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# Consumer Health Advocacy: A View from 16 States

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And finally, we are also very grateful to the W. K. Kellogg Foundation for its support of this project. The Foundation’s commitment to building and strengthening consumer voices has been steadfast.



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## Executive Summary

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### BACKGROUND

For more than a decade, significant aspects of health policy decision-making have been shifting from the federal government to the states. Important decisions about Medicaid eligibility and benefits, children's health insurance, hospital care for the indigent, and other health access issues are now made in state capitals instead of Washington. At the same time, the number of uninsured Americans – and those with inadequate coverage – continues to rise, while health care reform efforts at the federal level are stymied. Taken together, these realities have prompted a focus on states as the place where health policy is most likely to be made.

What is actually happening in state capitals and communities across the nation as these trends play out and crucial health policy decisions are being made? Can health care consumers actively participate in health policymaking? What political, economic, and organizational factors are making consumer health advocacy successful in some states and extremely challenging in others?

No national study has sought the answers to these questions, which are important not only to health advocacy organizations but also to policymakers, health funders, and scholars studying the evolution of health policymaking in the United States. Because of its organizational focus on state and community-level consumer health advocacy, Community Catalyst undertook an in-depth study of consumer health advocacy in a representative sample of 16 states: Arkansas, Colorado, Connecticut, Florida, Georgia, Illinois, Kansas, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, New Jersey, New Mexico, Ohio, and Oregon. Funding for the study was provided by the W. K. Kellogg Foundation.

### METHODOLOGY

Community Catalyst staff conducted more than 200 interviews with key people in the selected states, including leaders of advocacy, grassroots, and constituency organizations; legislators and other political leaders; and policy experts, funders, and other stakeholders in health care decision-making. In addition, more than 70 key health advocacy organizations completed a detailed survey. Other relevant data and information were gathered through a review of the literature and from health care databases.

### KEY OBSERVATIONS

#### ***Health care access problems are serious – and growing – in each of the 16 states.***

Across the 16 states, millions of people are unable to get the care they need. This is true even in states with relatively expansive public programs and high rates of employer-based coverage. Interviewees in all of the study states reported that numbers of uninsured people are growing, and that lack of health care access is an increasingly important problem for the people and communities they serve. As one interviewee put it, “What is most shocking is how many more uninsured there are. It is almost to the point that people don't expect to have access anymore.”

***Health care policies and access differ significantly among the states.***

Important policy differences among the study states have, in turn, a significant impact on how many people have access to care in each state. For example, in Illinois, parents with incomes up to 185 percent of the poverty level (\$37,000 for a family of four) are eligible for Medicaid. By contrast, in Maryland, only parents whose incomes are at or below 35 percent of the poverty level (\$7,000 or less for a family of four) are eligible for Medicaid.

***Strong state-based consumer health advocacy can make an important difference in a broad range of state environments.***

Consumer advocates across the 16 study states are influencing policy decisions on a wide range of issues affecting health care access. These issues include: Medicaid eligibility and benefits; tobacco taxes; free care and hospital financial assistance; employer-sponsored insurance coverage; insurance affordability; and tax and budget policies. Consumer advocacy has had a significant impact, both in promoting innovative new health policies and in defending against proposed cutbacks in health coverage and access.

***In a few states, consumer health advocacy is creating momentum for significant health policy innovation.***

In a few of the study states, consumer-based advocacy organizations have put expanding access to affordable, quality care for all residents high on the political agenda. Two of these states, Illinois and Massachusetts, demonstrate the potential power of consumer advocacy to achieve broad health care reform. In these states, advocates have successfully promoted a broad range of interrelated policy changes that respond to the needs of both people using the system and those who are shut out of it. The result has been an expansion of public and private sector access to health coverage and care.

***Three key factors are influencing the ability of consumer advocacy to shape state health policy outcomes.***

Why are consumer advocacy organizations in some states more successful in moving forward a consumer health agenda? The study concluded that three factors influence the ability of consumer advocacy to shape health policy outcomes:

1. **Organizational capacities of consumer organizations.** Such capacities include the abilities to: analyze complex legal and policy issues; use media and other communications strategies to build timely public and political support for reform and weaken opposition arguments; build a strong grassroots base of support; build and sustain strong, broad-based coalitions and maintain strategic alliances with other stakeholders; and generate resources from diverse sources for infrastructure and core functions as well as for campaigns.
2. **Funding support for consumer health advocacy.** Resource availability correlates with state advocacy capacity. The states with the greatest advocacy capacity also had the most funding support for consumer health advocacy. The study found a positive, ongoing relationship between funders and health advocacy organizations in those states.

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## Executive Summary *(Continued)*

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- 3. The political and economic environment.** The study found a wide range of political and economic environments among the 16 states. Key elements include: per capita income; rates of private health insurance coverage; the impact of tax policies on revenues for health care access; politicians' willingness to use public revenue for health care access; the ease of consumer access to the decision-making process; and the state's electoral process and structures. These factors affect the kinds of issues that advocacy organizations work on, the strategies they use, and the level of advocacy capacity needed to influence major policy decisions.

Based on the relative strength or weakness of these factors, consumer health advocacy in each of the 16 states falls into one of three general stages of development: **defensive** (characterized by an antagonistic political/economic environment and a low level of consumer capacity and funding); **intermediate** (fewer environmental obstacles than in the defensive stage, and somewhat more developed advocacy capacity); and **proactive** (a receptive economic/political environment and a well-developed advocacy capacity, with relatively high levels of funding support). There are distinct geographic characteristics to these groupings. Of particular note is that all of those in the defensive stage are Southern states with significant rural populations and high poverty rates. In contrast, proactive stage states are predominantly in the mid-Atlantic and the Northeast and, with one exception, they are industrialized, with large metropolitan areas and higher-than-average rates of union membership.

## RECOMMENDATIONS

As health care policymaking increasingly devolves to the states, consumer health advocacy organizations and coalitions in the states must be strengthened to counterbalance the influence of powerful industry lobbyists and to create momentum for health policy reform on the state level. There are opportunities to raise the levels and impact of health advocacy capacity in all of the 16 states studied. Innovative and promising practices need to be further developed, documented, and disseminated in order to strengthen consumer-based impact on key state health policies. Our recommendations go beyond building capacity in single organizations and toward developing an organized approach to building sustainable consumer health advocacy systems in every state.

We have four key recommendations for building a stronger, more effective consumer voice in state health care debates. Moreover, taking these steps at the state level will enhance the consumer voice at the national level.

- 1. In each state, assess consumer health advocacy capacity and seek to address gaps through collaborative partnerships, strategic alliances, and new funding.** The starting point of any such effort should be a systematic and realistic assessment of current consumer health advocacy capacity, the state's political and economic environment, and the funding opportunities for consumer health advocacy. The methodology developed by Community Catalyst for this study can serve as a model for such an assessment. The approach to addressing identified capacity

needs will differ from state to state, but it will likely include building collaborative advocacy partnerships, seeking strategic alliances with powerful stakeholders on a case-by-case basis, and engaging funders in developing and supporting a new vision of consumer health advocacy.

- 2. Develop a national program to coordinate and deliver strategic support to state consumer health advocacy organizations.** While work within each state is important, coordination of state efforts on a national scale is essential both to strengthen state-based consumer advocacy and to strive for national impact. A national program could assist state-based consumer health advocates in obtaining the support services they need – tailored to their individual circumstances and state political/economic environments – in order to increase their capacity for effective advocacy. Such a program would also facilitate cross-state coordination and learning and serve as the “launching pad” for concerted national efforts.
- 3. Organize strategic campaigns both within and across states.** Health reform success in one state can be a catalyst for strengthening advocacy capacity and impact in others. Moreover, creating capacity to move similar health care reform proposals in a critical mass of states can build momentum for reform at the national level.
- 4. Develop a stronger resource base to support consumer health advocacy, both within individual states and as part of a broader movement.** Raising the impact of consumer health advocacy requires new resources that are strategically targeted to three goals: achieving short-term impacts on policy, building capacity to engage in advocacy, and developing sustainable health advocacy *systems*. The study identified many promising funding practices that significantly raised consumer health advocacy capacity to higher levels.



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## Part 1: Introduction and Background

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This report addresses the status of consumer health advocacy in 16 states across the country, and provides recommendations for strengthening such efforts. **Part 1** provides the context for the assessment. **Part 2** describes the critical health care issues that state advocates currently focus on and the factors that influence the ability of consumer advocacy to shape health policy outcomes. It also assigns each study state to one of three stages of health advocacy impact, based on the state's level of consumer advocacy capacity, its political and economic environment, and the availability of resources. **Part 3** contains recommendations for increasing the effectiveness and impact of consumer health advocacy, both within each of the target states and nationally. **Part 4** profiles each of the 16 study states in depth, informed by demographic, economic, and health data, as well as by extensive interviews with people “on the ground.”

### THE IMPORTANCE OF CONSUMER HEALTH ADVOCACY IN THE STATES

For more than a decade, significant aspects of health policy decision-making have been shifting from the federal government to the states. Important decisions about Medicaid eligibility and benefits, children's health insurance, hospital care for the indigent, and other health access issues are now made in state capitals instead of in Washington. At the same time, the number of uninsured Americans continues to rise – as does the number of those with inadequate coverage – while health care reform efforts at the federal level are stymied. Taken together, these realities have prompted a focus on states as the place where health policy is most likely to be made.

In theory, this “devolution” of health policy should bring decision-making a step closer to the health care consumers who are directly affected, thereby increasing their ability to participate in the process. State-level health policymaking also enhances the potential for solutions tailored to the demographics and health problems of each state's population. Policy choices can consider state-specific factors – such as the number of medical providers and the geographic distribution of the population.

In practice though, devolution carries with it some inherent dangers. Without national standards, there are growing inequities in health care access between wealthier states and states with struggling economies. In many places, small consumer health advocacy groups with scarce resources find themselves ill-equipped to challenge the well-financed lobbying efforts of the health industry and business associations. In addition, vulnerable populations are particularly at risk when state-level policies exacerbate or fail to address disparities in care access and quality based on race, income, immigrant status, or other factors.

Compounding the effect of devolution is the trend toward deregulation of the health care industry. The policy turn toward the market as “decision-maker” in allocating health resources places more and more decisions about access to care, service delivery capacity, and other priorities into the hands of health care institutions and insurance companies, just when they are operating with less and less public regulation and oversight.

The actual impact of important health industry decisions often becomes visible, especially at the community level, only when individual health consumers seek care.<sup>1</sup> Unless consumers are organized into groups that can understand and monitor what is happening, and unless they can advocate for their individual and community needs, they are in danger of discovering too late that they have lost convenient or affordable access to health care.

What is happening in state capitals and communities as these trends play out? Can health care consumers actively participate in health policymaking? What political, economic, and organizational factors make consumer health advocacy more successful in some states and extremely challenging in others? What issues are consumer groups addressing, and what impacts are they having? Can successful advocacy strategies used in some states be replicated elsewhere? Does consumer advocacy capacity to affect the decisions of state and local public and institutional policymakers translate into potential for national action?

These questions are important not only to health advocacy organizations but also to policymakers, health funders, and scholars studying the evolution of health policymaking in the United States. In 2005, because of its organizational focus on state and community-level consumer health advocacy, Community Catalyst undertook an in-depth study of consumer health advocacy in a representative sample of states. They were: *Arkansas, Colorado, Connecticut, Florida, Georgia, Illinois, Kansas, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, New Jersey, New Mexico, Ohio, and Oregon*. Funding for the study was provided by the W. K. Kellogg Foundation.

This report presents the study findings, along with recommendations for strengthening consumer health advocacy at the state and community levels. Part 4 profiles each state in depth. Summarized here are key observations that are applicable to all of the study states.

### **Health care access problems are serious – and growing – in each of the 16 states.**

Across the 16 states, millions of people are unable to get the care they need. This is true even in states with relatively expansive public programs and high rates of employer-based health insurance coverage. Interviewees in all of the study states report rising numbers of people without health coverage, and they say that lack of health care access is an increasingly important problem for the people and communities they serve. As one interviewee put it, “What is most shocking is how many more uninsured there are. It is almost to the point that people don’t expect to have access anymore.”

A decrease in employer-sponsored coverage from 2000 to 2004 – and the inability of Medicaid coverage to fill that gap – has significantly increased the number of people without insurance. For example:

- > All 16 of the study states experienced declines in employer-sponsored insurance coverage, ranging from about 1 percent in *Louisiana* and *New Mexico* to almost 8 percent in *Maryland*. The decline was 4 percentage points or more in 10 states.

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<sup>1</sup> The term “consumer” is used throughout the report to describe the people who use the health care system and have a distinct interest from that of providers and payers. Consumer health advocacy works to build a strong consumer voice in health care decisions to make the system more responsive and accountable to the people who use it.

## Part 1: Introduction and Background *(Continued)*

- > Rates of uninsurance rose nearly 7 percentage points in 2 states, and increased 3 percentage points or more in 10 of the 16 states.

### **Health care policies and access differ significantly among the states.**

Important policy differences among the states included in the study have, in turn, a significant impact on how many people have access to care in each state. For example:

- > In *Illinois*, parents with incomes up to 185 percent of the poverty level – \$37,000 for a family of four – are eligible for Medicaid. By contrast, in *Maryland*, only parents whose incomes are at or below 35 percent of the poverty level – \$7,000 or less for a family of four – are eligible.
- > In *New Jersey*, uninsured people with incomes below 200 percent of poverty can get complete hospital financial assistance. In *Arkansas*, however, the only formal access to free care is through a voluntary program of services donated by hospitals, physicians, pharmacies, and drug companies. Only uninsured residents with incomes below 100 percent of the poverty level are eligible; and the supply is limited, so not all otherwise-eligible people can actually obtain services.

### **Strong, state-based consumer health advocacy can make an important difference in a broad range of state environments.**

Consumer advocates across the 16 study states are influencing policy decisions on a wide range of issues affecting health care access. These issues include: Medicaid eligibility and benefits; tobacco taxes; free care and hospital financial assistance; employer-sponsored insurance coverage; insurance affordability; and tax and budget policies. Consumer advocacy has had a significant impact in almost all of the study states, whether through promoting innovative new health policies or in defending against proposed cutbacks in health coverage and access. For example:

- > In *Maryland*, consumer health advocates won enactment of the “Fair Share Health Care” law despite the governor’s veto. The new law requires businesses with more than 10,000 employees to spend at least 8 percent of payroll on health coverage. Passage of this law represents an incremental step in the advocates’ comprehensive health care reform agenda.
- > Health advocates in *Colorado* led a successful effort in 2004 to pass a ballot initiative that more than tripled the state’s tobacco tax, generating \$175 million in new annual revenue. Those funds are dedicated to expanding access to Medicaid and the State Children’s Health Insurance Program (SCHIP), increasing the availability of primary care in community health centers, reducing smoking, and increasing the prevention, early detection, and treatment of cancer. “The tobacco tax victory re-energized the health care advocates. It got everyone together around a proactive agenda, which hadn’t happened since the mid-90s. All of our recent advocacy had been purely reactive,” said one interviewee.

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- > Consumer advocates in *Ohio*, working with providers, fended off significant Medicaid cuts in the 2003 and 2004 budgets.
- > In *Mississippi*, consumer health advocates' efforts postponed elimination of a Medicaid eligibility category until most recipients became eligible for drug coverage through Medicare Part D.
- > In *Georgia*, advocates reversed the governor's proposal to terminate PeachCare (*Georgia's* SCHIP program) coverage for children whose parents did not pay insurance premiums.

**In a few states, consumer health advocacy is creating momentum for *significant* health policy innovation.**

In a few of the study states, consumer-based advocacy organizations have put expanding access to affordable, quality care for all residents high on the political agenda. Two of these states, *Illinois* and *Massachusetts*, demonstrate the potential power of consumer advocacy to achieve major health care reforms. In these states, advocates have successfully promoted a broad range of interrelated policy changes that respond to the needs of both people using the system and those who are shut out of it. The result has been an expansion of public and private-sector access to health coverage and care.

In *Illinois*, recent consumer advocacy receives major credit for:

- > Enacting the "All Kids" program, making *Illinois* the first state to guarantee health insurance coverage for all children;
- > Enabling an estimated 280,000 uninsured adults to obtain Medicaid coverage by raising eligibility limits for parents from 39 percent of the poverty level (\$7,800 for a family of four) to 185 percent (\$37,000);
- > Winning a landmark legal case that ensures children enrolled in Medicaid and SCHIP will receive the full range of preventive and well-child care services;
- > Securing prescription drug assistance for seniors, including wraparound programs that close the gaps in Medicare Part D; and
- > Achieving passage of a law that makes it a state policy goal "to insure that all residents have access to quality care at a cost that is affordable" and establishes a process for developing a plan to provide coverage for all state residents.

In *Massachusetts*, consumer advocates have driven significant health policy innovations through 20 years of steady, highly coordinated work. Most recently, in April 2006, they achieved enactment of comprehensive health care reforms that will provide affordable new coverage for 350,000 low- to middle-income people. Prior victories included: expanded Medicaid access; creation of a pharmacy assistance program available to all seniors; guaranteed coverage for all uninsured children; guaranteed access to full or partial free care for people at or below 400 percent of the poverty level; and passage of legislation establishing a statewide Commission on Racial and Ethnic Disparities in Health.

As positive as these results have been, consumer advocacy has the potential to become more influential in protecting and advancing consumer interests. This is true even in favorable environments like *Illinois* and *Massachusetts*. Across the 16 study states, consumer advocacy capacity is highly variable. In each of

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## Part 1: Introduction and Background *(Continued)*

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those states, though, the problems people face in trying to obtain care, and the growing awareness of the role of state policy in expanding or reducing access to care, are creating opportunities to build and strengthen state consumer health advocacy movements.

### OUR ASSESSMENT APPROACH

Community Catalyst is a national non-profit organization that works with local and state consumer advocacy partners in all parts of the country to strengthen the voice of consumers and communities in decisions shaping the future of the health system. While our work focuses on people who are shut out of the current system, we believe that achieving health care access and equity for uninsured and underserved people and poor communities will improve the health system for everyone. For well over a decade, our staff of experienced policy analysts, attorneys, organizers, and organizational development specialists has worked in partnership with consumer and community groups in over 30 states, helping them achieve wide-ranging substantive policy reforms, and building capacity, influence, and power in the process.

#### Study Objectives

This study had three objectives:

- > Identify the key health and health-related policy issues that consumer health advocates are working on;
- > Analyze the organizational capacity of each state's network of consumer advocates and community-based groups working on these issues; and
- > Make recommendations for strengthening the knowledge, skills, and resources that will increase consumer health advocacy effectiveness and impact.

#### Methodology

We selected 16 states for in-depth study, based on several factors: geographic, racial, and political diversity; levels of consumer-based advocacy; and types of political culture. The states were: *Arkansas, Colorado, Connecticut, Florida, Georgia, Illinois, Kansas, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, New Jersey, New Mexico, Ohio, and Oregon*. We also selected a set of health issues that are important to vulnerable constituencies and to low- and moderate-income communities. We then identified organizations within each state that are working on those issues. The identification process initially involved contacting national organizations and asking them to share information on their local contacts or affiliates. Once we made contacts within a study state, we asked each individual interviewed to provide us with additional names of advocates and organizations we should speak with. **Appendix A** describes our methodology in detail. **Appendix B** contains the names of the national organizations we spoke, and **Appendix C** contains the names of the state-based individuals we interviewed.

