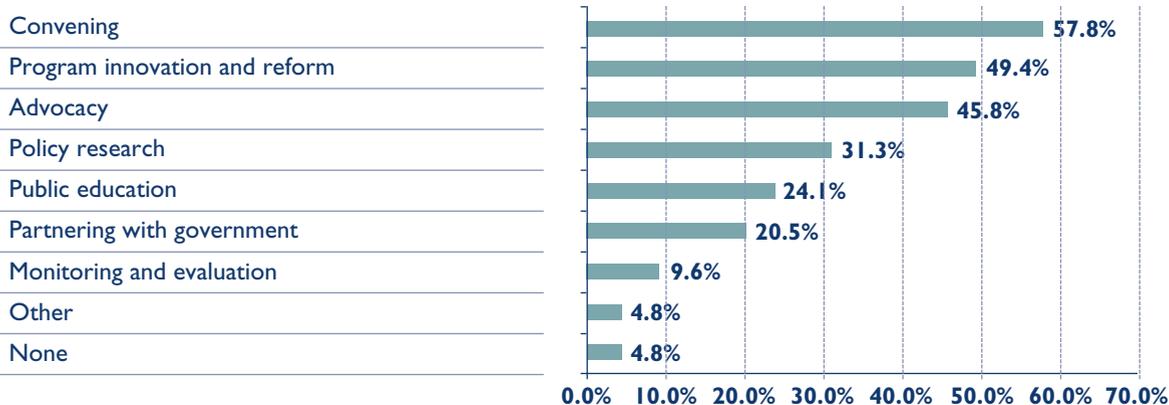


FIGURE 4

Do you currently fund consumer or other types of advocacy to work on health reform-related issues? (n=68)

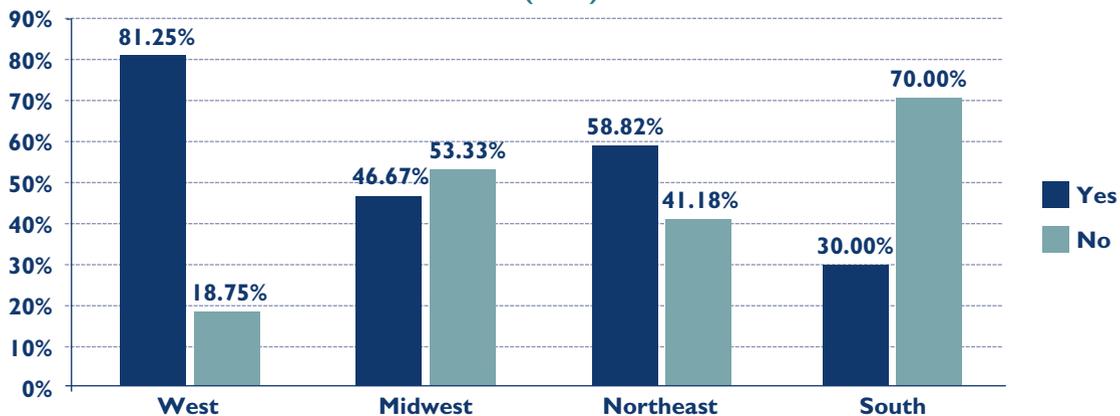


FIGURE 5

How would you characterize the capacity of the advocacy organizations and overall advocacy infrastructure in your state/nationally? (n=83)