Community Catalyst researchers conducted three stages of information gathering:

- > First, we conducted a review of published data about each state’s health status and health care access, political structures, and economic characteristics;
- > Second, we conducted interviews in each state with leaders of consumer advocacy, grassroots and constituency organizations, policymakers, policy experts, other key stakeholders in the health policy process, and funders of state and local health care advocacy. All interviewees were asked a series of questions about their state’s health care environment and the roles and capabilities of advocacy organizations. A total of 206 people were interviewed – an average of 13 people in each of the 16 study states.
- > Finally, we gathered in-depth information from key advocacy and organizing groups that had been identified through the interview process. Seventy of these organizations completed a survey about organizational capacity.<sup>2</sup>

To implement this data collection, Community Catalyst developed tools for assessing each state’s health care advocacy capacity in the context of its political and economic environment. The approaches developed for this study and used in the 16 study states can be adapted to assess health advocacy capacity in other states. **Appendix D** contains the interview questions and the survey instrument.

### Types of Advocacy Organizations Studied

The surveys and interviews demonstrate that many different kinds of organization are engaged in direct consumer health advocacy, often in coalition with one another. They can be characterized according to the following typology:

- > Statewide advocacy organizations that focus exclusively on health issues, representing a range of different constituencies;
- > Organizations that advocate on health issues, either alone or as part of a multi-issue agenda, in service of a particular constituency, such as seniors, adults with physical or mental disabilities, children, people with HIV/AIDS, or parents with special needs children;
- > Grassroots<sup>3</sup> and/or membership-based community organizations, some of which are faith-based;
- > Legal services organizations;
- > Research-focused health and multi-issue policy advocacy organizations;
- > Statewide, multi-issue “progressive” organizations; and
- > Labor unions and health care organizations created by labor unions.

<sup>2</sup> Areas of inquiry included: organizational mission; extent of consumer interest and voice; kinds of health care issues the organization works on; organization membership and role they play in decision-making; focus on local, state, and national policy issues; involvement in community organizing; involvement in advocacy; factors that limit organizational development; and major organizational assets.

<sup>3</sup> We use the term “grassroots” to describe organizations that reflect the voices of the people most affected by the issue being addressed *and* that are responsive to and largely led by these constituencies.

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## Part 1: Introduction and Background *(Continued)*

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Almost half of the organizations studied have multi-issue agendas that include health care. Only one-quarter work primarily on health care access and coverage issues. About 20 percent focus on the interests of specific populations (such as racial or ethnic minorities, seniors or children) rather than on a specific issue. Some of these are service organizations that include a focus on advocacy.

Most of the consumer-based advocacy organizations studied are small, with fewer than 10 staff. There is significant variety among their sources of funding, but resources for conducting advocacy come predominantly from foundations. What these organizations lack in size of staff or amount of resources, they make up for in length of experience. An overwhelming majority of the organizations have been in operation for 10 years or longer. Only 5 percent have been in operation three years or less. There were important differences in the racial and ethnic composition of the different types of organizations surveyed. The statewide advocacy organizations and other more policy- and legally-oriented organizations were largely white, while the grassroots and membership-based organizations were much more diverse.

### **Differences Between Consumer Advocates and Other Health Policy Stakeholders**

Most of the organizations we studied represent the interests of uninsured and underinsured people and people enrolled in Medicaid or other public programs. In general, these constituencies are not highly organized, and they are limited in their ability to influence health policy on their own. Most do not belong to unions or other organizations that can represent their interests.

Consumer health advocacy organizations in the study states are seeking to bring these underrepresented people together so that they can speak with a unified voice on key policy issues affecting their access to health care. These organizations are the *only* organizations whose *sole* interest is ensuring that affordable, quality health care is available to as many people as possible.

There was general agreement among the advocates we interviewed that health care is an environment dense with interest groups/stakeholders. Many of those other interests – such as insurers, hospitals, physicians, and the pharmaceutical and tobacco industries – are well-financed and have a strong presence in each of the states we surveyed. Interviewees cited many ways in which health industry stakeholders have opposed consumer interests in their states:

- > Most state hospital associations oppose policies that would require them to adhere to uniform financial-assistance, billing, and collection policies.
- > The pharmaceutical industry opposes policies that would regulate or otherwise reduce prescription drug prices, such as bulk purchasing programs for state health programs. Advocates in one of the study reported, for example, that in 2005, the pharmaceutical industry employed 17 full-time lobbyists.
- > The tobacco industry opposes efforts to increase sales taxes on cigarettes, which consumers promote because they reduce smoking and produce revenue that can be used to expand health coverage or access. In one state campaign, the tobacco industry spent \$5.1 million to defeat a tobacco tax increase initiative, almost 20 times as much as the \$270,000 spent by health advocacy organizations.



- > Business and trade association routinely oppose policies that would mandate employers to provide insurance coverage for their workers.

The study shows, however, that well-organized state consumer health advocacy movements can counter the influence of opposing interests in important policy debates. This occurs when they organize an articulate constituency voice and broaden support by pulling community-based providers, unions, health centers, and other organizations into advocacy on particular issues. In a few states, there are even promising examples of providers and other non-consumer stakeholders moving beyond their narrow, short-term interests to a realization that their broader long-term interests coincide with the interests of the uninsured and other disadvantaged consumers.

Even when consumer groups are weak, though, the number of competing stakeholders with different interests means that alliances will shift with great frequency. This means that consumer groups can intervene and tip the balance of power in a debate that they might not have initiated, but in which they have an interest.



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## Part 2: The Assessment

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### INTRODUCTION

An important question this study set out to answer is why consumer advocacy organizations in some states are more successful in advancing a consumer health agenda. Why, for example, have consumers been able to put universal health care on the political agenda in *Maryland, Illinois* and *Massachusetts*, while in other states it is nowhere to be found? Why are consumers leading the effort to expand Medicaid programs in some states, while consumers in other states are waging purely defensive battles against efforts to cut enrollment and eligibility? What factors account for these differences?

In researching these questions, we found significant differences among states in a number of important areas. After analyzing these differences, we concluded that three factors influence the ability of consumer advocacy to shape health policy outcomes in a state:

- > The capacities of consumer organizations;
- > The availability of resources to build and strengthen health policy advocacy; and
- > The political and economic environment.

Using these three factors, we categorized each of the sixteen states surveyed into one of three stages of consumer health advocacy development: Defensive, Intermediate, and Proactive. The stages are not static; some states have moved to a different stage of development based on changes in one or more of the three factors.

This categorization provides a framework that facilitates the identification of both opportunities for states to move to higher levels of consumer advocacy impact and risks for falling into a lower one. It also facilitates identification of appropriate interventions for particular states to move consumer advocacy to higher stages of impact.

### THE CURRENT ISSUE FOCUS OF HEALTH CARE ADVOCATES

With efforts to achieve universal health coverage stalled at the federal level, and with the devolution of so many health policy decisions to the states, consumer health advocates working in state capitals and local communities report they face increasing challenges. State by state and community by community, they see the numbers of uninsured and underinsured people rising. Budget deficits and tax limitation policies have created political pressure to cut back public health insurance programs that help fill the gap, programs like Medicaid and the State Children's Health Insurance Program. At the same time, more employers are reducing employee coverage or eliminating it altogether.

There are significant differences among the study states with respect to rates of employer-sponsored insurance, Medicaid enrollment, and the number of uninsured. For example:

- > The percent of non-elderly adults with employer-sponsored insurance ranged from a low of 48 percent in *New Mexico* to a high of 70 percent in *Connecticut*. The national rate is 61 percent.

- > There is significant variation in the percent of non-elderly adults covered by Medicaid in the 16 states, ranging from 8 percent in *Colorado, Maryland, and New Jersey* to 20 percent in *New Mexico*. The national average is 13 percent.

Even in states with high rates of employer-sponsored insurance, the actual numbers of people without health coverage are significant:

- > More than one million non-elderly adults are uninsured in *Ohio*, where 69 percent of residents are covered by employer-sponsored insurance and only 13 percent are uninsured.
- > In *Massachusetts*, where 68 percent of residents are covered by employer-sponsored insurance and 13 percent are uninsured, nearly 600,000 people are without coverage.

There are also some consistent patterns across states. For example, racial and ethnic disparities in health status and outcomes and in rates of health coverage are evident in all of the study states, albeit in varying degrees:

- > The difference in the infant mortality rate (deaths per 1,000 live births) between whites and blacks is significant in all of the study states, including states, like *Connecticut* and *New Jersey* that have some of the highest per capita incomes in the country.
- > In all of the study states, there are significant differences in the rate of employer-based coverage between whites and blacks. *New Jersey*, which has the second highest per capita income among all 50 states, offers the starkest example. Eighty-one percent of non-elderly whites have coverage through an employer, but only 51 percent of blacks do. *Michigan* is not far behind. Seventy-three percent of non-elderly whites have employer-sponsored coverage, but only 44 percent of blacks do.

Another cross-cutting trend was the decline in employer-sponsored insurance:

- > Between 2000 and 2004, all 16 of the study states experienced declines in employer-sponsored insurance coverage rates, ranging from about 1 percent in *Louisiana* and *New Mexico* to almost 8 percent in *Maryland*.
- > Employer-sponsored insurance rates fell four percentage points or more in ten of the states. There was no corresponding expansion in Medicaid coverage to meet the growing need, resulting in higher overall uninsurance rates in all sixteen states.

To address the effects of this crisis in health coverage and access to care, consumer health advocates in the 16 study states are working on a broad range of health policy and related issues. We learned the following:

- > Virtually without exception, consumer groups are engaged in advocacy to protect or expand Medicaid and the State Children's Health Insurance Program. A number of interviewees mentioned the underlying cost of health care as a concern, particularly with respect to Medicaid program costs.
- > Prescription drug access was raised as a concern. Some advocates were concerned about the impact of Medicare Part D on people who are dually eligible for Medicare and Medicaid. Others were concerned about Medicaid program trends that include charging prescription drug copayments or limiting the number of prescriptions that can be filled in a month.

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## Part 2: The Assessment *(Continued)*

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- > In a number of states, consumer-based coalitions are developing campaigns for universal coverage. Employer mandates are a feature of some of these.
- > At the local level, some groups are engaged in community benefit and hospital free care issues. In some states, these issues have provided a common focus for local groups and statewide health policy advocates.
- > Private insurance market reforms – with a particular focus on the non-group and small group markets – are a focus of consumer advocacy work in several places.
- > Immigrant access to health care was identified as an important issue in many states. In some states, Medicaid for legal immigrants was an important focus.
- > A number of interviewees talked about the importance of addressing racial and ethnic disparities, both in the immigrant context and also more broadly, but they also expressed frustration at being uncertain how to tackle the broader disparities issue.
- > Advocates in most states reported that they have become increasingly involved in tax policy, an area that is inextricably linked to access and coverage issues.

### ORGANIZATIONAL CAPACITY

#### **Key Capacities for Effective Consumer Health Advocacy**

The first factor in determining the stage of consumer health advocacy development is the capacity of consumer organizations in the state. The surveys and interviews conducted as a part of this study yielded valuable information about effective advocacy and organizing strategies. Using this data, we have identified six organizational capacities that are common to all successful health advocacy organizations and efforts. They are the capacity to:

- > Analyze complex legal and policy issues in order to develop winnable policy alternatives that will attract broad support;
- > Design and implement media and other communications strategies to build timely public and political support for reform and to weaken opposition arguments;
- > Develop and implement health policy campaigns;
- > Build a strong grassroots base of support;
- > Build and sustain strong broad-based coalitions and maintain strategic alliances with other stakeholders; and
- > Generate resources – from diverse sources – for infrastructure and core functions as well as for campaigns.

In general, these capacities do not exist within a single organization or even a single *type* of organization. Some organizations have strong policy analysis and research capacities but limited ability to mobilize constituents. Others can mount strong grassroots organizing campaigns but have limited ability to analyze policies or conduct action research. It takes all of these advocacy capacities to bring an effective consumer voice to bear on key health care decisions. And all of these capacities must be linked by strong leadership that can coordinate the strengths and roles of grassroots organizations, state policy groups, and stakeholder allies in common efforts to achieve shared goals.

The study found that health advocacy capacity – and hence impact – varies widely among the 16 states. At one end of the spectrum are advocates in states, like *Colorado, Illinois, Maryland, and Massachusetts*, where consumer organizations are relatively well-funded and well-staffed and have formed strong networks – or “systems” – of health advocacy. At the other end are states that have smaller organizations, more limited funding, and less ability to coordinate efforts. It is important to stress, however, that even in states with limited advocacy capacity, advocates are achieving significant gains with very limited resources and, in many cases, in extremely challenging political and economic environments.

Before addressing the three stages of advocacy impact, a more detailed description of the critical organizational capacities is necessary.

## 1. Conducting Legal and Policy Research and Analysis

The ability to analyze complex legal and policy issues, conduct research, and develop winnable policy alternatives is critical to successful consumer health advocacy. Advocacy groups that have this capacity can move forward by:

- Understanding the impact of health policy on constituencies and identifying galvanizing issues that can bring together a broad range of constituencies, organizations, and stakeholders;
- Providing data and facts that build a strong case for action; and
- Developing winnable policy solutions that make an important difference in health care access *and* provide a foundation for mobilizing key constituencies and building alliances with stakeholders.

Health policy is a complex arena. Within states, policies are made across a range of agencies, and important interactions among federal, state, and local policies often need to be understood. To be effective in a policymaking environment where well-funded interest groups can ensure that their preferences are heard, consumer advocates must carefully monitor and analyze health policies so that their implications can be understood by constituencies and the public at large. Effective consumer representation on entities such as statutorily required Medicaid advisory committees requires policy analysis that can help consumer leaders better understand and address policy issues.

There was a wide range of capabilities among states. In some states, consumer advocates, often working with legal service organizations, can carefully track legislative and regulatory changes. In others, consumer organizations have limited capacity to carry out this important function.

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## Part 2: The Assessment *(Continued)*

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A number of state advocates indicated that lack of tracking and analysis capacity prevented them from effectively evaluating policy proposals or offering alternatives for reform. Most state consumer organizations reported using information from national organizations to assist them in understanding complex policies related to Medicaid, Medicare, and other issues, although they also noted that this information is not always timely or tailored to particular state concerns.

Advocates from most states emphasized the importance of developing policy analysis capacity that is internal to the health advocacy community and is driven by an advocacy agenda. Some states have independent policy research institutes that produce reports on health policy issues. In states where health policy institutes are well connected to *advocacy* efforts, advocates saw them as playing an important role in their work.

However, advocates also observed that while those reports may have some utility, they are not always connected to current health policy debates, and they generally do not build public awareness and support. One advocate noted a “preponderance of studies of which nothing comes but reports that create an illusion of doing something.”

It is also necessary to ground policy analysis in people’s actual experiences. This requires an understanding of what is happening to people as they interact with the health care system. In several states, including *Oregon*, *Illinois*, and *Massachusetts*, this connection is made through health access “help lines” or similar linkages that assist consumers in navigating the system. They often function as “early warning” systems. In *Florida*, for example, a statewide health advocacy organization used information obtained through its network of community-based partners to document the beneficiary impact of proposed Medicaid policy changes. This analysis informed its advocacy strategy.

Advocates in a number of states are looking for new paths to universal access that combine different combinations of public and private sector reforms. In many cases, they have developed innovative approaches with little or no outside support. Crafting effective and winnable policies requires a systematic analysis of public and private-sector insurance and service delivery systems. It also requires the development of strategies for combining multiple reforms in ways that are suited to unique state environments.

Interviewees in a number of states where Medicaid is at constant risk of budget cuts cited the importance of refocusing the debate by developing creative approaches to reducing Medicaid costs without limiting Medicaid access. They noted that even if they could change the political environment, their states would still face significant revenue challenges. While new leadership might be open to exploring new revenue sources, it would also have to explore innovative ways to cut Medicaid spending without cutting eligibility and benefits. Advocates in *Florida* prepared a report on strategies to cut Medicaid costs without cutting access or benefits through a combination of service delivery changes, reductions in prescription drug expenses, and the shifting of appropriate costs to Medicare and veterans’ benefit programs. The report will be useful when the political environment improves.

Finally, policy and legal research and analysis can aid in the identification of legal challenges to policies that harm health access. The courts have been an arena for consumer advocacy in several states, and litigation has been an important tool for protecting or advancing consumer interests. In *Mississippi*, for example, a court injunction prohibited the state from eliminating a Medicaid eligibility category until most of the recipients in that category were eligible for Medicare Part D. In *Kansas*, consumer advocates were instrumental in a court decision that affirmed the denial of Kansas Blue Cross and Blue Shield's application to convert to for-profit status. In *Massachusetts*, advocates won a court case challenging shortcomings in Medicaid dental coverage. And in *Illinois*, advocates used litigation to enforce a requirement that Medicaid provide comprehensive preventive, screening, diagnostic, and treatment services to children. In most cases, these legal victories achieved results that would have been difficult to obtain in the administrative or legislative processes.

## 2. Media and Communications Expertise

The ability to use media and communications is essential to building timely public and political support and countering opposing arguments. Communications and media strategies are particularly important where interest group opposition conducts well-funded media campaigns. Despite the importance of this expertise, most of the advocacy organizations in the 16 study states reported that weak media and communications capacities are a barrier to success. In almost 60 percent of the groups, the executive director is responsible for communications. Only 25 percent have a communications plan, and substantially fewer use focus groups or polling to help shape their message.

Media and communications capacities contribute to advocacy success by:

- Effectively framing issues for the public at large and for particular audiences;
- Describing problems in ways that are accessible to grassroots and constituency organizations and create public and political demand for solutions;
- Making a strong public case for the proposed policy change and critiquing opposition positions;
- Getting the right data and information to legislators, policymakers, and stakeholders at the right time;
- Building broad editorial and op-ed support and obtaining other media coverage at critical junctures; and
- Developing electronic mechanisms and other communications strategies for conveying timely information to grassroots organizations, advocacy organizations, and other supporters.

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## Part 2: The Assessment *(Continued)*

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Advocates in several states highlighted the importance of framing issues. Policy advocates often get caught up in their jargon and need assistance “translating” policy analysis and research so it is accessible to the people affected by the policy, the broader public, and legislators and other decision makers who may not understand the nuances of complex policy issues. This is critical in broad-based campaigns. Accessible research and policy analysis play an important role in connecting grassroots organizing and statewide policy advocacy. In addition to performing that connecting function, the translation of complex issues helps grassroots and constituency organizations reach out to their own members. Most of those organizations lack – and will not develop – sophisticated communications capacity. They rely on other organizations to provide that.

The advocates who reported having some communications capacity identified several approaches they found effective. These include: generating media coverage for the release of research reports, public events, and hearings; coordinating the media contacts and relationships of all campaign partners to generate favorable coverage; and orchestrating editorial board contacts, op-ed columns, and letters to the editor. In many states, local media coverage in the districts of important decision-makers can contribute to success. The impact is greatest when media and communications strategies are a coordinated part of overall campaign planning, and when the right information gets to the right people at the right time.

A few organizations noted that the internet opens up new communications opportunities for advocates. In *Massachusetts*, for example, Health Care For All’s daily health advocacy blog was a very effective tool for getting the organization’s message out quickly to supporters and other stakeholders during negotiations over recent health reform legislation. Its importance will continue as advocacy shifts to implementation issues.

### 3. Developing and Implementing Health Policy Campaigns

Moving a proactive health policy agenda forward or defending an existing program often requires a campaign. The ability to plan and coordinate advocacy campaigns is particularly important in states where interest groups with large financial stakes in policy decisions fund sophisticated lobbying and media efforts. To counter these efforts, consumer health advocates must be able to:

- Identify “inside” decision-makers who can function as “champions” for the desired policy outcome;
- Build and maintain alliances to expand support and reduce opposition;
- Orchestrate the involvement of campaign partners and allies so they do the right thing at the right time in decision-making processes; and
- Closely track the policy process for intervention opportunities, then move quickly to take advantage of them.

*Massachusetts* and *Mississippi* provide examples of effective, well-coordinated campaign strategies, carried out in very different contexts.



In 2004, *Massachusetts'* leading consumer health advocacy organization, Health Care For All (HCFA), launched a comprehensive campaign to enact a range of reforms including: expanding Medicaid coverage; helping working people purchase insurance; helping small businesses pay premiums for their employees; and requiring employers to either provide health coverage or pay a fee to support public coverage. HCFA created the Affordable Care Today (ACT!) Coalition – a broad alliance that included consumers, community and religious organizations, businesses, labor unions, community health centers, and physicians, hospitals and health plans. While HCFA and other experienced advocates focused on the “inside” strategy, faith-based grassroots groups focused on the “outside” organizing strategy. The involvement of the faith-based community and its leaders also strengthened the campaign’s moral voice.

A key intervention opportunity was the state’s impending loss of significant federal Medicaid funds if it did not create a plan that redirected existing funds away from paying for care and toward expanding insurance coverage. ACT! increased the pressure further by collecting enough signatures to put an initiative petition on the ballot in 2006. If successful, the ballot initiative essentially would have enacted comprehensive reform outside of the legislative process. The expectation was that the ballot initiative would be withdrawn if the legislature passed – and the governor signed – a bill that met ACT!’s approval. The alliances that HCFA developed with other stakeholders, such as large provider systems and insurers, generated significant campaign resources and gave added legitimacy to the campaign. The effort succeeded, and the phase-in of the new law began on July 1, 2006.

*Mississippi* advocates demonstrated that creative campaign strategies can make a difference even in a state with few advocacy resources and adverse political and economic circumstances. A coalition comprised of a statewide health advocacy organization, a senior citizen advocacy group, a disability advocacy group, a children’s advocacy organization, several health-related organizations, and a public interest legal organization that had not previously worked on health care issues, and were able to delay the elimination of the “Poverty Level Aged and Disabled” (PLAD) category of Medicaid recipients until most of the individuals at risk were eligible for prescription drug coverage through Medicare.

The coalition put a human face on the issue, developing postcards and similar materials that contained the message that the proposed cuts could affect “your friends, neighbors, and family.” The coalition conducted public education sessions on the issue across the state to which it invited local legislators.

These efforts generated considerable public anger at the proposed cuts, and some legislators professed to have been unaware of the impact of their votes. As one organizer said, “We don’t create the fury. We just try to harness it!” Ultimately, the court issued an injunction delaying the cut until January 1, 2006, the day on which Medicare Part D coverage became effective for many of the PLAD recipients. Advocates believe that their efforts raised the visibility of Medicaid as a critical health care safety net program, and they expressed hope that the public engagement around the PLAD cut would mitigate future efforts to reduce the program.

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**“WE DON’T CREATE THE FURY.  
WE JUST TRY TO HARNESS IT!”**

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## Part 2: The Assessment *(Continued)*

### 4. Building a Strong Grassroots Base of Support

Grassroots organizing engages people at the local level, the arena in which uninsured and underserved people are most likely to experience the effects of health system breakdown. It is in their own communities where health consumers cannot find a doctor who accepts Medicaid reimbursement, wait months for a medical appointment, and are sued by hospitals when they cannot pay a bill. In the study states where grassroots organizations are both knowledgeable about health issues *and* connected to statewide advocacy groups, they play an important role in broader health advocacy efforts. For example, these grassroots organizations are:

- Building a base of popular support for reform among people who are directly affected by policy decisions, including people of color, the uninsured, and others disproportionately affected by disparities in health access and care;
- Putting a human face on the need for better health care access and demonstrating popular support for change;
- Influencing key decision-makers in local and regional settings; and
- Ensuring that state health advocacy addresses the needs of people who use the health care system.

“Organizing should inform the policy agenda, because the people relating to these organizations know the issues that are most important to change in terms of how they impact lives,” said one interviewee.

Grassroots organizing on health issues is on the upswing in several study states. Interviewees attributed this trend to the fact that more people and communities are experiencing problems with health care cost and access. As a result, more grassroots organization members are identifying health care as a high priority for action. In some states where there is strong opposition to expanding health access programs, interviewees viewed an organized grassroots base that can genuinely help or hurt policymakers as essential.

“Legislators will not be convinced by facts and figures,” said one interviewee. “They need to know there will be political consequences to pay. Without a grassroots base, we don’t have the connection to make the political establishment feel the consequences.”

Grassroots organizations have provided an effective and vocal base of popular support for significant health policy changes and played important advocacy roles. In addition to testifying at legislative hearings, they conduct “lobby days,” hold local accountability meetings with decision-makers, and meet with local and regional newspaper editorial boards. *Colorado, Illinois, and Massachusetts* all have strong grassroots organizing infrastructures.

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In *Colorado*, the grassroots Colorado Progressive Coalition (CPC) played a key role in a successful ballot initiative campaign that increased the tobacco tax and earmarked most of the proceeds for health care access. The organization conducted substantial door-to-door outreach and phone-banking in remote areas of the state and in communities of color. CPC registered more than 27,000 new voters in 2004 and visited the homes of 145,000 infrequent voters in over 300 communities, delivering literature on the ballot initiative. CPC's ability to increase voter turnout among low-income people and people of color made a significant difference in the election's outcome.

In *Massachusetts*, three grassroots organizations – the Greater Boston Interfaith Organization, the Coalition for Social Justice, and Neighbor to Neighbor – collected more than 80,000 of the 112,000 signatures that put a major health reform initiative on the ballot. Without their involvement, there would not have been enough signatures and important leverage for reform would have been lost.

As critical as grassroots organizations are to successful advocacy, they do present a challenge. Typically they are multi-issue groups, with the membership creating the issue agenda. Because their members usually are based in lower-income communities, health care access often is one among many critical issues that the membership is trying to address. There is always the potential for a group to shift its focus and energy to another issue.

Moreover, there is recognition in some places of the limits to what can be achieved at the local grassroots level. Organizing on hospital accountability issues is an example. Local victories on hospital community benefits and free care commitments are important, but they don't address broader health access issues.

"You can't just add local safety net capacity to meet the huge growth in the uninsured," explained one grassroots organizer. Moreover, local improvements can be imperiled by state policy changes. For example, cuts in Medicaid inevitably increase the demand on hospitals for financial assistance. In *Oregon*, this has led the hospitals to pull back from voluntary commitments they made to consumer advocates.

In contrast, *Connecticut* activists used a local campaign against hospitals affiliated with Yale University to raise public awareness of hospital billing and collection practices. The result was the enactment of a policy that places limits on those activities for *all* hospitals in the state.

There is potential – largely untapped – for connecting grassroots organizations serving communities of color with state consumer health advocacy organizations as a means of addressing racial and ethnic health disparities through policy change. Most of the policy-focused organizations are largely white and, with some exceptions such as *Massachusetts* and *Colorado*, health disparities are not an explicit focus of current consumer health advocacy. Those grassroots organizations and efforts do exist in minority communities, but a number of those interviewed identified a range of barriers to collaborative efforts. These include: lack of trust among different organizations; geographic concentrations of communities of color and their isolation from policymaking centers;

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## Part 2: The Assessment *(Continued)*

and a disconnection between the policymaking process and many of the groups working on disparities issue, whose focus often is service delivery. Overcoming these barriers will take explicit and long-term relationship building, both by organizations working on racial and ethnic disparities and by statewide health advocacy organizations.

### 5. Building and Sustaining Coalitions, and Maintaining Strategic Alliances

Strong, broad-based, consumer health advocacy coalitions in several of the study states bring together large numbers of different organizations and stakeholders in coordinated campaigns to achieve common policy goals. Advocates in other states have done an admirable job of pulling coalitions together around particular issues, but the absence of resources and infrastructure has limited the continuity of effort and activity between issues.

Strong coalitions were a driving force in almost all of the successful statewide consumer health advocacy initiatives that we found. The coalition structure made it possible to coordinate the advocacy capacities of the various members in the service of a common goal. The most effective coalitions are marked by strong personal and organizational relationships and connections that have been built and strengthened through past collaborative work. These organizations and their leaders have maintained communications and information sharing even in the absence of ongoing collaborative campaigns. They utilize specific issue campaigns to strengthen their constituent base and capacity to affect the outcomes of other policy decisions. They can bring together a broad range of advocacy organizations and stakeholders that have different capacities, missions, constituencies, and strategies to work collaboratively toward a common goal. “When we heard about the Medicaid cuts, we pulled a bunch of groups together whose constituents would be affected, and we split up the tasks. There was no ego – people just pulled together and did what had to be done.”

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The most effective coalitions coordinate activities of a core group that may include grassroots organizations, state advocacy organizations, and legal services groups. They also manage alliances with other potential stakeholder allies in the health care system, including hospitals, unions, tobacco control organizations, physician groups, and health organizations, such as the American Cancer Society and the American Heart Association. All play different roles, and all contribute to achieving success.

Two examples of effective coalition work are found in *Colorado* and *Illinois*. In the 2004 *Colorado* tobacco tax campaign, some 30 health care and multi-issue advocacy organizations, with more than 100 supporting organizations and stakeholders, came together to promote the ballot initiative. Advocates believe this was a key moment because it re-energized the movement and shifted the agenda from a reactive to a proactive one.

The coalition “knit together” the capacities and strengths of state advocacy and grassroots organizations, as well as those of many stakeholders and other groups. Key coalition members included: the American Cancer Society and other voluntary health organizations; four major insurers; nine provider organizations; twenty-one hospitals; and nineteen community health centers, clinics, and community providers. A broad range of religious organizations, children’s and women’s advocacy organizations, grassroots organizations from communities of color, and unions also participated. The campaign raised \$4 million – primarily from its corporate members – which helped counter the tobacco industry’s influence. The effort’s success strengthened the platform for proactive health advocacy. Most recently, the coalition supported a successful effort to suspend the state’s revenue limitation law (the so-called Taxpayers’ Bill of Rights) for five years, and it succeeded in blocking a Medicaid waiver that advocates said would have put health care access at risk.

In *Illinois*, several coalitions have succeeded in enacting major health access expansions and making the political environment more receptive to such initiatives. In 2003, an advocacy campaign led the state to obtain a Medicaid waiver that permitted reallocation of unspent SCHIP funds to expand adult eligibility for Medicaid from 49 percent to 185 percent of the federal poverty level. However, the legislature failed to appropriate the state funds necessary for the expansion. In response, the initial advocacy effort evolved into the “100 Percent Campaign,” led jointly by a statewide law and policy advocacy center and a faith-based organization of more than 300 member organizations in the Chicago metropolitan area. The coalition integrated grassroots organizing and health policy advocacy, and it succeeded in obtaining enough state financing to enroll 280,000 additional people in Medicaid. What was particularly noteworthy is that the expansion was funded despite a serious state budget shortfall and during what was, at the time, a difficult political environment.<sup>4</sup>

As a footnote to that effort, in late 2005 a new governor pushed through passage of the first uncapped universal coverage program for children in the nation. Advocates did not have to do “heavy lifting” to pass this groundbreaking legislation, but their efforts over time had created the political climate and political leadership that made passage possible.

Another coalitional effort in *Illinois* resulted in passage of a law that declared it a policy goal “to insure that all residents have access to quality health care at costs that are affordable.” The law also established a process for developing a universal coverage plan. The coalition in this case was the Illinois Campaign for Better Health Care (CBHC), a statewide organization of more than 300 local and statewide organizations representing consumers, health care workers, providers, labor, disability rights groups, and many others. CBHC is also an active participant in the process that is developing the universal coverage plan.

Building alliances with less traditional allies, while very important, can also present significant challenges. While consumers and other stakeholders may have common interests on particular issues, they can be on opposite sides of other issues. In *Illinois*, the hospitals participated in statewide coalitions to expand Medicaid coverage, but they were targets of hard-hitting local organizing on community benefits and hospital accountability that was led by grassroots organizations involved in the same statewide coalitions.

<sup>4</sup> For a description of this effort, see John Bouman, “The Power of Working with Community Organizations: The Illinois FamilyCare Campaign – Effective Results through Collaboration,” *Clearinghouse Review*, January-February 2005.

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## Part 2: The Assessment *(Continued)*

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Despite these tensions, alliances between consumer advocates and key stakeholders are reaching a higher level in a few states. For example, some *Massachusetts* stakeholders have moved beyond a focus on narrow, short-term self interest to an understanding that they hold long-term interests in common with those of consumers. This broader view of mutual interest is emerging from longstanding organizational and personal relationships developed by working together on issue campaigns that led to mutually beneficial policy decisions. For example, Medicaid expansion initiatives have sometimes included – or been followed by – increases in Medicaid provider reimbursement.

### 6. Generating Resources for Infrastructure, Core Functions, and Campaigns

A critical capacity for any organization is the ability to raise resources to carry out its mission. As the next section details, the funding environment differs dramatically among states. Across the study states, foundations represent the most important source of funding for consumer advocacy. Some organizations have expanded their funding base beyond foundation support. These organizations are also building a membership base, holding funding events, soliciting campaign partners for support, and seeking contracts from the state and others.

### **Integrating the Six Capacities: Creating “Systems” of Consumer Health Advocacy**

In general, not all six of the key capacities described here exist within a single organization or even a single *type* of organization. Some advocates are addressing this challenge by building integrated advocacy *systems*. These systems transform many separate organizations into a coherent whole, combining many of the most promising strategies and practices to achieve broad health care reform. Our study shows a positive correlation between strength of advocacy capacity and policy impact, and the adoption of the integrated system approach.

States where health advocates are making progress toward building integrated advocacy systems demonstrate some or all of the following characteristics:

- > They combine strong research and policy analysis, grassroots organizing, “inside” and “outside” advocacy, stakeholder alliances, and media and communications capacities, with a high level of strategic coordination.
- > They maintain a permanent infrastructure of collaborative leadership, partnerships, relationships, and information sharing *even when they are not engaged in campaigns on particular issues*. As a result, they can identify emerging or galvanizing issues that would have a significant impact on health care access, and they can quickly mobilize their component parts.
- > They use campaigns to strengthen their constituent base, organizational capacities, and coalition infrastructure and partnerships in order to increase their ability to have an impact on important policy decisions.
- > They have the resources necessary to support the critical “hub” functions of the system.

An integrated system approach offers multiple benefits. An advocacy system makes it possible for multiple coalitions to work effectively on a range of different issues that engage different constituencies under the tent of a broad health care reform movement. This engagement of a broader range of constituencies makes it possible to build broader public support and gain access to more decision makers. It also expands the “tool box” of advocacy and organizing capacities.

Finally, a system approach facilitates the movement of partnerships and alliances beyond mutual self-interest on particular issues and toward a shared vision of health care reform based on common long-term interests. Understanding broad common interests makes it possible to sustain these critical relationships in the face of different interests on particular issues.

## FUNDING SUPPORT FOR CONSUMER HEALTH ADVOCACY

The second factor influencing the ability of consumers to impact state health policy is the availability of resources. A related aspect is the strength and quality of the connection between advocates and funders. Not surprisingly, the study identified a correlation between resource availability and state advocacy capacity. The states with the highest levels of advocacy capacity also had the highest levels of funding support. Conversely, all of the states with the lowest levels of funding support also had the least advocacy capacity.

However, while adequate resources are necessary, they are not the only measure of support. State advocacy capacity is strongest where funders engage in regular dialogue with advocates and are “on the same page” with regard to understanding opportunities to impact policy through consumer advocacy.

As part of the study, we interviewed funders across the spectrum of states. A number of them have been steadfast supporters of consumer health advocacy work, and their support has had a significant impact on policymaking and capacity building. They shared their observations on promising “investment” strategies, which include the following:

- > *Providing core funding* for long-term organization- and coalition-building, in addition to short-term and project-based funding, is necessary to build sustainable, effective consumer advocacy capacity on health care.
- > *Assessing advocacy capacity and issue priorities in a systematic way* is necessary to inform funding decisions. From a national funder perspective, this is particularly important because advocacy priorities and capacity-building needs differ from state to state.
- > *Supporting capacity-building priorities* can be a wise investment of foundation dollars, for example, by making it possible to connect grassroots organizing on health issues to state policy advocacy or to integrate policy research and analysis into ongoing advocacy campaigns.
- > *Supporting health advocacy “system-building”* that can raise consumer health advocacy to higher stages of capacity is an emerging funding strategy in certain states. One funder describes this as supporting the “three legs of the stool” – grassroots organizing, policy and legal analysis, and coalition-building.



## Part 2: The Assessment *(Continued)*

Different organizations may be providing these functions, but they must be brought together into coordinated advocacy systems. In one of the study states, funders are coordinating funding for system-building through a multi-pronged approach that includes:

- ✓ Investing in the growth and ongoing work of a new statewide health advocacy organization that is coordinating the efforts of a wide range of state and local health advocacy groups;
  - ✓ Helping several community organizations working with underinsured and uninsured people, including people of color and others who are underrepresented in state policymaking, to develop the structures they need to become more mature organizations;
  - ✓ Building collaboration among these organizations, other state organizations serving communities of color, and an established statewide consumer advocacy organization, in order to bring underserved communities into state health policy debate;
  - ✓ Supporting the development of a statewide policy institute – responsive to the needs of state’s consumer health advocacy network – that provides legal advocacy, policy analysis, and research calibrated to consumer advocacy priorities and campaigns; and
  - ✓ Making a significant investment in leadership development within all of these groups to assure that there is an “informed group of leaders in good organizations who can make a difference in policy.”
- > *Investing in building collaborative relationships between funders and health advocates* is important to increase the effectiveness of both parties. In states where funders and advocacy organizations are in regular dialogue, both are better informed about what needs to be done and how to do it.
- > *Pooling resources of several funders* around a shared agenda can increase the level and effectiveness of support for advocacy and leverage greater impact on issues of common concern.
- > *Enabling joint planning and implementation of coordinated advocacy campaigns* among grassroots and statewide organizations can be an important aspect of funding priorities in the states.

Funders in many states are receptive to collaborative partnerships with national funders. Several reported positive experiences with national and state funder collaborations. However, they were clear about the kinds of mutually beneficial relationships they would welcome, i.e., they are looking for real partnerships.

One funder said, “It would not work if the national foundation comes to our state with a project already defined and asks us to participate in it. If a nonprofit organization comes to us and says they

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**“IT WOULD NOT WORK IF THE NATIONAL FOUNDATION COMES TO OUR STATE WITH A PROJECT ALREADY DEFINED AND ASKS US TO PARTICIPATE IN IT. IF A NONPROFIT ORGANIZATION COMES TO US AND SAYS THEY WANT TO BE A PLAYER IN A NATIONAL FOUNDATION INITIATIVE, AND IF THEY WANT TO PARTNER WITH US TO LEVERAGE NATIONAL FOUNDATION RESOURCES, WE WOULD BE WILLING. BUT SOMEONE ON THE GROUND HAS TO WANT TO MAKE IT HAPPEN.”**

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want to be a player in a national foundation initiative, and if they want to partner with us to leverage national foundation resources, we would be willing. But someone on the ground has to want to make it happen.”

Several funders described national partnerships that they had found valuable. In one, a national grantmaker enabled funders and advocates from several states to meet with each other and develop ideas about disseminating best practices and expanding resources for communication. A participating funder reported, “Lots of good tools and training came out of the collaboration. This is a model for the movement.”