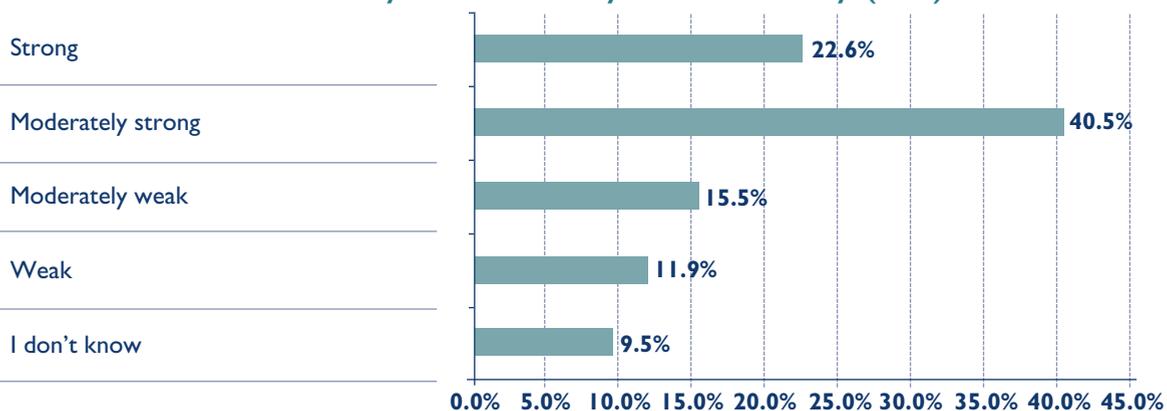


FIGURE 6

How would you characterize the capacity of the advocacy organizations and overall advocacy infrastructure in your state? (n=70)

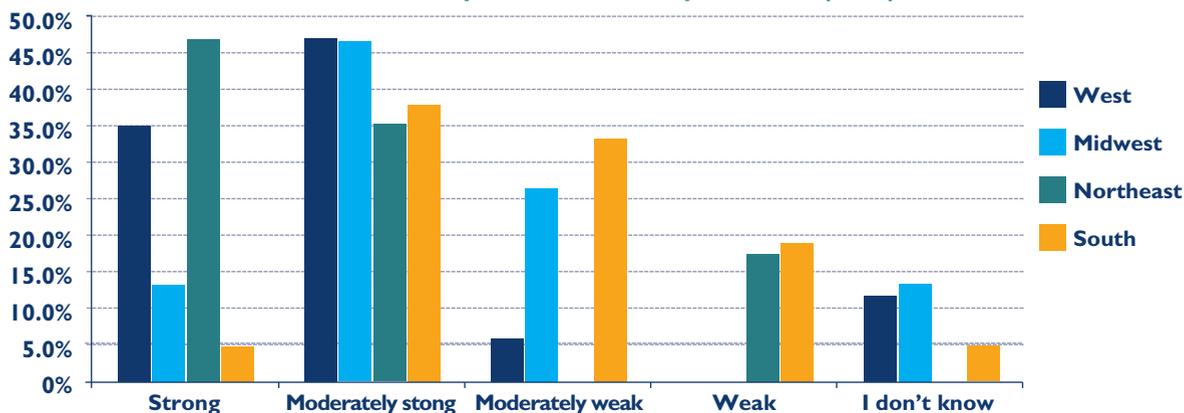


FIGURE 7

What types of funders did your foundation collaborate with on health reform-related activities? (n=85)

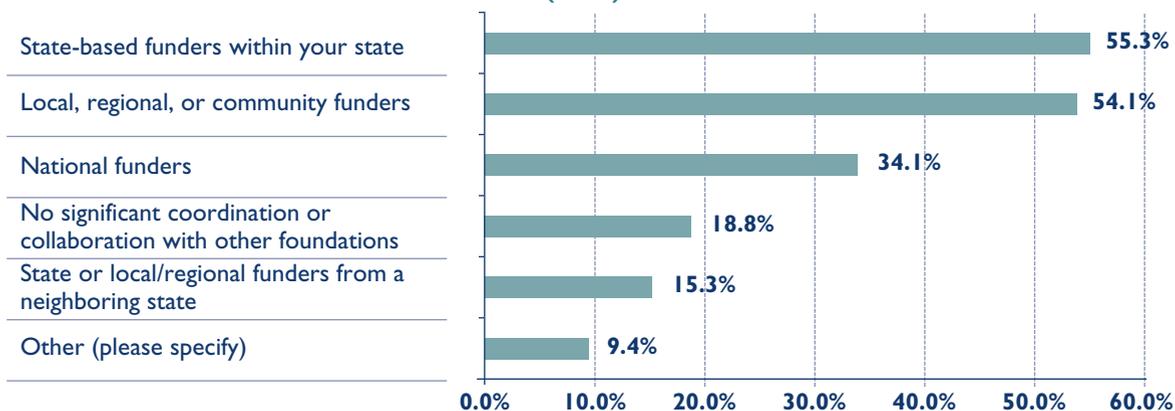


FIGURE 8

Which issues did you collaborate on with other foundations? Top six choices shown. (n=63)