## STATE POLITICAL AND ECONOMIC ENVIRONMENTS

The third key factor influencing the ability of consumer advocacy to shape state health policy outcomes is the political and economic environment of the state. Consumer health advocacy can be effective within all types of environments, but environmental differences affect the kinds of issues that advocacy organizations work on, the strategies they use, and the level of advocacy capacity needed to influence major policy decisions.

At one end of the spectrum, some states have weak economies and limited resources, often coupled with strong political opposition to consumer-oriented reform. In these states, political systems limit taxes and state revenue, oppose the use of public revenue to meet health care or other basic needs, and support market solutions to public problems. Medicaid and other public programs are under constant risk of being reduced or eliminated for budget reasons. Health advocacy is primarily defensive, and its principal focus is preserving existing access.

At the other end of the spectrum are states with strong economies and more robust public revenue streams, as well as public and political support for expanding health care access and implementing broader system reform. In these states there is greater political willingness to use public revenue to meet health care and other basic needs. As a result, there are opportunities for consumer health advocacy to expand health care access in both public programs and the private sector. There is less focus on defensive advocacy to preserve existing access and greater emphasis on proactive advocacy for broader system reforms.

The key elements in an evaluation of a state’s political and economic environment are:

- > Differences in per capita income and rates of private coverage;
- > Impact of tax policies on revenues for health care access;
- > Willingness to use public revenue for health care access;
- > Differences in consumer access to the decision-making process; and
- > Political and electoral structures.

### Differences in Per Capita Income and Rates of Private Coverage

*Mississippi* and *Connecticut* illustrate the striking contrasts in income and coverage that consumer health advocates face.

- > *Mississippi* has the lowest per capita income in the nation, a little more than \$23,000 per person, while *Connecticut* has the highest per capita income in the United States, almost \$43,000 per person.



## Part 2: The Assessment *(Continued)*

- > Thirty-eight percent of *Mississippi* residents do not have private insurance or Medicare, while in *Connecticut* only 23 percent have no private insurance or Medicare.
- > State policies and programs have to meet a much higher level of need in *Mississippi* than they do in *Connecticut*. Even though *Mississippi* covers 19 percent of its population through Medicaid, 18 percent of all *Mississippi* residents remain uninsured. In *Connecticut*, 11 percent of residents are covered by Medicaid, but only 11 percent of the residents are uninsured.
- > *Mississippi* residents paid a higher percentage of personal income in state and local taxes than do *Connecticut* residents, even though their amount per capita was \$1,700 (39<sup>th</sup> in the nation), compared to \$3,100 in *Connecticut* (1<sup>st</sup> in the nation). Thus, the public revenue that is theoretically available to finance health access in *Connecticut* was nearly double the amount available in *Mississippi*, where the need is much greater.

We found that resistance to raising taxes to expand coverage and services for the uninsured was strongest in those study states with weak economies and low per capita incomes. The learning in this regard is that it takes stronger advocacy capacity to enact policy changes that significantly expand access to care in these states than in states where per capita incomes and rates of employment-based insurance coverage are higher.

### Impact of Tax Policies on Revenues for Health Care Access

Advocates in a number of states reported that tax cuts had resulted in structural deficits that made access expansions challenging, *even where* executive or legislative leaders were supportive. States with structural deficits include: *Arkansas, Kansas, Illinois, Louisiana, Massachusetts, Michigan, New Jersey, and Oregon*. There were also several states that either had enacted, or were contemplating enacting, constitutional or legislative revenue limitation policies. These include *Colorado, Kansas, Ohio, Michigan, and Oregon*. When a revenue limitation policy is enacted, the resulting fiscal constraints create formidable obstacles to expanding – or preserving – access to health care through public programs. Health care advocates understand that it is critical to oppose these efforts, but they also recognize they cannot do it alone. *Colorado* and *Ohio* offer examples: “All social justice issues start and end with state revenues. People say they want there to be access to programs like Medicaid, but too often they don’t want to go the next step and contribute to funding them.”

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**“ALL SOCIAL JUSTICE ISSUES START AND END WITH STATE REVENUES. PEOPLE SAY THEY WANT THERE TO BE ACCESS TO PROGRAMS LIKE MEDICAID, BUT TOO OFTEN THEY DON’T WANT TO GO THE NEXT STEP AND CONTRIBUTE TO FUNDING THEM.”**

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- > In *Colorado*, the political environment has been dominated by the impact of the Taxpayer Bill of Rights (TABOR) legislation enacted in 1992. TABOR limits increases in revenue and spending to changes in population and inflation. Broad dissatisfaction with the impact of TABOR on core government services, and the belief that spending limits were hurting the economy, enabled a coalition led by health care and multi-issue advocacy organizations to pass a referendum in

2005 that suspends TABOR for five years. The initiative was even supported by the governor, as well as by the business community, which had played an important role in its original enactment.

- > In *Ohio*, per capita tax rates are well below the national average, but some legislators are introducing a TABOR-like tax limitation ballot initiative. Health advocacy and multi-issue human services organizations are working together to educate the public about its potential impacts and to achieve common budget and revenue goals, including restoring previously lost public revenue.

### **Willingness to Use Public Revenue for Health Care Access**

There are significant differences among the study states with respect to the willingness of political leaders and the public to use public revenue to meet health care needs. This appears to reflect different views on the proper size and role of government.

At one extreme, dominant political leadership emphasizes, and the electorate supports, “small government” that intervenes in the private market as little as possible. Inability to access health care is viewed as a private problem for which individuals have to take responsibility. In other states, there is broad support for use of public funds to expand health care access for greater numbers, and a greater willingness to shape private market behavior to serve public needs. In the most recent gubernatorial elections in *Illinois* and *New Jersey*, the winners’ victories are widely credited to their having made expansion of health coverage a key campaign issue.

### **Differences in Consumer Access to the Decision- Making Process**

Access to the decision-making process can change significantly when there are major changes in the political environment.

- > In *Illinois*, the election of the current governor, who campaigned on a promise to expand health care access, along with the presence of legislative leaders who share that outlook, has dramatically increased consumer advocacy visibility and influence in the policymaking process through a variety of avenues. These include appointment of consumer advocates to governmental commissions and policymaker collaboration with independent public education advocacy initiatives.
- > In *Massachusetts*, health reform “champions” have appeared only intermittently in the executive branch since the late 1980s, but legislative leadership and support has remained strong for 20 years. Consumer health advocates have steadily expanded their influence on the policy process during that time.
- > In *Maryland*, which has a “strong executive” political system, the 2002 election of the first Republican governor in 36 years has significantly reduced the access of consumer advocates to the executive branch. A number of those interviewed report that the influence of corporate lobbyists has increased substantially, while consumer advocates have had to fight harder than ever to be heard.
- > Advocates in a several states report that their access to policymakers is extremely limited under current administrations. In some cases, there are examples of what they characterize as retaliation

## Part 2: The Assessment *(Continued)*

against organizations that take policy positions in opposition to those in power. In some of these places, advocates also find it difficult, if not impossible, to obtain information from executive branch officials and agencies, and some report that even legislators have trouble accessing important data.

### Political and Electoral Structures

Certain political and electoral structures, such as term limits and short legislative sessions, pose serious challenges to consumer advocates in a number of states. While they differ in character, their effect is essentially the same: legislators develop less subject-matter expertise, and they rely for their policy information and analysis on special interests with far greater resources than consumer advocacy groups.

With respect to term limits, advocates report that their introduction has eliminated institutional knowledge of health care and health access issues. In *Michigan*, for example, term limits resulted in the dissolution of an important legislative coalition representing low-income populations in both Detroit and rural areas that previously had moved health care reforms on a bipartisan basis. Consumer advocates report that newly elected legislators from rural parts of *Michigan* are more responsive to ideological directives on complex issues, such as health care, and less willing to engage in political compromise. Other advocates observed that term limits appear to make some officials less concerned about the longer-term implications of their policymaking.

Very short legislative sessions also pose serious barriers to health advocacy. In *Georgia*, the legislature meets for only 40 days each year. This means that advocates have a very narrow window of time in which to educate policymakers about their issues, and they are competing with all of the other advocates for the attention of their legislators. As one interviewee noted, “These short terms mean that advocates have to develop relationships with legislators and then work like hell for 40 days.”

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### STAGES OF HEALTH ADVOCACY IMPACT

To provide a framework for analysis, we placed each state into one of three categories of consumer advocacy impact — Defensive Advocacy, Intermediate Advocacy, and Proactive Advocacy. The categorization is based on an analysis of each state’s political and economic environment, the availability of resources to build and strengthen advocacy, and the current status of advocacy capacity. Taken in combination, these factors are highly predictive of the impact of health care advocacy.

Each “stage” is a *broad* category: consumer advocacy varies in its capabilities and impacts, and advocacy impact in some states may be closer to the boundaries of higher or lower stages of impact than others in the same “stage.” In addition, states can be in stages for different reasons — because of particular strengths or weaknesses in one or two of the three factors. Indeed, one key factor may place a state in a higher or lower category relative to states that otherwise seem fairly similar.

The framework facilitates identification of opportunities for states to move to higher levels of consumer advocacy impact or risks for falling into lower stages. It also facilitates the identification of appropriate interventions for particular states to move consumer advocacy to higher stages of impact. Although the study represents a “snapshot in time,” it shows that states can move to higher or lower stages, in some cases very quickly, as the result of changes in any combination of the three key factors.

### **DEFENSIVE Advocacy Stage: *Arkansas, Florida, Georgia, Louisiana, Mississippi***

The five states in the Defensive Advocacy stage face the greatest environmental obstacles and have the lowest levels of funding for health advocacy. They are all Southern states with significant rural populations and high poverty rates. These states also have serious health care access problems, low rates of employer-sponsored health insurance, extremely limited tax bases and state revenues, and strong opposition – in the legislative or executive branch or both – to proposals to raise revenues.

A particularly high level of advocacy capacity is needed to affect policy outcomes in these antagonistic – or challenging – political and economic environments, but advocacy capacity generally is limited by low levels of in-state funding support. Increasing funding for health advocacy, which may require investments by national funders, is critical to strengthening advocacy impact in these states. Some of the obstacles faced by advocates in these states are as follows:

- > Advocacy organizations in most of these states have to defend against repeated political efforts to reduce health care access by cutting Medicaid eligibility or benefits or by raising copayment levels.
- > They also face strong anti-tax and small-government political agendas, and they have to defend against sustained political efforts to cut or limit taxes and revenues.
- > Medicaid and other public program expansion initiatives that require additional revenues have little chance of success in current political and economic environments.
- > Advocacy organizations have little access to the decision-making process in most of these states. The consumer voice frequently is not at the table when health care decisions are made.

Given the challenging political environments and limited funding support for consumer health advocacy in Defensive Advocacy states, few of these states have a strong statewide consumer health advocacy organizations. Those that do exist tend to be poorly funded. In many cases, advocacy is led by a combination of organizations that focus on relevant constituencies, such as children, seniors, or people with disabilities, with an occasional provider group participating. Many of the organizational capacities needed for effective advocacy are missing or weak. Lack of grassroots organizing that is connected to statewide advocacy is commonly seen as a key gap that makes it difficult to influence elected officials who are strongly opposed to expanding health care access or raising new revenues.

Organizing on hospital financial assistance and community benefit issues has won some important local victories in a few of these states. Typically, though, advocates have been unable to build on such local victories to strengthen a statewide constituency base or to increase their organizational capacities.

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## Part 2: The Assessment *(Continued)*

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Nevertheless, advocacy organizations in these states are getting the most out of the limited resources they have by using creative campaign strategies. The few consumer advocacy organizations that do exist often play an important role by preventing or mitigating program cuts.

Additional resources to build and strengthen advocacy capacity are needed, but local and state funders either have limited ability to provide additional resources to support advocacy or have different priorities. These are states where national foundations, working in collaborative partnerships with state and local funders, could have an important impact on keeping already serious health access problems from getting worse. They are also places where collaborative funder partnerships could build a foundation for developing capacity for long-term, proactive advocacy impact.

### **INTERMEDIATE Advocacy Stage: *Kansas, Michigan, New Mexico, Ohio, Oregon***

Intermediate Advocacy states have political and economic environments that are challenging to varying degrees, but generally they have fewer limitations than Defensive Advocacy states in raising public revenues for health care. These states generally are located outside the South and the Northeast. They are a mix of urban and rural. They also represent a mix of economic climates: some have a declining industrial base, while others have a stable but limited industrial base.

All of the Intermediate Advocacy states have more limited advocacy capacity than the average Proactive Advocacy state. Compared to states in the Defensive Advocacy stage, they have fewer gaps and more strength in the core capacities of their advocacy organizations and more funding support for advocacy. Nevertheless, their challenging environments require greater advocacy capacity than is needed in Proactive Advocacy states to influence policy decisions. Some of the characteristics of these states are as follows:

- > There are fewer – and less politically strident – efforts to cut Medicaid eligibility and benefits or raise copayment levels than in Defensive Advocacy states. Consumer advocacy is still primarily defensive, but it is better able to prevent further cuts.
- > While they often can prevent policy changes that would cut access, consumer advocates have limited capacity to engage in successful proactive advocacy to expand Medicaid access, and they are poorly positioned to achieve comprehensive reforms.
- > Several Intermediate Advocacy states have both serious fiscal constraints and strong anti-tax public and policymaker sentiment. TABOR legislation limits increases in tax revenues in a few, and serious efforts to enact TABOR laws are underway in others. State fiscal constraints pose a serious barrier even in states where governors are relatively responsive to advocacy efforts to expand health care access.

Investment and capacity-building priorities vary among Intermediate Advocacy states because of the broad range and diverse combinations of their political and economic environments, resources to support advocacy, and health advocacy capacity. Some of the states potentially could move back to the Defensive Advocacy stage, while others could become Proactive Advocacy states.

Funders and advocates in these states should assess which capacities are missing or need to be strengthened. Then, based on the broader state context, they should identify interventions that can best help the consumer health advocacy community move toward higher capacity and impact. Lack of strong grassroots organizing capacity is seen as a major weakness in almost all of these states. Priorities for strengthening advocacy capacity include development of grassroots organizing, building connections between local organizing and statewide policy advocacy, building or strengthening statewide health care advocacy organizations, strengthening leadership, and developing new revenue sources.

**PROACTIVE Advocacy Stage:**

***Colorado, Connecticut, Illinois, Maryland, Massachusetts, New Jersey***

In Proactive Advocacy states, consumer advocates have the best chance of making gains in the short term by pursuing major health access initiatives. These states are predominantly in the mid-Atlantic and the Northeast. With one exception, they are industrialized states with large metropolitan areas and higher-than-average rates of union membership.

All of the Proactive Advocacy states have relatively high levels of funding for advocacy. With one exception, they also have reasonably responsive political environments. Two of these states had health advocacy capacity strong enough to make significant progress in expanding health care access.

Some of the characteristics of these states are as follows:

- > There are fewer attempts to cut Medicaid eligibility and benefits or to raise copayments, and health advocates can focus most of their efforts on proactive advocacy to expand Medicaid or achieve comprehensive public and private-sector reforms.
- > Despite moderate economic and fiscal concerns in these states – and a serious fiscal crisis in one – advocacy has succeeded in expanding Medicaid access within several of them. Some of these states increased tobacco taxes to pay for health services.
- > Political support for tax cuts and opposition to raising new revenues exists in a number of these states, but it is more moderate than in either Defensive Advocacy or Intermediate Advocacy states.

Proactive Advocacy states are building – or have the potential to develop – sustainable advocacy “systems,” while breaking ground in developing policy and system change solutions. Their work can help chart new paths to comprehensive reform leading toward affordable quality health care for all residents.

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## Part 3: Recommendations

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Recent health reforms in Proactive Advocacy states, including *Massachusetts, Colorado, and Illinois*, expand access to care for hundreds of thousands of people. These achievements demonstrate both the *importance of state action* to benefit health consumers *and* the impact that *strong state-based consumer advocacy* can have. Consumer-led reforms in these states are giving new life to policy discussions in other states, and also at the national level. The reforms highlight the potential for consumers to exert a much more powerful influence on policies related to the health of low-income people. They also serve as compelling evidence of the importance of an organized base of consumer support in states and communities that can affect the national political agenda. There is compelling evidence of the importance of consumer advocacy in *all* the study states. Even in Defensive Advocacy states, consumer organizations are fighting, with very few resources, to prevent or mitigate serious health access program cuts.

While boosting individual organizational capacity is important, our recommendations focus on building consumer health advocacy *systems* in every state as a durable and sustainable approach to institutionalizing the consumer voice in health policymaking. However, state-based advocacy will not, by itself, lead to broader system reform. Thus, we also recommend taking the steps necessary to build a broad movement that can affect health policy decisions nationally as well as on the state level.

While consumer advocates and other stakeholders are collaborating in a number of places, we envision taking this collaboration and mutual support to a higher level. In places where such collaboration is less developed, we envision a more intensive effort that lays the groundwork for a cohesive and coherent *system*. Regardless of where a state falls along our spectrum of advocacy stages, increasing consumer capacity will require a concerted and strategic effort among state, local, and national consumer health advocates, along with funders, safety net providers, and other stakeholders.

We propose four strategies for building a strong, effective consumer voice in both state and national health care debates:

- > **Strategy 1:** In each state, assess consumer health advocacy capacity and address gaps through collaborative partnerships, strategic alliances, and new funding.
- > **Strategy 2:** Develop a national program to coordinate and deliver strategic support.
- > **Strategy 3:** Organize strategic campaigns both within *and* across states.
- > **Strategy 4:** Develop a stronger resource base to support consumer health advocacy.



**STRATEGY 1:**

*In each state, assess consumer health advocacy capacity and address gaps through collaborative partnerships, strategic alliances, and new funding.*

Steps can be taken to strengthen consumer advocacy capacity in states in all three stages. However, this will require a concerted effort among consumer health advocates, funders, and other stakeholders. While each state has a unique combination of demographic, economic, and political factors that shape the environment for health policymaking, the basic characteristics of effective consumer health advocacy are the same. Our report describes the capacities that are critical for effective and sustained consumer health advocacy. Building upon these capacities, at whatever level they exist, can lead to developing *systems* of advocacy that will greatly enhance the influence of consumers. Integrated advocacy *systems* built over time will have the most effective impact in all political environments, in the study states and beyond.

The starting point of any such effort is a systematic, realistic assessment of the needs and limitations of current consumer health advocacy organizations. The approach developed by Community Catalyst for this study can serve as a model for such an assessment. In addition to extensive conversations with people “on the ground,” the assessment would include a careful review of each state’s political and economic environment and funding opportunities.

Building on the assessment, a plan to advance consumer capacity to a new stage must be developed. The approach and progression will vary from state to state, depending on the levels of capacity that exist and the particular opportunities and needs that are identified. For example, in states with very limited coalition capacity and infrastructure, developing a statewide consumer advocacy umbrella organization that could galvanize and coordinate activity and sustain communication among participants between periods of mobilization could increase policy impact in the short term. It would also create the foundation for building a sustainable advocacy *system*. In contrast, the focus in states with more advanced grassroots organizing, coalition building, and policy advocacy capacities would be on building stronger, more sustainable partnerships with key stakeholders. These partnerships are essential to an advocacy *system* that can achieve comprehensive public and private-sector reforms.