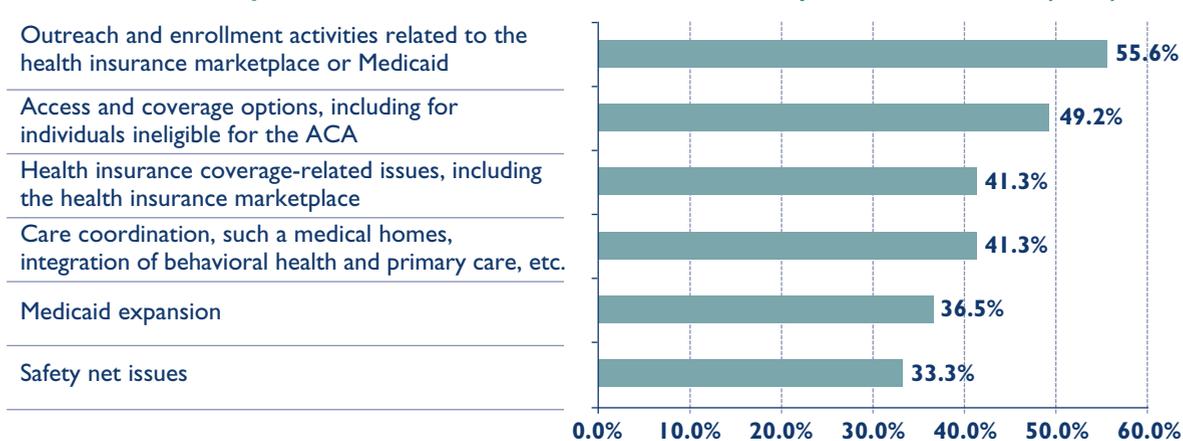
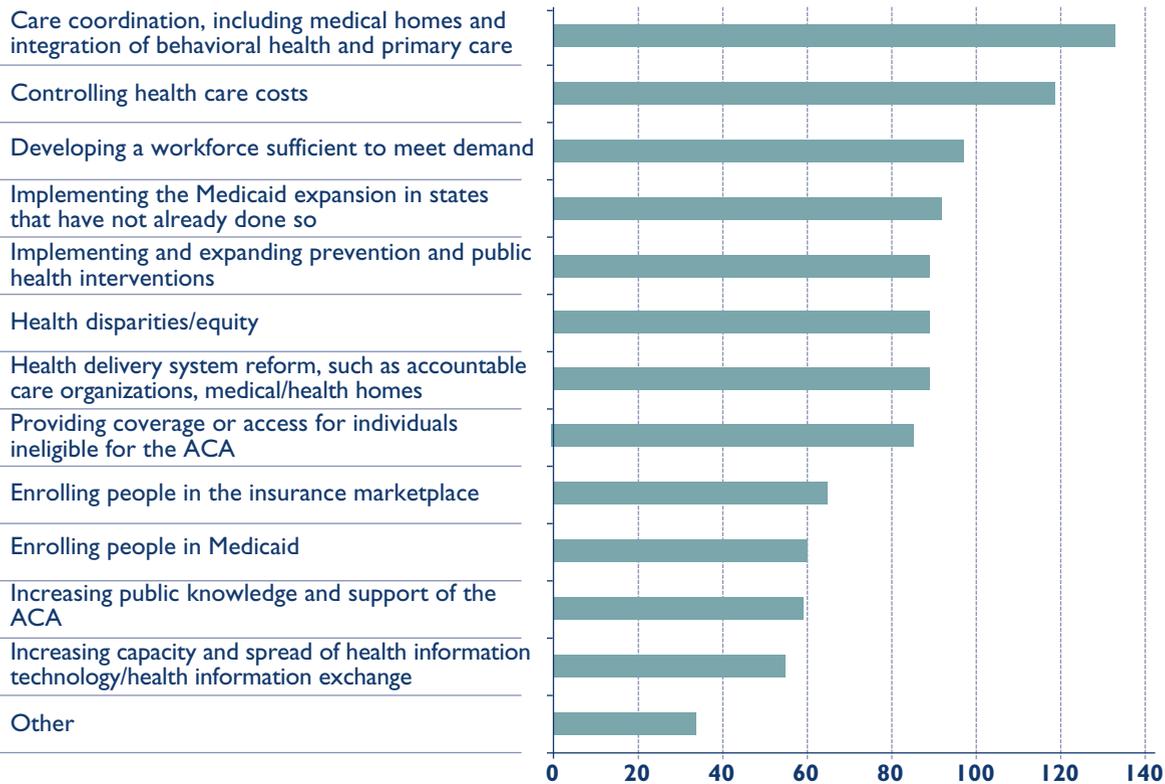


FIGURE 9

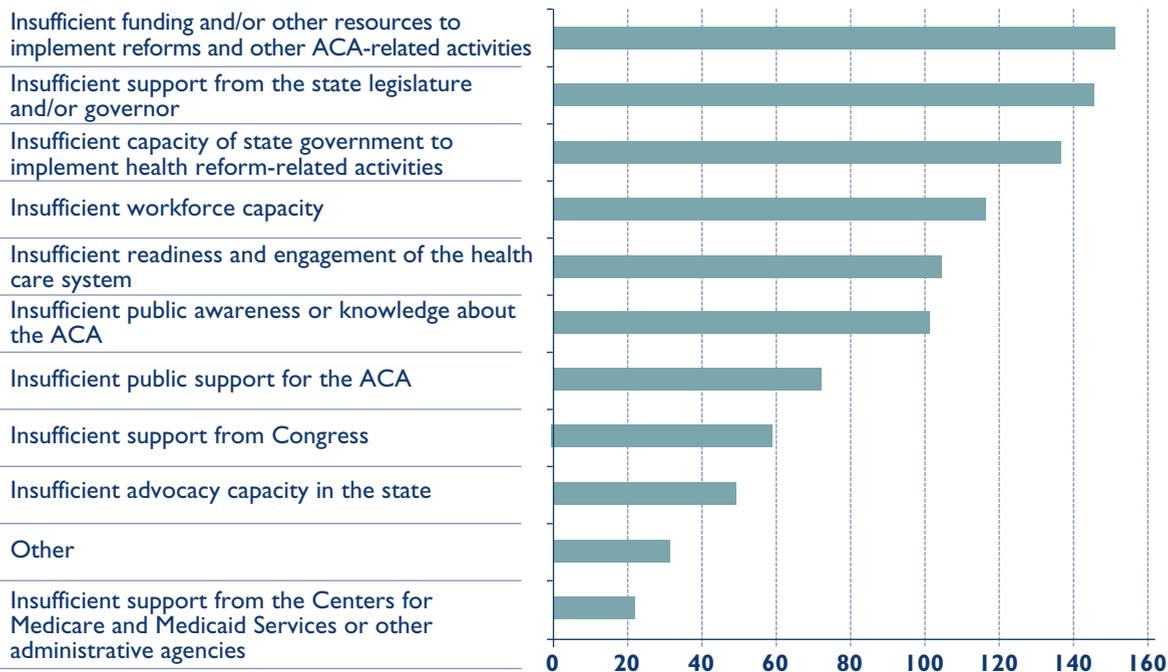
What do you think are the most critical issues related to health reform that need to be addressed in your state (or nationally, if you are a national funder) over the next two years? Please rank from one to five where one is the most critical. (n=78)



Note: raw count based on weighted ranking values.