The complementary capacities of the different advocacy organizations and other stakeholders must be knit together to create a coherent whole. Funders can play an important role by supporting collaboration, but it is the organizations and stakeholders themselves that must do the hard work of creating *systems* of advocacy. This work is a challenge because it requires key parties to operate in ways that may be new and – at least initially – uncomfortable. For example, consumer advocates need to develop a vision of effectiveness that goes beyond their own organizational interests. Funders need to provide resources for critical campaigns and capacity building, both of which may deviate from their traditional grant-making models. New strategic alliances will need to be developed, and other stakeholders will need to recognize the importance – and the benefits – of collaborating with consumers when their interests converge.



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## Part 3: Recommendations *(Continued)*

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### STRATEGY 2:

*Develop a national program to coordinate and deliver strategic support.*

Coordinating state efforts on a national scale is essential, both to strengthen state-based consumer advocacy and to strive for national impact. A national program would coordinate assessments of additional states, and it would ensure that states get the support services – tailored to their individual circumstances and environments – they need to increase their advocacy capacity and effectiveness. This program would facilitate cross-state coordination and learning, and it would serve as a “launching pad” for concerted regional and national efforts. The specific functions of the program would include:

- > Creating a community of practice among state consumer health advocates around common issue work and common capacity challenges;
- > Supporting communications strategy development, issue framing, fundraising, and resource development;
- > Providing a framework for state strategic planning, capacity building, and leadership development;
- > Providing timely policy support and assistance in coordinating state policy support from national policy organizations;
- > Evaluating and documenting best practices and campaigns;
- > Promoting collaboration between state organizations and national grassroots networks; and
- > Coordinating connections with stakeholders at a national or regional level (e.g., trade associations, associations of providers, labor unions).

### STRATEGY 3:

*Organize strategic campaigns both within and across states.*

Health reform in one state can be a catalyst for reform in others. For example, some of the lessons learned in Massachusetts with respect to policy solutions and advocacy strategies will be useful to consumer advocates in states with different environments and political opportunities and challenges. Creating state health advocacy capacity to move similar health care reforms in a critical mass of states can build momentum for reform at the national level. Experience has demonstrated that federal policymakers welcome opportunities to enact – and take credit for – reforms that have already been proven politically viable.

Multi-state campaigns would be an important means for moving an agenda on a number of issues. The ongoing discussions our approach envisions among funders, advocates, and stakeholders could identify emerging opportunities to influence state and national campaign directions. The potential of this approach could best be realized through targeting support to campaigns with the greatest opportunities to achieve policy impact, create tipping points to higher stages of advocacy capacity, or catalyze policy

changes in other states. Although they may vary by stage of advocacy capacity, some policy opportunities to consider are:

- > Defending Medicaid and related public coverage programs like the State Children’s Health Insurance Program;
- > Advocacy around community benefits, hospital financial assistance, and billing and collection activities;
- > Multi-state efforts to increase tobacco taxes in the service of protecting or expanding health access; and
- > State-level “breakthroughs” toward enacting comprehensive public and private sector reforms.

Specific types of support that would be useful include the following:

- > Strengthening media and communications capacity;
- > Coordinating and coaching, including “just in time” policy and strategic support;
- > Producing localized reports and proactive/reactive communications materials;
- > Developing model policies and accompanying public education materials;
- > Evaluating and documenting campaigns and dissemination of lessons; and
- > Organizing conference calls and meetings (including national meetings with other stakeholder leaders as appropriate).

#### **STRATEGY 4:**

*Develop a stronger resource base to support consumer health advocacy.*

Raising the impact of consumer health advocacy requires new resources that are strategically targeted to achieving short-term policy impact, advocacy capacity building, and the development of sustainable health advocacy *systems*. The presence – or absence – of funding was a significant factor with respect to the strength and effectiveness of health advocacy capacity in the study states. Not surprisingly, we found the most effective advocacy capacity in states with the most resources for advocacy. Advocacy capacity was most limited in states with the least resources.

Foundation funding was the most common source of support reported by consumer advocacy organizations in our study. While most of those interviewed acknowledged the importance of diversifying their funding sources and identified that as a goal for their organizations, it is clear that there will continue to be an important role for the philanthropic community. This is true with respect to both program support and support for capacity development.

Philanthropic support for health advocacy in the 16 study states varies widely, depending primarily on the philanthropic resources available within each state *and* the willingness of funders, both local and national, to support advocacy. The level of philanthropic support is very limited in some states, particularly those in the Defensive Advocacy category. This makes it difficult to generate significant new revenues to support advocacy within the state. Raising health advocacy impact to higher stages in such states will have to rely on the development of collaborative partnerships between national and state funders.

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## Part 3: Recommendations *(Continued)*

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In other states, there is potential to increase funding for health advocacy by raising the amount of philanthropic resources allocated for advocacy. Funders can play key roles in building support for advocacy among their philanthropic peers. They can do this by building awareness that consumer advocacy can help health foundations achieve their health care goals, particularly if those goals include expanding access.

The study also shows that the most effective advocacy is taking place in states where there are collaborative relationships between health advocates and funders. Funders and advocacy organizations are more likely to achieve health access expansions when funders and advocates are “on the same page” with respect to what needs to be done and how to do it. Both funders and advocates in successful states believe that their mutual effectiveness is the result of honest dialogue and ongoing collaboration.

The study identified many promising funding practices that significantly improved advocacy capacity. These practices share several core principles:

- > They target resources strategically, based on a systematic assessment of issue opportunities, current advocacy capacity, and short- and long-term capacity-building priorities.
- > They focus on system-building by providing support for key components of effective advocacy *systems* – such as statewide advocacy organizations, policy resources, and grassroots organizing – and linking them to create a coherent whole.
- > They are consciously designed to strengthen collaboration by funding multiple organizations to engage in common planning, issue development, and issue campaigns.

A critical step in increasing funder support of advocacy is building the legitimacy and credibility of the approach. A key function of the national program would be to document and disseminate state health advocacy successes. This would: make funders more aware of the impact of state health advocacy on policies that affect uninsured and underserved people; promote the value of state-based health advocacy within the state and national foundation community; and increase awareness of allowable advocacy activities for nonprofit organizations.

Efforts to develop non-philanthropic resources are also critical. Advocates realize that philanthropic resources are not unlimited. Thus, there must be a systematic program of technical assistance and support that contributes to sustainability by helping state advocacy organizations diversify their financial bases of support and identify new funding opportunities. A range of possible funding sources exists, including individual membership, earned income, stakeholder investments, government contracts, financial support from providers and insurers of low-income populations, and large-donor funding, both at the state level and through a nationally coordinated program.

What is needed is assistance in evaluating the potential of each of these strategies and in implementing those that make sense for the individual organization. As part of this effort, promising local and state funding strategies that do not rely on philanthropic support should be documented and disseminated. Finally, program planning, proposal development, and revenue generation should be acknowledged and supported as a critical component of state-based strategic planning and coaching support.

## Part 4: State Reports

### INTRODUCTION

This section consists of summary reports on each of the 16 study states. Rather than arrange them alphabetically, we have grouped them by stage of advocacy impact, starting with those in the Defensive Advocacy stage, followed by those in the Intermediate Advocacy stage, and ending with those in the Proactive Advocacy stage.

The groupings are as follows:

- > **DEFENSIVE** Advocacy Stage: *Arkansas, Florida, Georgia, Louisiana, and Mississippi*
- > **INTERMEDIATE** Advocacy Stage: *Kansas, Michigan, New Mexico, Ohio, and Oregon*
- > **PROACTIVE** Advocacy Stage: *Colorado, Connecticut, Illinois, Maryland, Massachusetts, and New Jersey*

### INFORMATION SOURCES

The data and information used to develop the summary reports were gathered through a review of published health care, political, and economic data; media searches; interviews with advocates and other experts on each state's political and health policy environment; interviews with funders with a demonstrated interest in state and local health care issues, including those who fund health advocacy; and surveys of key advocacy and organizing groups identified through the interview process.

The data in the individual state reports is from a variety of sources. The bulk of it is drawn from the Kaiser Family Foundation State Health Facts Online.<sup>5</sup> Other data sources were:

- > 2002 U.S. Census – The breakdown of urban vs. rural population
- > Bureau of Primary Health Care of the U.S. Department of Health and Human Services: Number of medically underserved areas
- > “A Nation’s Health at Risk”, March 2005, produced by George Washington University Center for Health Services Research and Policy and the National Association of Community Health Centers<sup>6</sup> – Number and percentage of people living in poor counties, and poor counties without health centers
- > State free care requirements – Community Catalyst research current as of 2003
- > Campaign for Tobacco Free Kids – Tobacco taxes and tobacco control statistics from. CDC recommended spending and cost of smoking are for 2005, and other data is for 2004
- > Tax Policy Center – State and local taxes as a percent of Gross State Product. Data is for 2004
- > Centers for Disease Control – Prostate Cancer and Asthma Mortality rates. Asthma mortality rate is pooled 1998-2002.

<sup>5</sup> <http://www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi>

<sup>6</sup> <http://www.nachc.org/research/Files/poorcountiesSTIB9.pdf>

# Arkansas



## HEADLINES

- > Health care is an important part of Governor Mike Huckabee’s platform, and there is significant public support for Medicaid. His support in the 2000 election of an initiative to use all tobacco settlement funds to improve the health of Arkansas residents was a major factor in the gubernatorial campaign.
- > A 2000 campaign, led primarily by health care providers and supported by the Governor, resulted in passage of a referendum requiring use of all tobacco settlement funds (\$62 million a year for 25 years) for programs to improve health. Funds are to be used for smoking cessation programs, expansion of coverage through Medicaid, health promotion strategies for the elderly, and specific programs to address minority health issues. Worse-than-average health indicators and a very high adult smoking rate in the state were key factors that influenced passage of the referendum.

## KEY DATA

- > AR’s population is approximately 2.7 million. Seventy-eighty percent of the population is White, well above the national rate of 67%. The Black population is 16%, compared with 12% nationally, and the Hispanic population is very small at 3%, compared with 14% nationally.
- > Its per capita income is the second lowest in the nation at \$24,384, compared with the US at \$31,472.
- > AR is 53% urban and 47% rural.
- > AR’s poverty rate – those with incomes below 100% of the Federal Poverty Level (FPL) – is 20%, while the poverty rate for the US as a whole is 17%. Thirty-eight percent of the state’s Black population lives in poverty, compared with 33% nationally; 17% of its White population lives in poverty, compared with 12% nationally; and 27% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the AR population, relative to the US population as a whole, is as follows:

Type of Coverage	AR	US
Private Insurance	51%	59%
Medicaid	16%	13%
Medicare	14%	12%
Uninsured	17%	16%

- > About 17% of AR residents are uninsured, compared with a national rate of 16%. Eighteen percent of White residents are uninsured, compared with 13% nationally, and 23% of Blacks are uninsured, compared with 21% nationally. No uninsured data were available for the Hispanic population. Fewer residents have private insurance than the nation as a whole—51% to 59%. Only 40 percent of Blacks and 43% of Hispanics have private insurance, compared with 57% of Whites.

- > AR has experienced a 4.7% decline in employer-sponsored insurance since 2004, compared with the US decrease of 4.8%. Coverage among the non-elderly who have Medicaid coverage in AR from 2000-2004 increased by 0.7%, compared with the 1.5% increase in the US. As a result, uninsurance grew at a faster rate than the national average from 2000-2004, a 4.9 percentage point increase, compared with a 2.7 percentage point increase for the nation as a whole.
- > AR has a high federal Medicaid matching rate, 73.7%. The state spends 0.80% of its GSP on Medicaid, somewhat below the national rate of 0.87%. AR ranks 23rd in the amount of its own state spending for Medicaid.
- > AR's Medicaid eligibility standards for parents are very low, ranked 50<sup>th</sup> for working parents at 19% of FPL, and 48<sup>th</sup> for non-working parents at 15% of FPL. The eligibility standard for infants under age 1 is 200% FPL (7<sup>th</sup> highest in the nation); for children ages 1-6, 200% FPL (ranked 6<sup>th</sup> in the nation); and for children 6 and over, 200% FPL (6<sup>th</sup> in the nation).
- > Dual eligibles in AR account for 19% of Medicaid recipients (US average is 14%) but account for 48% of Medicaid costs (US average is 40%).
- > About 71.8% of AR's residents live in poor counties. Seventy-three of AR's 75 counties are considered either fully or partially "medically underserved areas" by the federal government. There are 12 federally qualified health centers, which have 53 delivery sites, but there are a number of counties with no delivery site. Among the 75 counties, there are 69 poor counties in AR, 32 of which have a health center and 37 of which do not.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	7.2	12.8	4.5
Prostate cancer mortality per 100,000	29.0	75.7	No data
HIV/AIDS incidence per 100,000	5.4	25.1	9.8
Asthma mortality rate per 100,000	1.7	3.0	No data
Uninsured rate (non-elderly)	18%	23%	No data

- > AR spent \$17.6 M (about 98.2% of the recommended CDC standards) on tobacco prevention programs, and it has the 4<sup>th</sup> highest spending based on CDC's minimum standards. The annual health cost directly caused by smoking is estimated to be \$748 million, of which \$223 million is covered by Medicaid. The tobacco tax rate is 59 cents per pack, ranked 32<sup>nd</sup> in the US (1 = highest).
- > The adult smoking rate for AR is 25.7% with an adult smoking rank of 46<sup>th</sup> in the US (1 = low).
- > Although AR has the 2<sup>nd</sup> lowest per capita income in the country, state and local taxes as a percent of Gross State Product (GSP) are well above the national average—7%, compared with 5% nationally. Taxes as a percent of personal income ranked 9<sup>th</sup> highest in the nation.

Arkansas *(Continued)*

AR

## POLITICAL ENVIRONMENT

- > Democrats have majorities in both Houses, whereas the Governor is a Republican. Republicans are also making modest gains in the legislature.
- > Term limits and the need for ongoing education of legislators consume an extraordinary amount of resources from the advocacy community. There is some concern about lack of accountability of legislators; they have such a short term in office that they often do not experience the effects of their cuts to social programs.
- > Policy change is more possible in AR than in many other southern states because it is a small state where the political environment is more moderate. The state house and legislature are controlled by different parties, and the Republican Governor is a moderate with concerns about health care.

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**“TERM LIMITS ARE A BIG CONCERN—A THIRD OF OUR LEGISLATORS ARE NEW EVERY SESSION. WE ARE CONCERNED BECAUSE IT TAKES A LONG TIME TO UNDERSTAND SOME OF THE ISSUES. . . . MANY LEGISLATORS HAVE NEVER HAD EXPERIENCE WITH THESE ISSUES BEFORE, SO THEY HAVE A STEEP LEARNING CURVE.”**

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## KEY ADVOCACY ISSUES

**Medicaid**

- > Medicaid eligibility for parents is among the lowest in the nation—only 20% of the FPL. A substantial portion of parents are still enrolled, only slightly below the national average, because of the low per capita income and high poverty rate.
- > The Medicaid program includes a substantial inpatient hospital co-payments as well as co-payments for prescription drugs.
- > Governor Huckabee is supportive of Medicaid and says it is important for children. There is strong public support for the Medicaid program because it touches many Arkansas families—half of the children in the state receive Medicaid coverage.
- > AR is expected to receive approval for a Medicaid waiver that would provide insurance for 80,000 uninsured, low-income workers. Employers that participate would have to guarantee that all employees would receive coverage regardless of income. The program would cover six physician visits, seven days of inpatient hospital care, and two outpatient hospital procedures or emergency room visits each year, as well as two monthly prescriptions. Employers would pay part of the costs for their employees.



**Tobacco issues**

- > AR was one of the least healthy states in the nation in 1998, before it received tobacco settlement revenues. It had an age-adjusted death rate 19% above the national average. Much of the poor health burden is related to high tobacco use—39<sup>th</sup> in smoking rates among adults and 43<sup>rd</sup> among high school students. Through intensive tobacco control and smoking prevention work, the numbers are improving.
- > AR is one of the few states that come close to meeting CDC guidelines for tobacco control – ranking fourth in the nation. Tobacco taxes are somewhat higher than in most neighboring states and were raised from 34 cents to 59 cents in 2003.

**Safety Net**

- > There is no formal safety net program, although there is a coordinated voluntary program for residents below 100% of the FPL, called the Arkansas Health Access Foundation. It relies on donated services from hospitals, physicians, pharmacies, and drug companies.
- > In some communities, there is no safety net provider, which leads to overuse of emergency rooms.
- > Hospitals generally will provide care to those that are uninsured, but they do not advertise this to patients or the broader community.
- > The local health departments used to provide direct services, but they no longer do so. Most people who used those services now go to community health centers or to the emergency room, or they do not get medical care.

**ADVOCACY CAPACITY**

- > A broad coalition of more than 100 health care providers, education/research institutions, and health advocacy organizations won a 2000 referendum to use all of the multi-state tobacco litigation settlement funds to improve the health of Arkansans. The governor made the initiative one of his primary campaign goals in 2000. While other states used only 36% of tobacco funds on average for health-related programs, the referendum mandated that all AR funds be used for prevention and to improve overall health in Arkansas. The Arkansas Center for Health Improvement, an independent research center, published a report in 1999 that served as a catalyst for the successful tobacco settlement campaign.
- > Mobilizing coalitions is the key strategy used to move policy issues forward. The leadership of each coalition depends on the issue being addressed, but in general the coalitions tend to be provider focused, as was the coalition that mobilized to prevent cuts to Medicaid in 2003.
- > Advocates for Children and Families is seen as a lead health advocacy organization. It has a network of organizations that is able to mobilize throughout the state. AARP and the Community Health Centers of Arkansas are also seen as key advocacy organizations that are able to mobilize their constituents.



Arkansas *(Continued)*

AR

**FUNDING**

> Lack of resources is a key barrier to strengthening consumer health advocacy.

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**“THERE ARE NO FUNDERS IN ARKANSAS THAT FUND SOCIAL CHANGE WORK; ONE FOUNDATION THAT USED TO DO THAT NOW FUNDS POLICY REPORTS RATHER THAN ADVOCACY OR ORGANIZING.”**

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FL

Florida

**HEADLINES**

- > FL’s private insurance rate is well below the national average – 52% compared with 59%. Eighteen percent of FL residents are uninsured compared with the national average of 16%. This number would be higher except that FL’s Medicare coverage rate is well above the national average. Uninsurance among children is also much higher than in the nation as a whole – 16% in FL compared with 12% nationally. Medicaid coverage is also below the nation as a whole – 11% compared with 13%.
- > Private insurance decreased at a higher rate than the national average from 2000 to 2004 – a 6.1 percentage point decline, compared with a 4.8 point decline for the nation as a whole—while Medicaid coverage increased at only one-third the national average – 0.5 percentage points, compared with 1.5 points. As a result, FL’s uninsurance rate increased at a significantly higher rate than that of the nation as a whole – 4.4 points, compared with 2.7.

**KEY DATA**

- > FL’s population is approximately 16.6 million. The White population is lower than the national average – 62%, compared with 68% – and the Black population is slightly above the national average – 15%, compared with 12% nationally. The Hispanic population is well above the national average – 19%, compared with 14% nationally.
- > FL is a highly urban state – 89% of its population lives in urban areas and only 11% live in rural communities outside of metropolitan areas.
- > FL’s per capita income is 25<sup>th</sup> in the nation, \$30,098, compared with \$31,472 nationally. Its overall poverty rate is slightly below the national average.
- > FL’s poverty rate (i.e., those with incomes below 100% of the Federal Poverty Level [FPL]) is 17%, the same as the US average. Thirty-four percent of the state’s Black population lives in poverty, compared with 33% nationally; 11% of its White population lives in poverty, compared with 12% nationally; and 24% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the FL population, relative to the US population as a whole, is as follows:

Type of Coverage	FL	US
Private Insurance	52%	59%
Medicaid	11%	13%
Medicare	16%	12%
Uninsured	18%	16%

- > About 18% of FL residents – about 3 million people – are uninsured. Seventeen percent of Whites are uninsured, compared with 13% in the US, 27% of Blacks, compared with 21%, and 35% of Hispanics, compared with 34%. FL has experienced a 6.1% decline in employer-sponsored insurance

Florida *(Continued)*



since 2004, compared with the US decrease of 4.8. From 2000 to 2004, the number of non-elderly who had Medicaid coverage in FL increased by 0.5 percentage points, compared with a 1.5 point increase in the US as a whole. As a result, uninsurance increased at a faster rate, at 4.4 percentage points, compared with a 2.7 point increase nationally.