FIGURE 10

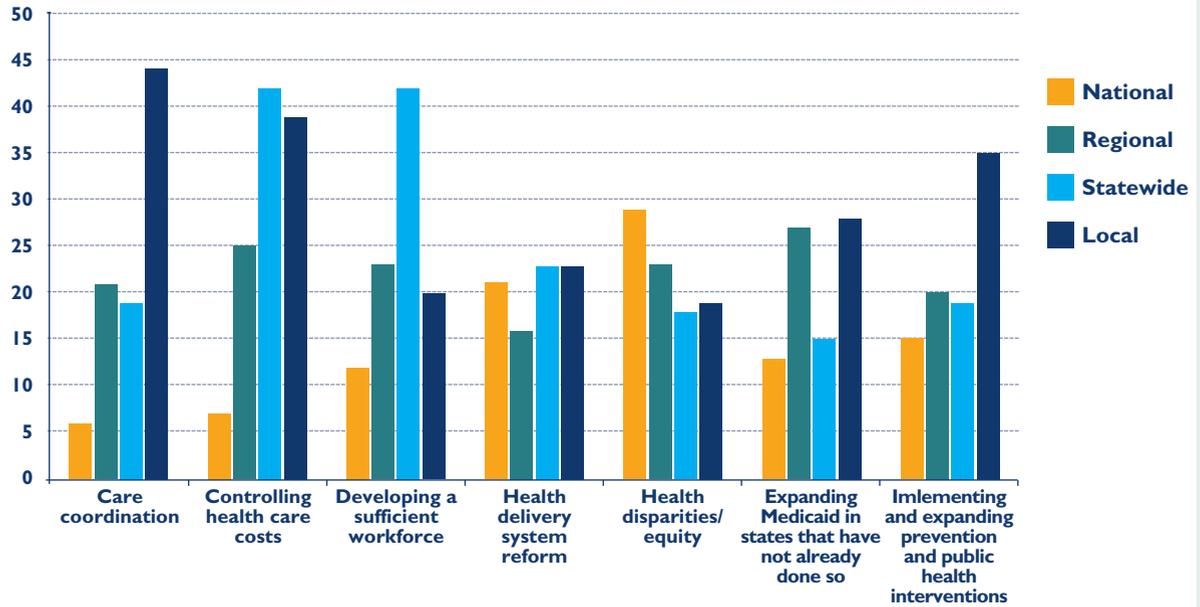
What do you think are the biggest challenges to addressing the most critical health reform-related issues? Please rank from one to five where one is the biggest challenge. (n=75)



Note: raw count based on weighted ranking values.

FIGURE 11

What do you think are the most critical issues related to health reform that need to be addressed in your state (or nationally, if you are a national funder) over the next two years?
Please rank from one to five where one is the most critical. (n=78)



Note: raw count based on weighted ranking values.

FIGURE 12

The Four Main U.S. Census Regional Designations

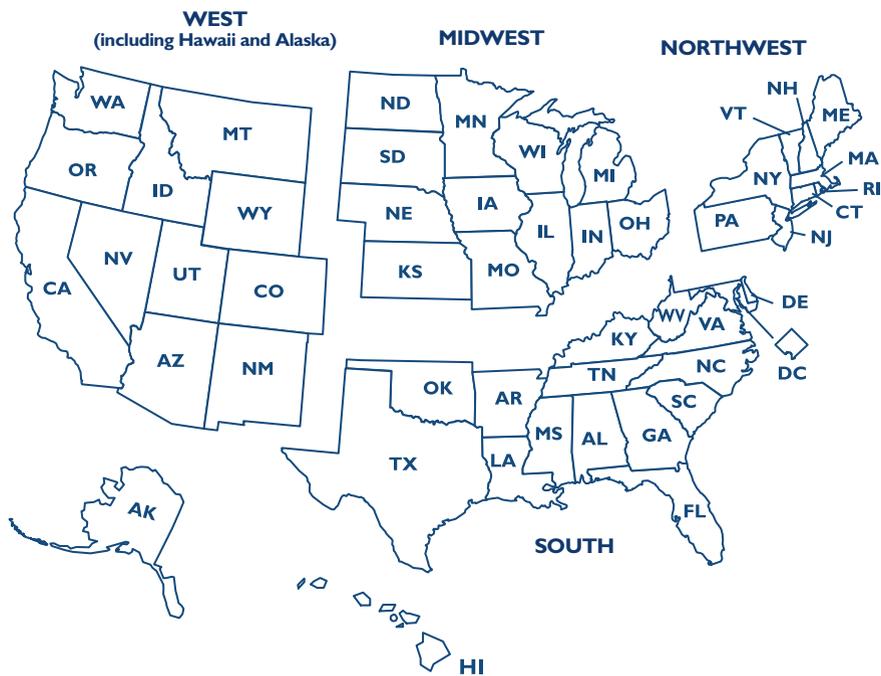
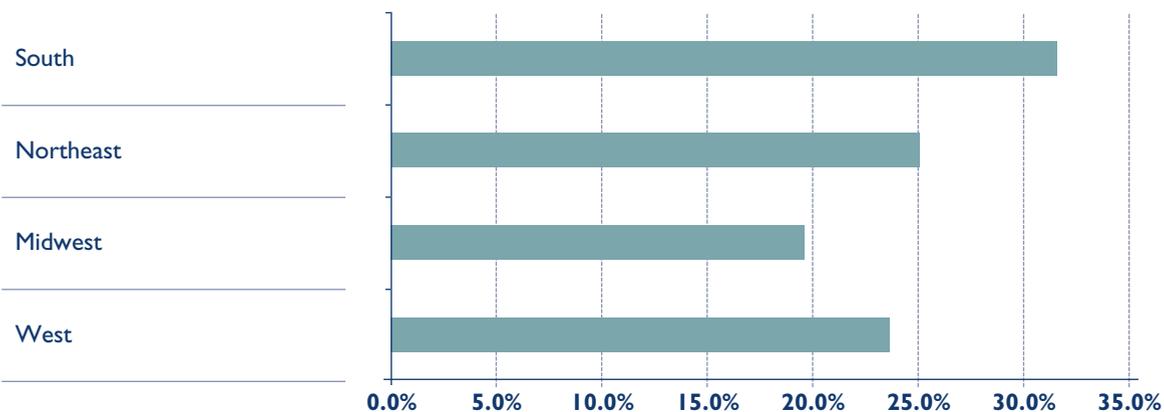


FIGURE 13

Regional Distribution of Survey Respondents* (n=76)



*national funders excluded

FIGURE 14

**Which of the following health reform-related issues are your foundation's highest priorities?
Please choose up to six. (n=69)**

REGIONAL FUNDERS' PRIORITY ISSUES

Priority Issues

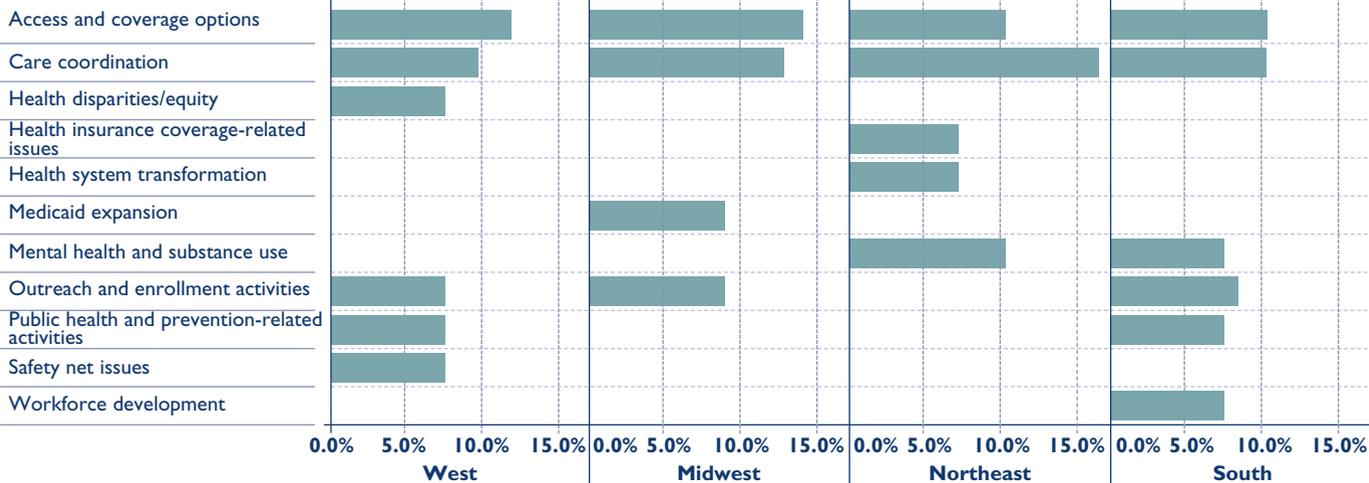


FIGURE 15

What do you think are the most critical issues related to health reform that need to be addressed in your state over the next two years? Please rank from one to five where one is the most critical. (n=64)