**“WHAT IS MOST SHOCKING IS HOW MANY MORE UNINSURED THERE ARE. IT IS ALMOST TO THE POINT THAT PEOPLE DON’T EXPECT TO HAVE ACCESS ANYMORE. EQUALLY SHOCKING IS THE ALMOST SYSTEMATIC WAY THAT GOVERNOR BUSH AND THE LEGISLATURE HAVE TRIED TO CUT FUNDING AND ACCESS TO SERVICES BY DIMINISHING ACCESS TO KIDCARE, CUTTING MEDICAID, AND REDUCING THE SAFETY NET FOR HEALTH CARE.”**

- > FL has a Medicaid matching rate of 58%. It ranks 28<sup>th</sup> in spending its own state resources for Medicaid. Medicaid spending accounts for 0.74% of its GSP, slightly below the national rate of 0.87%.
- > FL ranked 30<sup>th</sup> in eligibility for working parents, at 62% of the poverty level; and 45<sup>th</sup> for non-working parents, at only 23% of poverty. The eligibility standard for infants under age 1 is 200% of FPL (ranked 7<sup>th</sup> in the US); for children ages 1-6, at 133% of FPL (ranked 28<sup>th</sup> in the US); and for children 6 and over, 100% of FPL (ranked 31<sup>st</sup> in the US). FL’s SCHIP program has an eligibility standard of up to 200% for children.
- > Dual eligibles in FL account for 15% of Medicaid recipients (US, 14%) but account for 38% of Medicaid costs (US average is 40%).
- > Thirty-two of FL’s 67 counties are poor. Seventeen of these do not have a health center, and nearly 25% of FL residents live in these poor counties. Sixty-five out of the 67 counties have medically underserved areas.
- > Differences in health status, health outcomes, and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	5.6	12.9	5.2
Prostate cancer mortality per 100,000	24.6	69.8	26.3
HIV/AIDS incidence per 100,000	28.4	52.5	17.6
Asthma mortality rate per 100,000	1.0	3.0	1.1
Uninsured rate (non-elderly)	17%	27%	35%

FL

Florida *(Continued)*

- > FL has a Charity Care/Indigent patient program that is overseen by the Agency for Health Care Administration. FL residents may qualify for this program if they are below 100% of the FPL, if they are not eligible to participate in any other government program, if they have no private insurance or have inadequate private insurance, and if they do not reside in a public institution.
- > FL only spends about 1% of the CDC's recommended standard for tobacco prevention programs, and it's ranked 43<sup>rd</sup> in tobacco prevention spending in the US. The annual health cost directly related to smoking accounts for \$5.8 billion, and Medicaid covers \$1.1 billion of the cost. The tobacco tax is only 33 cents per pack, the 6<sup>th</sup> lowest tobacco tax in the nation. The adult smoking rate for FL is 20.4%, with an adult smoking rank of 21<sup>st</sup> in the US (1 = low).
- > Total state and local taxes, about \$30.8 billion, account for 5.1% of GSP, slightly above the national average of 5.0%. FL is the 38th highest relative to total taxes as a percent of personal income.

## POLITICAL ENVIRONMENT

- > The Governor, Jeb Bush, is a Republican. There is a two-to-one Republican majority in the House and an almost two-to-one majority in the Senate. The legislative session is very short, only 60 days, and there are eight-year term limits in both the House and the Senate.
- > County-level policies and funding are important to health care safety net issues. In places like Miami, there is a large county-level public hospital that is undergoing major change. In other places, county taxes fund health districts that support hospitals or other safety net services.
- > The influence of corporate interests in state policymaking is perceived as very strong. It was noted that term limits have been especially harmful to health care policy. Because of its complexity, policymaker's reliance on lobbyists for special interests is greater.
- > The geographic size and diversity of the state presents challenges to effective advocacy. There are over half a dozen major metropolitan areas, each with distinct cultures and political environments. The state capitol is physically distant from where most of the people live. Long travel distances and high cost make it logistically difficult for people – and minorities in particular – to participate in hearings.

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**"EIGHTY FIVE PERCENT OF THE POPULATION IS AT LEAST FOUR HOURS OR A \$400 AIRFARE AWAY FROM TALLAHASSEE. MOST CULTURES OF DIVERSITY ARE CONCENTRATED FAR WAY FROM THE CAPITAL."**

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- > Inability to get information about public policy developments from the executive branch creates a major obstacle for health advocates. In some instances, department staff have been instructed not to discuss issues with advocacy and constituency organizations. There has been no functioning Medicaid Medical Care Advisory Committee for years.

## Florida *(Continued)*

FL

### KEY ADVOCACY ISSUES

- > **Medicaid:** The status of Medicaid and KidCare is a major concern for all of the people interviewed.
  - **Revenues:** There are annual budget battles around cuts to KidCare and Medically Needy programs. While some of these cuts have been restored, a great deal of time and effort was spent achieving restored services, and people lost coverage during the process.
  - **KidCare and Medicaid access:** Constant policy shifts, increased premiums, reduced outreach funding, and more onerous administrative procedures have resulted in fewer children covered under KidCare. This is particularly important given the already high number of uninsured children in the state. Cuts in eligibility and services in Medicaid and the Medically Needy programs have also hurt participation in those programs.
  - **Medicaid waiver proposal:** Attention from all sectors was focused on the state's far-reaching Medicaid waiver proposal, which has been approved. The waiver will shift coverage in two pilot geographic areas to a defined contribution approach that relies on the beneficiary's choice of private managed care plans. Almost all beneficiaries including children and very-low-income pregnant women will be required to enroll. Adults, including disabled adults, will face maximum benefits limits, and their benefits will largely be determined by the health plan in which they are enrolled. The pilot would be expanded to other areas after initial implementation in Broward and Duval counties. Despite the importance and impact of this policy change, many details associated with the waiver were unknown less than two months before planned implementation.
  - **Prescription drug issues:** Changes in Medicaid prescription drug coverage that include a restrictive formulary and limits on the number of prescriptions have raised concerns about access and quality, particularly among mental health and disabled constituencies. Many interviewees also noted the large and uncertain impact that Medicare Part D would have on both beneficiaries and on state policy.
- > **Free care and safety net issues:** A broad range of concerns were raised by people we interviewed: hospital charity care policies, inadequate access to primary care for uninsured people, a weaker safety net as the result of state policies that shift greater responsibility to local government, and public hospital financial stress. Reduced coverage by employers is creating greater demand for free care and safety net services. Safety net concerns focused primarily on people under 200% of the poverty level. Improved hospital charity care and financial assistance policies, including care for immigrants, were seen as key issues by many interviewees. Greater accountability for how hospitals use state and county indigent care funding is viewed as an important aspect of this issue. Coverage for non-hospital care is also seen as an important issue, including expanded Medicaid coverage with a sliding fee scale, universal coverage for children, and greater primary care access for lower-income people. Immigrant access to primary care and existing coverage programs is identified as an important part of a health care safety net.

FL

Florida *(Continued)*

- > **Revenue issues:** State revenue policies were identified as an important issue because lack of public spending prevents public solutions to inadequate health care access and it pits vulnerable constituencies against each other. Raising the state's low tobacco tax was mentioned as a potential revenue source for health access.

## ADVOCACY CAPACITY

- > Several people interviewed noted the relatively weak advocacy and organizing capacity in the state. They mentioned that there is not a strong history of social justice organizing. Agencies and programs that receive public funds often fear retaliation if they engage in advocacy. Much of the consumer advocacy occurs through coalitions and service organizations, but service organizations are constrained by fears of reprisals because of their public funding sources.
- > Florida CHAIN is recognized as playing an important advocacy and coordination role around Medicaid and KidCare as well as helping to connect state health policy issues to the local level. Its board has representation from grassroots constituency-based organizations, advocacy groups, and local community-based organizations. The Human Services Coalition of Miami-Dade is a multi-issue organization that includes health in its agenda, and it was a founder of Florida CHAIN. There are formal and ad hoc coalitions of human services advocates and local legal services organizations in other areas of the state concerned with health care access as part of a broader agenda. A number of these networks are formally connected to Florida CHAIN. For example, advocates worked with local networks and organizations to ensure strong turnouts at a series of legislative hearings about the proposed Medicaid waiver.
- > The Coalition for Responsible Health Care Reform has developed specific proposals for Medicaid cost savings that will not harm consumers.
- > Florida Legal Services' policy support center is a critical source of policy and legal analysis around low-income health issues, and it plays a leadership role in coordinating policy advocacy around Medicaid.
- > Health care issues have become increasingly important for grassroots organizations. Grassroots organizations with locally based low- to moderate-income members are finding that health care and coverage are an increasing concern for their members. They are paying more attention to health care, focusing on a mix of Medicaid, KidCare, and hospital free care issues. The Miami-Dade population center has many local groups engaged on advocacy with county hospital and health system issues as well as Medicaid and KidCare issues. Both advocacy and grassroots organizations recognize the need for building stronger grassroots consumer voices in the health care debate. Several interviewees noted that grassroots organizations need knowledge and skills development to effectively engage their constituencies in health issues. There is also expressed need for more capacity to translate policy into user-friendly information for public education.
- > Organizations of people with special health needs are active in policy discussions and they inform and engage their members. These include Florida Institute for Family Involvement (FIFI) and NAMI as well as adult disability organizations.

**Florida** *(Continued)*

FL

- > Organized pediatricians have been active and supportive of advocacy on Medicaid issues, as has the Florida Association of Family Physicians. Major health policy debates have significant implications for the counties, and the Association of Counties has been somewhat involved.
- > The high stakes associated with Medicaid and KidCare have led to some support for policy analysis from some national organizations. While this analysis has been good and informative, several interviewees noted that after an initial splash with a policy-centered audience, the reports have had little impact. They see a need to connect policy analysis with ongoing advocacy and public education, putting a human face on the issue to generate broader public.

**FUNDING**

- > People interviewed perceive that funders generally do not support advocacy or grassroots organizing.
- > Despite funder recognition of and concern about the significant implications of key policy proposals, it was noted by one person interviewed that “by not embracing the possibility of effective organizing and legal advocacy, funders turned the clock back on policy advocacy.” One interviewee described the funder situation as “schizophrenic—they recognize the importance of policy decisions but are doing little to empower or build the voice of those who are affected.”



**HEADLINES**

- > GA, which has a very strong executive branch, elected its first Republican governor since the Civil War – Sonny Perdue – in 2002. Although previous Democratic governors had been conservative, advocates report that the current political environment is becoming significantly more challenging. Hot-button issues often dominate debate, and advocates have to work hard to achieve the level of access to the decision-making process they had under previous administrations.
- > There is very limited funding for advocacy, and most statewide advocacy is conducted by ad hoc networks of advocates and allies, who have to operate without any coalition staff or infrastructure.
- > GA has experienced a pronounced decline – 5.9 percentage points – in employer-sponsored insurance from 2000 to 2004. The national rate for that period was 4.8 percentage points. Medicaid coverage among the non-elderly increased during that same period by 1.6 percentage points, compared to a national average of 1.5 percentage points.
- > GA’s prostate cancer mortality rate among Black men is considerably higher than the national average—79.2 per 100,000 in GA compared with 70.4 per 100,000 nationally.

**KEY DATA**

- > GA’s population is approximately 8.6 million. Sixty-one percent of the population is White, compared with 67% nationally. The Black population is substantial – 29%, compared with 12% nationally. In contrast, its identified Hispanic population is very small – 7%, compared with 14% nationally—but growing quickly.
- > GA is a largely urban state, with 72% of its population living in urban areas and 28% outside of metropolitan areas.
- > GA is ranked 29<sup>th</sup> in the nation in per capita income, \$29,000, compared with \$31,472 nationally.
- > GA’s poverty rate is 17%, identical to the national rate of 17%. Twenty-six percent of the state’s Black population lives in poverty, compared with 33% nationally; 11% of its White population lives in poverty, compared with 12% nationally; and 30% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the GA population, relative to the US population as a whole, is as follows:

Type of Coverage	GA	US
Private Insurance	60%	59%
Medicaid	13%	13%
Medicare	10%	12%
Uninsured	18%	16%

Georgia *(Continued)*



- > About 18% of GA’s residents –about 1.4 million people – are uninsured, compared with a national rate of 16%. Fifteen percent of non-elderly Whites, compared with 13% nationally, 20% of non-elderly Blacks, compared with 21% nationally, and 41% of non-elderly Hispanics, well above the national average of 34%, are uninsured.
- > GA faced a severe decline in private insurance from 2000-2004. While the decline of private insurance was a national trend, it was more pronounced in GA, with a reduction of 5.9 percentage points, compared with 4.8 percentage points for the nation as a whole. Medicaid coverage among the non-elderly increased by 1.6 percentage points during this period, a rate similar to the nation as a whole. Because Medicaid did not fill the gap created by the steep decline in employer coverage, uninsurance grew at a faster rate than national average during that 4 year period – 4.2 percentage points, compared with a 2.7 point increase for the nation as a whole.
- > GA has a Medicaid matching rate of 61%. The state spends 0.47% of its GSP on Medicaid, substantially below the national rate of 0.87%. It ranks 49<sup>th</sup> out of 50 states in spending its own state revenues for Medicaid.
- > Medicaid eligibility standards are as follows: for children from birth to age 1 it is 200% FPL compared with 133% nationally (7<sup>th</sup> in the nation); for children from ages 1 to 5 it is 133% FPL, which is the same as the nation as a whole; and for children ages 6 to 19 it is 100% FPL, which is also the same as the nation as a whole. The state ranks 35<sup>th</sup> for working parents, at 58% FPL, and 32<sup>nd</sup> for non-working parents, at 37% FPL.
- > Dual eligibles in GA account for 12% of Medicaid recipients (US, 14%) but account for 31% of Medicaid costs (US average is 40%).
- > One hundred forty-four of GA’s 159 counties have areas that are considered medically underserved. One hundred five of its counties are considered poor, with nearly one third of its population living in poor counties. Thirty-eight poor counties have health centers and 67 do not.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	6.3	13.4	6
Prostate cancer mortality per 100,000	28.8	79.2	No data
HIV/AIDS incidence per 100,000	8.4	73.1	24.6
Asthma mortality rate per 100,000	1.2	3.0	No data
Uninsured rate (non-elderly)	15%	20%	41%

- > GA has a Hospital Care for the Indigent Program that enables individuals who are “financially unable to meet the full cost of hospital care as prescribed or ordered by a physician” to receive free care.
- > GA spends about 27% of the recommended CDC tobacco prevention standard, and it is ranked 27<sup>th</sup> in the US. Annual health care costs directly caused by smoking are estimated to be \$2.1 billion, of which Medicaid covers nearly \$500 million. It ranks 41<sup>st</sup> in tobacco taxes, at 37 cents per pack. Surrounding states also have very low tobacco taxes—lower than GA’s in four nearby states.

GA

Georgia *(Continued)*

- > State and local taxes account for 4.3% of its Gross State Product (GSP), well below the national average of 5.0%. GA ranks 43<sup>rd</sup> highest in total taxes as a percent of personal income. Combined with lower-than-average personal income, this leaves the state with very constrained resources. Advocates view this as a significant challenge to any type of access expansion.

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**“UNTIL WE DEAL WITH PAYMENT STREAMS EVERYTHING WE DO IS A BAND-AID.”**

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## POLITICAL ENVIRONMENT

- > GA, which has a very strong executive branch, has a Republican governor for the first time since the Civil War. The state legislature is also Republican.
- > The legislature is in session for only 40 days each year. This makes it difficult to build relationships with legislators and to build year-long advocacy campaigns.

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**“THESE SHORT TERMS MEAN THAT ADVOCATES HAVE TO DEVELOP RELATIONSHIPS WITH LEGISLATORS AND THEN WORK LIKE HELL FOR 40 DAYS.”**

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- > Although previous Democratic governors were conservative, advocates report that the political environment has become significantly more challenging. Advocates no longer have the same access to the decision-making process that they had under previous administrations. They report some progress, however, noting that the chair of one key House appropriations panel has afforded unusually open opportunities for involvement.
- > Recently, the Governor met with federal officials behind closed doors to talk about a Medicaid waiver proposal that would fundamentally change the program. Advocates heard about the proposal only through the media, and they experienced great difficulty getting information from the administration.
- > GA's lower-than-average tax collections as a percentage of the state's economy and personal income, coupled with its high poverty rates and low per capita income, would make any expansion of health care coverage using public dollars extremely challenging.

## KEY ADVOCACY ISSUES

- > **Medicaid:**
  - GA's investment in Medicaid relative to its available resources is significantly below the national average—the 2<sup>nd</sup> lowest in the nation. GA ranked 49<sup>th</sup> out of 50 states in spending its own state revenues for Medicaid. Budget shortfalls have led to ongoing efforts to roll back the hard-won

Georgia *(Continued)*

increases in Medicaid and SCHIP that advocates had achieved. Advocates had been successful in reversing the governor-sponsored SCHIP program change that terminated coverage for children whose parents did not pay insurance premiums on time, but it took a year to do so.

- The governor sought a far-reaching Medicaid waiver that would include higher participant cost sharing, a cap on federal spending, and limits on care for children with disabilities. He met with federal officials behind closed doors despite the profound changes the waiver would make in the program, and advocates had difficulty getting information about the proposed changes. Advocates were successful in deterring the Medicaid waiver proposal by raising public awareness of its potential impact. The Governor's office had planned to get legislative sign-off for the proposal during the 2006 General Assembly, but because of the controversy, it was tabled, to be addressed at some unspecified future time.
  - The state has also implemented a Medicaid managed care system, and it has awarded contracts to managed care networks for the enrollment of more than 1 million Medicaid and PeachCare participants during 2006. Advocates are still uncertain of the impact.
  - Grady Memorial Hospital, the state's largest provider of care for Medicaid patients and the uninsured, regularly struggles with budget shortfalls, as do many other providers, especially in rural areas.
- > **Tax and revenue issues:** Several advocates cited the need to raise taxes as the core issue the state must address before conversations about health care expansion can take place. GA's state and local tax collections are low relative to the state's economy. Just raising total tax revenues relative to the GSP to the national average would generate an additional \$1.2 billion. Unless there is a fundamental shift in the anti-tax political environment, Georgia's low tobacco tax, which was raised to only 37 cents per pack in 2003, may offer the best opportunity to fund Medicaid expansion. Tobacco taxes were not raised as an issue by advocates.
- > **Racial and ethnic disparities:** A funder sees health disparities as an important issue that includes both equal access *and* the structure and design of health delivery programs. A particular concern is how to reach immigrant populations, as GA has one of the fastest growing Hispanic populations in the country.

### ADVOCACY CAPACITY

- > Funding for consumer health advocacy is extremely limited, and advocacy organizations are operating with very few resources. Georgia Citizens United for a Responsible Budget (GA CURB), which plays a lead role in convening statewide advocates on health care and other human services issues, does not have a budget or any staff. Health care advocacy occurs through well-established informal and unfunded networks of individual advocates and organizations. This unstaffed, informal network engaged groups from around the state as it tracked the governor's Medicaid waiver process and advocated against the regressive aspects of the proposal.

- > With such limited funding, the majority of advocacy is done by “professional advocates” such as leaders of nonprofit organizations, ad hoc coalition coordinators, and hired lobbyists, most of whom have other responsibilities in addition to their issue advocacy.
- > Lack of capacity for grassroots organizing and mobilizing community groups at the necessary level is seen by advocates as a key barrier to becoming more effective. Grassroots organizing is gaining in importance in a political environment where health care policy changes are implemented with little, if any, consumer voice. Advocates believe that capacity to mobilize grassroots support is critical, regardless of how much access professional advocates have.
- > Grassroots membership-based organizing does occur in GA, but it is primarily at the local level and it is not connected in a coordinated way to statewide policy advocacy. The AIDS Survival Project regularly engages its membership constituency around health care issues, and its voter education efforts resulted in 76% of the members voting in 2004.
- > From 1999 to 2003, the ad hoc Grady Coalition, made up of clergy, health care advocates, providers serving the homeless, and other allies, organized to defeat a proposal by Grady Memorial Hospital—the state’s largest provider of care for Medicaid recipients and the uninsured—to raise co-payments on prescription drugs for its lowest-income patients. The Coalition was able to use the local victory to leverage tens of million of state and local dollars for a prescription drug subsidy pool for eligible low-income Georgians.
- > A recently-formed Georgia Budget and Policy Institute, affiliated with the national Center on Budget and Policy Priorities, focuses on policy and budget impacts on low-income people. It includes health issues because of their economic impact on low-income people. A funder sees this as a very important development.
- > Without staff and infrastructure, advocacy has been largely focused on particular issues and is often reactive. While there have been local and state policy victories, advocates say the biggest need is to build and strengthen advocacy capacity in order to have greater impact on, and to consistently drive, proactive agendas to improve the quality of life in a challenging political environment. As proof that it can work, they point to how disability groups have made progress in increasing the number of slots in community-based care through a statewide campaign to “Unlock the Waiting List,” aided by the fact that those organizations have funding that enables them to develop and nurture networks.
- > As lack of access to health care affects Georgians with higher incomes, advocates are seeking to build alliances between low-income residents and moderate- and middle-income people.
- > There is substantial advocate and public support for single-payer health care. In 2002, Georgians for a Common Sense Health Plan, a coalition of health care workers, advocates, and allies, received funding to research a single-payer plan for GA. Their research concluded that a single-payer system would cost less and cover more people than the current health care system. They contracted with a polling firm to conduct a detailed statewide survey, which showed that 62% of Georgians, after hearing arguments for and against the proposal, would support such a plan. The coalition has been unable to raise the further funding needed to conduct community and public education.

**Georgia** *(Continued)*



**FUNDING**

- > The Healthcare Georgia Foundation, which is devoted to achieving better health and health care for all Georgians, is the primary health issue funder. It funds 14 diverse organizations and coalitions that are working on health advocacy and policy issues, including disparities, children’s issues, and physical activity and nutrition. Among the groups it funds are the Georgia Budget and Policy Institute. The Foundation also provides support for community outreach, health navigators, and community-wide networks to link uninsured people with free clinical care.
- > Georgia funders would welcome collaboration with national funders, but the collaboration would have to benefit the people of Georgia, and organizations on the ground would have to be genuinely interested in the collaboration.

LA

Louisiana

The data in this report were collected before Hurricane Katrina. Damage from the Hurricane has put significant pressure on the state's already limited tax revenues, and it has increased demand for health care and other human services significantly. A post-Katrina update is available at the end of this report.

## HEADLINES

- > LA's per capita income ranks 42<sup>nd</sup> in the nation – \$26,312, compared with \$31,472 nationally – and its poverty rate of 16.9% is significantly higher than the national average of 12.1%.
- > Because of its low per capita income, it has one of the lowest per capita levels of tax revenue in the nation at \$1,611 per person – lower even than Mississippi, even though its state and local taxes relative to gross state product are higher than the national average.
- > Sixty-one of LA's 64 counties are considered “medically underserved areas” by the federal government. About 63% of the population lives in poor counties. Fifty-four of its counties are classified as “poor,” and of those, only 15 have community health centers.
- > LA's low per capita income, high poverty rate, and high uninsurance rate create a significant need for expansion of health care access. Its ability to meet health care needs is limited though, by its low state and local tax collections per person.

## KEY DATA

- > LA's population is approximately 4.4 million. The Black population is substantial – 32%, compared with 12% nationally. In contrast, its identified Hispanic population is very small – 3%, compared with 14% nationally. Its White population is slightly below the national average at 63%, compared with 67%.
- > LA is a largely urban state, with 73% of its population living in urban areas and 27% living outside of metropolitan areas.
- > LA's per capita income ranks 42<sup>nd</sup> in the nation—\$26,312, compared with \$31,472 nationally.
- > LA's poverty rate (i.e., those with incomes below 100% of the Federal Poverty Level) is 22%, well above the national rate of 17%. Forty percent of the state's Black population lives in poverty, compared with 33% nationally; 13% of its White population lives in poverty, compared with 12% nationally; and 18% of its Hispanic population lives in poverty, compared with 29% nationally.



Louisiana *(Continued)*



- > Health coverage status of the LA population, relative to the US population as a whole, is as follows:

Type of Coverage	LA	US
Private Insurance	53%	59%
Medicaid	15%	13%
Medicare	13%	12%
Uninsured	19%	16%

- > About 19% of LA residents are uninsured, significantly above the national rate of 16%. Uninsurance is higher than in the nation as a whole for Whites – 17% of Whites are uninsured, compared with 13% nationally – and Blacks – 28% are uninsured, compared with 21% nationally. There are no uninsured data available for Hispanics.
- > LA has experienced a 0.9 percentage point decline in employer-sponsored insurance since 2004, compared with the US decrease of 4.8. Medicaid coverage for the non-elderly increased by 0.1 point, compared with the 1.5 point increase in the US, for the period from 2000 to 2004. As a result of a lower-than-average loss of employer-sponsored insurance and an increase in Medicaid coverage, uninsurance grew at a slower rate than the national average from 2000 to 2004 – 1.7 percentage points, compared with a 2.7 percentage point increase for the nation as a whole.
- > LA has a high Medicaid matching rate of 69%. Medicaid spending accounts for 0.79% of its GSP, somewhat below the national rate of 0.87%. It ranks 27<sup>th</sup> in spending state resources for Medicaid.
- > LA has very low eligibility standards for working parents—20% of the FPL, 41<sup>st</sup> in the nation—and 13% for non-working parents, 45<sup>th</sup> in the nation. The eligibility standard for children is 200% FPL.
- > Dual eligibles in LA account for 14% of Medicaid recipients (US, 14%) but account for 36% of Medicaid costs (US average is 40%).
- > Sixty-one of LA’s 64 counties are federally designated “medically underserved” areas. About 63% of the population lives in poor counties. Fifteen of the 54 poor counties have health centers, but 39 do not. Approximately 63.1% of the state residents live in poor counties.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	6.8	13.8	6
Prostate cancer mortality per 100,000	29.3	68.1	21.7
HIV/AIDS incidence per 100,000	12.1	63.4	28.7
Asthma mortality rate per 100,000	1.2	3.7	No data
Uninsured rate (non-elderly)	17%	28%	No data

- > LA has a Community Indigent Health Care Program for LA residents whose income is below 185% of the FPL.

LA

Louisiana *(Continued)*

- > The adult smoking rate in LA is 23.6%, with an adult smoking rank of 38<sup>th</sup> in the nation (1 = low). LA ranks 16<sup>th</sup> in the nation for spending on CDC tobacco prevention standards, spending 29% of the CDC recommended level. The annual direct health costs caused by smoking are estimated to be nearly \$1.4 billion (about what the state spends for Medicaid), almost \$600 million of which is borne by Medicaid. LA ranks 42<sup>nd</sup> in the nation in its tobacco tax, at 36 cents per pack.
- > State and local taxes account for 5.3% of state GSP, slightly above the national average of 5.0%. LA ranked 20<sup>th</sup> in total taxes relative to personal income. Its high poverty rates and low per capita income, combined with average tax rates, suggest that the need for public services far outstrips the available resources.

### POLITICAL ENVIRONMENT

- > Unlike many Southern states, the LA state government has remained largely Democratic. The Governor, Kathleen Blanco, is a Democrat, and there are Democratic majorities in both houses of the state legislature.
- > The Governor, who was elected in 2002, has prioritized health and education as her key issues.
- > Health care is not a dedicated line item in the state budget.
- > The Governor's health care reform initiative created regional consortia to provide information to the statewide reform planning body. The goal was to give local communities power to develop local health care solutions. This process has strengthened provider collaboration.

### KEY ADVOCACY ISSUES

- > **Safety net and free care issues:** The Charity Care Hospital system gets 94% of the state's Medicaid Disproportionate Share funding. People interviewed report that Charity Care hospitals need to be more efficient. There is often a 6- to 8-month wait to see a specialist, and there is a lack of basic resources such as rubbing alcohol. In 2004 and 2005, there was a cutback in services provided by the Charity Care system, including hours of operation. Because of the Charity Care system, the private sector generally has not had to deal with the uninsured to date, but that is changing. Private hospitals are seeing more patients in their emergency rooms and are providing more care for which they are not reimbursed, because the Charity Hospitals get all of the funding. A few interviewees believe that the public hospital system should be done away with and money diverted to increase Medicaid resources.
- > **Health center capacity:** About 63% of the population lives in poor counties, but 39 poor counties do not have health centers. The Charity Care system, which provides free care to uninsured people, has resulted in limited use of health centers by the uninsured because they would have to pay a sliding scale fee at the health centers. One person interviewed believed that the state has limited the establishment of health centers in order to support the Charity system. The state recently approved six new health centers.

## Louisiana *(Continued)*

LA

- > **Inadequate transportation:** Medical access points are highly centralized, and many low-income people do not have cars, making it very difficult to get to medical appointments that are often many miles away.
- > **Health professional shortages:** Although there are medical schools in the state, LA cannot attract enough physicians to practice in the state. This is a particular problem in rural areas, which have a very difficult time recruiting physicians.

### ADVOCACY CAPACITY

- > The Louisiana Hospital Association did not care about the issue of health care access until about two years ago, when care provided by the Charity Care system began to decline. The Association has become one of the most vocal advocates in the state since cutbacks in the Charity Care system have increased the number of uninsured people who come into the emergency rooms of private hospitals, significantly increasing the amount of care these hospitals have to provide without reimbursement.
- > Provider organizations such as the Hospital Association and Louisiana Medical Association play lead roles in health care advocacy, while capacity for consumer health advocacy is limited.
- > Grassroots coalitions of consumers, business, social service agencies, and clinical service providers are working to increase health access at the local level. These coalitions focus on assessing community needs and resources to develop solutions to health access problems. A number of people and organizations involved in these coalitions also participate in the governor's regional consortia. They believe that it is through the mechanism developed by the governor that local communities will get their voices heard and that health system changes will be implemented.
- > Some people interviewed commented that advocacy is not part of the state's culture. It was difficult to identify organizations working at the statewide level whose focus was on mobilizing constituencies affected by health care policy issues.

### FUNDING

- > Foundations in LA focus primarily on providing grants to organizations that are working to increase access to health care from a service delivery perspective, whether by building a local hospital or integrating the local delivery system. There is little funding for consumer health advocacy.

### POST KATRINA

Once home to 484,672 people, New Orleans was the 31<sup>st</sup> largest city in the country. Sixty-seven percent of the population was Black, but today only about one fifth of the pre-Katrina population, mainly White, is residing in the city. Before the storm, New Orleans was characterized by sharp segregation,

high concentrations of extreme poverty (particularly in communities of color), and a declining economy with high rates of unemployment, especially among Blacks.

- 38% of the population lived in extremely poor census tracts.
- 84% of the poor were Black.
- The median income of Black households was half that of Whites (\$21,461 compared with \$40,390).
- 44% of Black men 16 and older were not participating in the labor force; only 30% of White men were not.
- Black college attainment was 4 times lower than that of Whites and only two thirds of Black adults had high school degrees, compared with 89% of Whites.
- Nearly 10% of the city's population, nearly all Black, resided in 10 public housing projects, contributing to racial segregation and unhealthy living conditions.<sup>7</sup>

### ***The New Orleans health care system today***

The health care system that existed prior to the storm has been effectively dismantled. According to newspaper reports in January 2006, only eight hospitals in greater New Orleans are currently open, serving 550,000 people.<sup>8</sup> At least three of the community health centers are closed, although some mobile units are in operation. In New Orleans proper, six hospitals are closed, including Charity and University Hospitals. Temporary sites to replace Charity's Level 1 trauma services and to provide teaching sites for the city's two medical schools have been temporarily designated. Memorial Medical Center, operated by for-profit Tenet Healthcare, is also closed. Tenet plans to rebuild and may be looking for federal funds for this purpose. Most recently, a plan has emerged to build a replacement hospital that would care for the charity population and the population eligible for treatment through the federal Veterans Administration. It would also serve as a medical teaching facility for the academic medical programs at Louisiana State University and Tulane University.

Private hospitals and other public hospitals in the New Orleans area that remain open are providing care for many more uninsured patients, now that Charity is closed. Their costs have risen dramatically, and they have received some emergency disproportionate-share funding.<sup>9</sup>

The long-term care system and services for the elderly have been disrupted, with 5,000 local nursing home beds closed since the storm. Some are predicting that the elderly population will be smaller for some time, given the few nursing home beds and the difficulties that all displaced and frail elders would face in returning to the city.<sup>10</sup>

<sup>7</sup> Brookings Institution, *New Orleans after the Storm: Lessons from the Past, a Plan for the Future*, in Metropolitan Policy Program, 2005, Brookings Institution: Washington, D.C.

<sup>8</sup> Muller, G., *Rebuilding New Orleans*. www.ModernHealthCare.com, 2006.

<sup>9</sup> Harvey, C., *Bill may finance hospital care for indigent*, in Times Picayune. 2005: New Orleans, and Darce, K., *Forced to Change*, in Times Picayune. 2006.

<sup>10</sup> Pope, J., *Hospitals size up new business climate*, in Time Picayune. 2005: New Orleans.

# Mississippi



## HEADLINES

- > MS's per capita income is the lowest in the nation, \$23,466, compared with \$31,472 nationally.
- > Its Governor, Haley Barbour, is a former National Republican Committee chair and former lobbyist who is rumored to have presidential ambitions.
- > MS's health indicators are generally poorer than those in the nation as a whole. It has a higher infant mortality rate among both Black and White mothers, a higher prostate cancer mortality rate among both Black and White men, and a higher asthma mortality rate among Blacks. Its rate of HIV/AIDS is lower among Blacks and Whites than in the nation as a whole, but it is substantially higher among Hispanic residents than nationally.

## KEY DATA

- > MS's population is approximately 2.8 million. The White population is 59%, compared with 67% in the US, whereas the Black population is substantial – 37%, compared with 12% in the US. In contrast, its identified Hispanic population is very small – 2%, compared with 14% in the US.
- > MS is a largely rural state, with 60% of its population living outside of metropolitan areas.
- > Its per capita income is the *lowest in the nation* at \$23,466, compared with \$31,472 nationally.
- > MS's poverty rate (i.e., those with incomes below 100% of the Federal Poverty Level) is 23%, whereas the poverty rate for the US as a whole is 17%. Thirty-eight percent of the state's Black population lives in poverty, compared with 33% nationally; 14% of its White population lives in poverty, compared with 12% nationally; and 23% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the MS population, relative to the US population as a whole, is as follows:

Type of Coverage	MS	US
Private Insurance	51%	59%
Medicaid	19%	13%
Medicare	11%	12%
Uninsured	18%	16%

- > MS has experienced a 3.6 percentage point decline in employer-sponsored insurance since 2004, compared with the US decrease of 4.8. Non-elderly Medicaid coverage in MS increased by 2.8 percentage points from 2000 to 2004 compared with a 1.5 percentage point increase in the US as a whole. The total rate of uninsurance grew at a faster rate than the national average from 2000 to 2004, 3.0 percentage points, compared with a 2.7 point increase for the nation as a whole.

- > Almost 500,000 people are uninsured. Fifteen percent of Whites are uninsured, compared with 13% nationally, and 25% of Blacks are uninsured, compared with 21% nationally. No data were available for the Hispanic population.
- > MS has the highest Medicaid matching rate in the US at 76%. Medicaid spending accounts for 0.88% of its GSP, slightly above the national rate of 0.87%. MS ranks 17<sup>th</sup> in the amount of its own state resources spent for Medicaid.
- > Eligibility standards for working parents are 34% of the FPL, 41<sup>st</sup> in the US, and 27% for non-working parents, 44<sup>th</sup> in the US. The eligibility standard for infants under age 1 is 185% of FPL (ranked 25<sup>th</sup> in the US); for children ages 1-6, it is 133% of FPL (ranked 28<sup>th</sup> in the US); and for children 6 and over, it is 100% of FPL (ranked 31<sup>st</sup> in the US).
- > Dual eligibles in MS represent 19% of Medicaid recipients (US, 14%) but account for 34% of Medicaid costs (US average is 40%).
- > Eighty-one of MS's 82 counties are federally designated "medically underserved" areas. Also, 78.5% of the state's residents live in poor counties. There are 48 poor counties with a health center, and 26 poor counties without a health center.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	7	14.8	No data
Prostate cancer mortality per 100,000	30.1	79.4	No data
HIV/AIDS incidence per 100,000	5.9	49.8	35.2
Asthma mortality rate per 100,000	1.2	3.7	No data
Uninsured rate (non-elderly)	15	25	No data

- > There is no regulatory or statutory requirement that hospitals provide charity care.
- > In 2003, MS spent \$20M (about 106.4% of the recommended CDC standards) on tobacco prevention programs. It ranked 3<sup>rd</sup> in the nation as far as CDC standard compliance. Adult smoking rate in MS is 24.6%, with an adult smoking rank of 42<sup>nd</sup> in the US (1 = low). The direct health care cost of smoking to MS is \$662M, with \$243M covered by Medicaid.
- > MS's tobacco tax rate is 18 cents per pack, which ranks 48<sup>th</sup> in the US for tobacco tax rates.
- > The low per capita income means that MS has a relatively weak tax base. State and local taxes as a percentage of GSP are well above the national average – 6.7%, compared with 5.0% nationally. MS ranks 13<sup>th</sup> highest in total taxes relative to personal income.

Mississippi *(Continued)*



**POLITICAL ENVIRONMENT**

- > The Governor and the Lieutenant Governor are Republicans, but the majority of legislators are Democrats. Some House members have played leadership roles on health advocates’ issues such as tobacco taxes, but their efforts have been stymied in the Senate, where the executive branch is able to exercise considerable control over the legislative agenda through the Lieutenant Governor’s power to appoint committee chairs.
- > The close alignment between the Governor and Lieutenant Governor was recently breached when the Lieutenant Governor supported a tobacco tax increase that was paired with a reduction in the sales tax on groceries. The bill passed both houses but was vetoed by the Governor, and the Senate was unable to override the veto.
- > The majority of MS’s congressional delegation is Republican, including its two senators – Trent Lott, and Thad Cochran who is chair of the Senate Appropriations Committee – as well as two of its four representatives.
- > There is a general perception among the advocates interviewed that the governor and his appointees are hostile to poor people.