REGIONAL FUNDERS' MOST CRITICAL ISSUES GOING FORWARD

Most Critical Issues

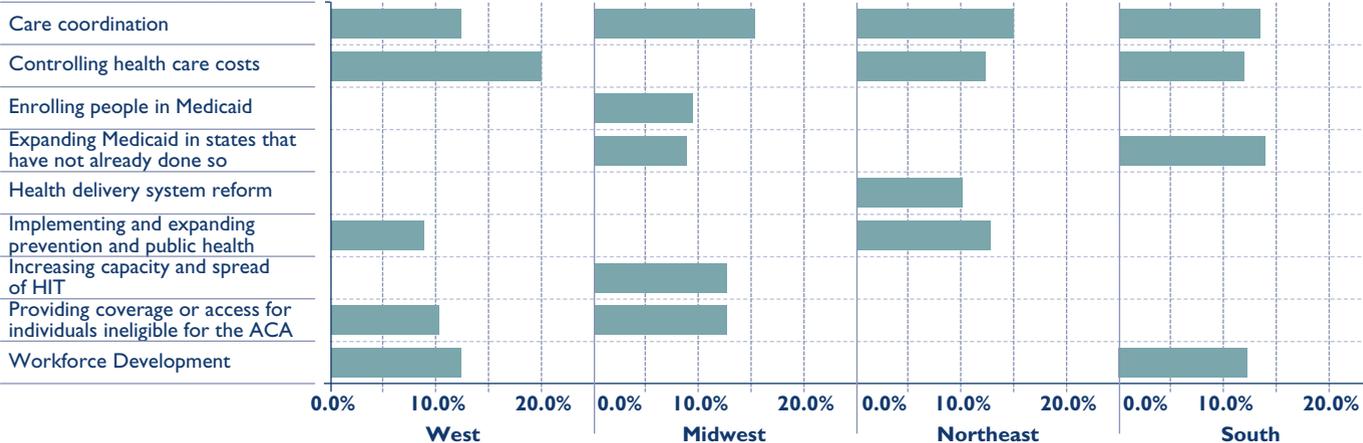


FIGURE 16

What do you think are the biggest challenges to addressing the most critical health reform-related issues? Please rank from one to five where one is the biggest challenge. (n=62)

REGIONAL FUNDERS' BIGGEST CHALLENGES

Biggest Challenges



APPENDIX B: CATEGORIZATION OF KEY ISSUES

DELIVERY SYSTEM REFORM

- Care coordination, such as medical homes, integration of behavioral health and primary care, etc.
- Care transitions, such as long-term care
- Health system transformation, such as accountable care organizations
- Health information technology/health information exchange, including electronic health records
- Mental health and substance use-related issues
- Non-expansion Medicaid-related issues, such as integration of care for dual-eligibles
- Oral health
- Payment reform and cost containment strategies
- Safety net issues
- Workforce development, such as primary care and frontline workers
- Hospital community benefits and community needs assessment requirements*
- Value-based/quality outcomes*

INSURANCE EXPANSION

- Access and coverage options, including for individuals ineligible for the ACA
- Children's health and health coverage issues
- Health insurance coverage-related issues, including the health insurance exchange
- Medicaid expansion
- Outreach and enrollment activities related to the health insurance exchange or Medicaid
- Insurance market reforms*
- Health literacy*

OTHER

- Health disparities/equity
- Immigrants and health
- Public health and prevention-related activities, such as healthy eating and active living activities*
- Women's health

**Added as a result of interviews*

APPENDIX C: METHODOLOGY

This report synthesizes the findings of a survey of GIH Funding Partners and the content of 36 interviews with state and national funders and advocates.

The online survey was administered via email from May 19 to June 18, 2014. Ninety-one foundation representatives responded out of a total potential of 224 respondents, for a 41 percent response rate. Of those respondents, 86 percent completed the entire survey. More than 50 percent of respondents said that they were either the CEO or executive director of their organization, and the respondents were representative of geography, funder type (e.g., local, statewide, regional, and national), and current state status of ACA implementation.

In selecting the health foundations for interviews, a variety of perspectives were sought, with the goal of having a mix of funders of different sizes, funder type, and geography. Accordingly, four national funders and 18 state-based and local funders were interviewed.

Because health reform implementation played out differently across the country, depending on the policy and political environment, a further consideration was to select foundations from states that used different models of the health insurance marketplace (e.g., federally facilitated or state-based), as well as states that did and did not implement the Medicaid expansion.

The survey data found clear regional variations among funders from the four major regions of the country. Therefore, two states from each of the four regions were identified for further investigation. Two foundations (three in the case of the Midwest) and one advocate from each of the states were then interviewed to inform a high-level picture of that state's experience. Although every state is unique and made decisions based on its own history with health care and health reform, data from the two states' interviews, in combination with the survey data, were used to generate the Regional Snapshots.

A full list of the individuals interviewed can be found in Appendix D. All interviews were conducted by phone during the months of August and September 2014, and lasted between 45 minutes and an hour. In addition, websites, issue briefs, and other materials produced by funders and advocates were consulted, as well as health policy literature.

APPENDIX D: LIST OF INTERVIEWEES

NATIONAL FOUNDATIONS

Andrew D. Hyman

Senior Program Officer, Robert Wood Johnson Foundation

Rachel Nuzum

Vice President, Federal and State Health Policy, The Commonwealth Fund

Diane Rowland

Executive Vice President, The Henry J. Kaiser Family Foundation

Alice Warner-Mehlhorn

Director of Policy, W.K. Kellogg Foundation

STATE-BASED AND LOCAL FOUNDATIONS

Patricia Baker

President and CEO, Connecticut Health Foundation

Sandra Welch Boren

Vice President and Senior Program Officer, Cone Health Foundation (North Carolina)

Sheila Bugdanowitz

President and CEO, Rose Community Foundation (Colorado)

Myrna Deckert

CEO, Paso del Norte Health Foundation (Texas)

Richard Figueroa

Director, Health and Human Services, The California Endowment

Billie Hall

President and CEO, Sunflower Foundation (Kansas)

Nancy L. Heaton

CEO, Foundation for Community Health (Connecticut)

Chet Hewitt

President and CEO, Sierra Health Foundation (California)

Robert Hughes

President and CEO, Missouri Foundation for Health

Octavio N. Martinez, Jr.

Executive Director, Hogg Foundation for Mental Health (Texas)

Jodi Mitchell

Health Policy Program Officer, Mt. Sinai Health Care Foundation (Ohio)

Ann F. Monroe

President, Health Foundation for Western and Central New York

Christopher Perrone

Director, Health Reform and Public Programs Initiative, California HealthCare Foundation

David Sandman

Senior Vice President, New York State Health Foundation

Brenda Sharpe

President and CEO, REACH Healthcare Foundation (Kansas and Missouri)

Allen Smart

Vice President, Programs, Kate B. Reynolds Charitable Trust (North Carolina)

Anne Warhover

President and CEO (Emeritus), The Colorado Health Foundation

NATIONAL ADVOCATES

Joan Alker

Executive Director, Center for Children and Families, Georgetown University Health Policy Institute

Kathy Ko Chin

President and CEO, Asian and Pacific Islander American Health Forum

Ron Pollack

Executive Director, Families USA

Susan T. Sherry

Deputy Director, Community Catalyst

Judith Solomon

Vice President for Health Policy, Center on Budget and Policy Priorities

STATE-BASED AND LOCAL ADVOCATES

Elisabeth Benjamin

Vice President of Health Initiatives, Community Service Society (New York)
Lead, Health Care for All New York

Jen Bersdale

Executive Director, Missouri Health Care for All

Anne Dunkelberg

Associate Director, Health and Wellness Program Director, Center for Public Policy Priorities (Texas)

Gretchen Hammer

Executive Director, Colorado Coalition for the Medically Underserved

Adam Linker

Co-Director, Health Access Coalition, North Carolina Justice Center

Scott McCown

Clinical Professor and Director, Children's Rights Clinic, The University of Texas School of Law

Jane McNichol

Executive Director, Legal Assistance Resource Center of Connecticut

Will Petrik

State Director, Advocates for Ohio's Future

Sheldon Weisgrau

Director, Health Reform Resource Project (Kansas)

Anthony Wright

Executive Director, Health Access (California)

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