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**“OUR GOVERNOR IS THE ONE WHO COINED THE TERM ‘WELFARE QUEEN’ THAT PRESIDENT REAGAN LIKED TO USE SO MUCH.”**

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- > Prior to Hurricane Katrina, the Governor’s popularity was on the wane, in part because of his policies related to education and health funding. It’s currently enjoying a resurgence, though, largely because his Washington connections are expected to yield significant federal disaster aid for the state.
- > Health and human services advocates report they have little, if any, access to administration officials. Whereas they had contacts within the governor’s office and the executive agencies during prior administrations, few of those interviewed have any official channel now. Public opposition to the Governor’s policies is seen as carrying the risk of official retaliation, and there are accounts of individuals and organizations losing state contracts or being subject to non-routine program audits.
- > A number of individuals interviewed believe racism is still a significant factor in the state’s culture, and that it drives some policy decisions. An example is the recent institution of strict Medicaid eligibility redetermination requirements.

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**“RACISM IS AN ISSUE. SOME PEOPLE THINK THE [PUBLIC PROGRAM] PARTICIPANTS ARE MAINLY AFRICAN AMERICAN AND THAT THEY ARE JUST LAZY.”**

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MS

Mississippi *(Continued)*

## KEY ADVOCACY ISSUES

> **Medicaid**

- **Limits on prescription drugs:** Effective 7/1/05, the number of prescriptions Medicaid recipients could fill each month dropped from seven to five, of which no more than two can be brand name. The only exception is for individuals with HIV/AIDS. Advocates are seeking ways to restore full coverage to people and potentially achieve cost savings that will relieve some of the financial pressure on the Medicaid program.
  - **Medicaid eligibility redetermination process:** Effective 1/1/05, the state instituted a face-to-face eligibility redetermination process for all Medicaid recipients. The Governor characterized it as an effort to stop recipients' abuse of the system. Advocates expressed concern that the policy reflects a deliberate effort to scare eligible people into leaving the program. After the first 6 months, the Medicaid rolls had decreased by 20,000.
  - **Implementation of the *Olmstead* decision:** The *Olmstead* case, which affects all states, requires that community-based placements be made available to disabled Medicaid recipients who would otherwise have no option but to live in a nursing home or state institution. When the state failed to make progress toward compliance, it was sued by the Mississippi Coalition for Citizens with Disabilities. A settlement was reached in early 2006. Ongoing advocacy and monitoring will be required to ensure that the funding and programming are actually made available.
  - **Elimination of the PLAD category of Medicaid beneficiaries:** In mid-2004, the Governor, with support from the legislature, moved to terminate the Poverty-Level Aged and Disabled (PLAD) category of Medicaid beneficiaries, an action that would have affected 65,000 low-income retirees and permanently disabled individuals. Advocates quickly mobilized and undertook an effective public education campaign. Responding to public pressure, a number of legislators claimed that they had been unaware of the impact of their vote and they vowed to take action to fix it. Before the legislature reconvened, however, advocates brought a lawsuit, and the court issued an injunction that prevented the state from terminating the program until 1/1/06 – the date on which many of the PLAD beneficiaries became eligible for prescription drug coverage under Medicare Part D. While many former PLAD enrollees now have access to medication through Medicare or have been moved into other Medicaid eligibility categories, challenges remain for some. For example, advocates had to step in and broker a temporary solution to one serious problem – transportation to dialysis treatments.
- > **Tobacco tax:** Consumer health advocates were very successful in bringing together a coalition of groups committed to raising the tobacco tax, with a goal of using some of the proceeds to fund health access. In past years, the proposal never made it to the Senate floor, but as described above, the tax increase recently passed both houses. It was, however, vetoed by the Governor, and the Senate was unable to override the veto.

Mississippi *(Continued)*



**ADVOCACY CAPACITY**

- > There is effective consumer health advocacy leadership, but it is hampered both by a lack of resources and by the challenging political environment. The Mississippi Health Advocacy Program (MHAP) is respected as an effective builder and convener of coalitions on health access issues.
- > In addition to MHAP, which conducts annual policy forums around the state, the Coalition for Citizens with Disabilities and AARP are effective in organizing and mobilizing their constituents on health access issues. Other contributors on particular issues are the state chapters of the American Heart Association, the American Lung Association, the American Cancer Society, and the Children’s Defense Fund.
- > There is some legal back-up through the Mississippi Center for Justice, which has served as co-counsel with national legal services organizations in lawsuits to stop the termination of the PLAD Medicaid category, and to challenge the Medicaid program’s limits on prescription drugs.
- > Advocates identified the need for credible, MS-specific policy analysis and strategic advice to bolster their work.

**FUNDING**

- > The Bower Foundation is the only foundation in MS that has a statewide health care focus.

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**“THERE IS NO MONEY TO SUPPORT ADVOCACY—WE ARE A PRETTY POOR STATE;  
OTHER STATES HAVE MUCH BETTER RESOURCES TO DO THE WORK THAT NEEDS TO BE DONE.”**

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KS

Kansas

## HEADLINES

- > KS's governor, Kathleen Sebelius, is a Democrat. In her prior position as Insurance Commissioner, she denied the application of Blue Cross/Blue Shield of Kansas to convert to for-profit status.
- > The legislature is predominantly Republican—there is a 2-to-1 majority in the House, and a 3-to-1 majority in the Senate. Interviewees noted that the House is extremely conservative, whereas the Senate is more moderate.
- > The Governor will be up for reelection in 2007, and it is expected that health care will be a key issue for all candidates.
- > There is a well-funded effort to put a Taxpayers' Bill of Rights (TABOR) law on the ballot. The law, which would limit state revenue increases, was described by one person interviewed as "the biggest threat to the state." There may also be an effort to pass legislation making it more difficult to raise taxes by requiring a supermajority. People interviewed expressed fears that TABOR or other tax limitation policies would result in cuts to health care access as well as other services. This comes at a time when the state revenue picture is much improved and could ease pressure on efforts to cut Medicaid coverage. Tax limitation initiatives are a galvanizing issue that is bringing together health advocates and a broad range of organizations concerned about low-income people.

## KEY DATA

- > KS's population is approximately 2.7 million. Eighty-one percent of the population is White, well above the national rate of 67%. The Black population is only 6%, compared with 12% nationally, and the Hispanic population is 7%, compared with 14% nationally. The population is, however, becoming more diverse, as the state is experiencing rapid growth in its minority population. The Hispanic population grew by nearly 125,000 from 1980 to 2000 – a 189% increase. In the rural counties, the increase was more dramatic – 330%, with some counties as high as 400%.
- > KS is 71% urban and 29% rural.
- > KS's per capita income is \$29,438, compared with \$31,472 nationally. KS ranks 27<sup>th</sup> in the nation.
- > KS's poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 15%, whereas the poverty rate for the US as a whole is 17%. Thirty-one percent of the state's Black population lives in poverty, compared with 33% nationally; 11% of its White population lives in poverty, compared with 12% nationally; and 28% of its Hispanic population lives in poverty, compared with 29% nationally.

> Health coverage status of the KS population, relative to the US population, is as follows:

Type of Coverage	KS	US
Private Insurance	65%	59%
Medicaid	9.0%	13%
Medicare	12%	12%
Uninsured	11%	16%

- > About 11% of KS residents—almost 300,000 people—are uninsured, compared with a national rate of 16%. About 11% of non-elderly Whites are uninsured, compared with 13% nationally, and 30% of Hispanics are uninsured, compared with 34% for the nation as a whole. No data were available for the Black population.
- > KS has experienced a 2.9 percentage point decline in employer-sponsored insurance since 2004, compared with the US decrease of 4.8 percentage points. Coverage trends among the non-elderly who have Medicaid coverage in KS from 2000 to 2004 has increased by 2.2 percentage points, compared with the 1.5 point increase in the US. As a result, uninsurance grew at a slower rate than the national average from 2000 to 2004, a 1.5 percentage point increase, compared with a 2.7 point increase for the nation as a whole.
- > KS has a Medicaid matching rate of 60%. The state spends 0.61% of its GSP on Medicaid, substantially below the national rate of 0.87%. KS ranks 41<sup>st</sup> in the amount of its own state resources for Medicaid. In terms of Medicaid eligibility, the state ranks 42<sup>nd</sup> for working parents at 38% of FPL, and 39<sup>th</sup> for non-working parents at 31% of FPL. The eligibility standard for infants under age 1 is 150% of FPL (37<sup>th</sup> in the U.S.); for children ages 1-6, it is 133% of FPL (28<sup>th</sup> in the US); and for children 6 and over, it is 100% of FPL (31<sup>st</sup> in the U.S.). SCHIP expansion brought coverage for children up to 200% of FPL.
- > Dual eligibles in KS account for 15% of Medicaid recipients (US, 14%) but account for 50% of Medicaid costs (US average is 40%).
- > Ninety four of KS’s 105 counties have federally designated “medically underserved” areas. There are 11 community health centers, one federally qualified health center “look alike,” and a number of primary care clinics. Among the 105 counties, 41 are classified as poor, and 32 of those do not have a community health center.

KS

Kansas (Continued)

- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	6.5	14.6	7.1
Prostate cancer mortality per 100,000	27.3	75.9	No data
HIV/AIDS incidence per 100,000	3.2	19.6	2.0
Asthma mortality rate per 100,000	1.2	5.6	No data
Uninsured rate (non-elderly)	11%	No data	30%

- > Uninsured people earning at or below 200% of the FPL are eligible for indigent care at indigent health care clinics, federally qualified health centers, or participating local health departments. The Charitable Health Care Provider Program provides liability coverage to health care professionals in return for provision of care to medically indigent people.
- > KS ranked 42<sup>nd</sup> in the nation for compliance with CDC tobacco prevention standards. The annual health cost directly caused by smoking is estimated to be \$850 million, of which \$180 million is covered by Medicaid. The adult smoking rate for KS is 19.8%, with an adult smoking rank of 11<sup>th</sup> in the US (1 = low).
- > State and local taxes account for 5.4% of Gross State Product (GSP), slightly above the US average of 5.0%. KS is the 29<sup>th</sup> highest in total taxes relative to personal income.

**POLITICAL ENVIRONMENT**

- > The Governor is a Democrat who supports expansion of health care access, but both houses of the legislature are controlled by large Republican majorities. According to people interviewed, the Republican Party is divided into a moderate wing, which controls the Senate, and a very conservative wing that controls the House. This division played a role in enabling a Democratic governor to be elected. On some issues, there are alliances between moderate Republicans and Democrats. As a result, the governor has had to identify policy initiatives that could gain the support of moderate Republicans as well as Democrats.
- > When she was Insurance Commissioner, the Governor played an important role in protecting consumer and public interests in a proposed conversion of Kansas Blue Cross/Blue Shield.
- > There is a well-funded effort to get a TABOR initiative on the ballot, which would limit state revenue increases. One person interviewed described this as “the biggest threat to the state.” People interviewed expressed fears that TABOR or other tax limitation policies would result in cuts to health care access as well as other services. During the 2006 legislative session, the Coalition for a Prosperous Kansas was successful in defeating efforts to pass TABOR and a supermajority bill that would have applied to tax increases. It is expected that this issue will be back in force during the November elections and in the next legislative session. The state revenue picture is improving, which could ease pressure on efforts to cut Medicaid coverage. At issue is whether potential new revenues will be used to provide health care and other basic services or to support tax cuts.

### KEY ADVOCACY ISSUES

- > **Medicaid access:** People we interviewed say that there has not been a significant assault on Medicaid. This could change, however, with creation of a new health care authority that will have statutory oversight of the Medicaid program. Advocates and funders see a need to expand Medicaid access for adults by raising the poverty level eligibility standard and making coverage available for all children. Republicans portray Medicaid as a program with runaway costs, and some legislators see cuts in other states as models for KS. A funder believes it is important to increase awareness, among the public and legislators, that care for seniors and disabled people is the major driver of Medicaid costs rather than coverage for uninsured low-income children and adults. Advocates have been discussing the potential implications for health care access of the federal Deficit Reduction Act.

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**“WE HAVE TO HAVE PRESUMPTIVE ELIGIBILITY TO THE POINT WHERE ALL  
CHILDREN ARE PRESUMED TO BE ELIGIBLE FOR COVERAGE.”**

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- > **Rural health care access:** Nearly 30% of Kansans live in rural areas, and the lack of rural health care access is a major concern. Many counties do not have enough physicians or medical facilities. These problems are magnified by lack of a statewide transportation system.
- > **Access to dental care:** Lack of access to dental care is a major issue for both uninsured and insured residents. A number of counties have no dentists or other providers. The state has a difficult time attracting dentists, partly because it does not have a dental residency program.
- > **Taxes and public revenues:** TABOR and other revenue limitation policies are seen as a major barrier to protecting or expanding Medicaid access.

### ADVOCACY CAPACITY

- > Historically, KS has not had a statewide health advocacy organization. Providers such as the Kansas Association for the Medically Underserved (KAMU), the state primary care association, have played a lead role on health advocacy, particularly with regard to strengthening the health care safety net. Many people interviewed see the Kansas Health Consumer Coalition (KHCC), which was created in 2004, as an organization that can “lead the charge for consumer health advocacy” and “act as a unifying force to bring together all those interested in health access.” KAMU was instrumental in development of KHCC.
- > The Coalition for a Prosperous Kansas was formed in 2005 by Kansas Action for Children, to defeat TABOR. It includes health and social service providers, faith-based organizations, and unions. Potential tax cuts are a galvanizing issue that is bringing a broad range of constituencies and organizations together.

KS

Kansas *(Continued)*

- > The Big Tent Coalition focuses on restoring and protecting essential services, with a specific emphasis on people with disabilities. The coalition is involved in advocacy, grassroots organizing, and engaging its constituents.
- > Providers play an important role in health advocacy in KS. KAMU is an advocacy organization for health centers that plays an important role in working for health care access for uninsured and underinsured people. Recognizing the need for a stronger consumer voice, KAMU helped form the Kansas Health Consumer Coalition. Oral Health Kansas is a diverse coalition working to improve oral health through advocacy and public education.

## FUNDING

- > Funders are taking a long-term approach to capacity building, focused on support for building statewide consumer organizations. One of the funders sees KS as “fertile ground” for national funders and other organizations to provide support for capacity building.
- > Several advocates indicate that organizations working on health advocacy are generally not well funded, and a number of organizations have only one or two staff. While local foundations are supportive, their resources are limited.

## Michigan

MI

## HEADLINES

- > MI has one of the lowest uninsurance rates in the country, the result of a higher-than-average private insurance rate and Medicaid coverage that matches the national average. Despite its relatively low uninsurance rate however, approximately 1.1 million residents are without insurance coverage. In addition, from 2000 to 2004, private insurance decreased 3.6 percentage points, compared with a national decline of 4.8 points, and its uninsurance rate increased 3.6 percentage points, compared with a national average of 2.7 points.
- > In her State of the State address in January 2006, Governor Jennifer Granholm announced the development of the Michigan First Healthcare Plan, which has as its goals the provision of affordable coverage to 550,000 uninsured residents, the promotion of healthy lifestyles, and the reduction of health care costs. Negotiations with the federal government were underway, as was assistance from a national consulting firm. Ongoing activities will draw on ideas generated by a wide range of participants in the state's uninsured planning process, funded by the federal Health Resources and Services Administration [HRSA]. In May 2006, the Governor expressed interest in expanding the program to those who are uninsured with incomes above 200% of the federal poverty level (FPL). The plan continues to assume subsidies for those under 200% FPL.
- > MI residents rank poorly for a number of health conditions: they are 3<sup>rd</sup> in obesity, 5<sup>th</sup> in number of adults with asthma and percent of adults reporting poor mental health, 11<sup>th</sup> in deaths from heart disease, 23<sup>rd</sup> in deaths from strokes, and 27<sup>th</sup> in deaths from cancer.
- > MI has higher infant mortality rates among Black, White, and Hispanic mothers than the national average, and a higher prostate cancer mortality rate among Black, White, and Hispanic men than nationally. Its rate of HIV/AIDS is significantly lower among Blacks, Whites, and Hispanics than in the nation as a whole. The uninsured rate is lower than the national average for Whites and Blacks, and it is significantly lower for Hispanics. There are, however, serious racial and ethnic disparities within MI with respect to both access and health status.
- > MI has had a well-developed industrial economy and a high level of membership in politically powerful unions. This has led to a higher percentage of people covered by private insurance and a lower uninsurance rate. There have, however, been structural economic changes that affect health care need and ability to meet it. State revenues have declined since 2000 due to both economic weakness and planned reductions in tax revenues. Recent census data indicate that MI is one of only seven states to show an increase in poverty, reduction in per capita income, and an increase in uninsured people.

## KEY DATA

- > MI's population in 2000 was approximately 9.9 million. Of that total, 14% was Black, compared with 12% nationally; 78% was White, well above the national average of 67%; and only 3% was Hispanic, well below the 14% national average. The population as of 2005 is estimated at 10.2 million.





- > MI is 75% urban and 25% rural.
- > MI's per capita income is \$31,178, 19<sup>th</sup> in the nation, compared with \$31,472 nationally.
- > MI's poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 17%, which is the same as the poverty rate for the nation as a whole. Thirty-eight percent of the state's Black population lives in poverty, compared with 33% nationally; 12% of its White population lives in poverty, compared with 12% nationally; and 25% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the MI population, relative to the US population as a whole, is as follows:

Type of Coverage	MI	US
Private Insurance	63%	59%
Medicaid	13%	13%
Medicare	13%	12%
Uninsured	11%	16%

- > About 11% of MI residents are uninsured compared with a national rate of 16%, one of the lowest rates in the nation. The actual number of people without insurance is almost 1.1 million. The uninsured rate for Whites is 11%, compared with 13% nationally; 18% of Blacks are uninsured, compared with 21% nationally; and 22% of Hispanics lack insurance, well below the national average of 34%.
- > MI has experienced a 3.6 percentage point decline in employer-sponsored insurance since 2004, compared with the US decrease of 4.8 points. The number of non-elderly who have Medicaid coverage in MI from decreased by 1.8 percentage points from 2000 to 2004, compared with a 1.5 point increase in the US as a whole. As a result, uninsurance grew at a slower rate than the national average from 2000 to 2004, 1.7 percentage points compared with a 2.7 point increase for the nation as a whole.
- > MI federal Medicaid matching rate is 56% for FY2006. The state spends 0.91% of its GSP on Medicaid, slightly above the national rate of 0.87% and 15<sup>th</sup> highest in spending its own state resources for Medicaid.
- > Medicaid eligibility standards are as follows: for infants under age 1 is 185% FPL (25<sup>th</sup> in the US); for children ages 1-6, it is 150% FPL (20<sup>th</sup> in the US); and for children 6 and over, it is 150% FPL (19<sup>th</sup> in the US). SCHIP expansion covers children in MI up to 200% FPL.
- > Eligibility standards for working and non-working parents are low – 59% FPL for working parents (33<sup>rd</sup> in the US) and 35% FPL for non-working parents (32<sup>nd</sup> in the US). The eligibility standard Dual eligibles in MI account for 13% of Medicaid recipients (US, 14%) but account for 31% of Medicaid costs (US average is 40%).
- > About 3.8% of MI's residents live in poor counties. Sixty-three of MI's 83 counties have federally designated "medically underserved" areas, including Wayne County where Detroit is located. Eleven of the 17 poor counties – accounting for 4% of the state's population – do not have a health center.

**Michigan** *(Continued)*



- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	6.3	16.9	6.7
Prostate cancer mortality per 100,000	29.9	64.3	20.1
HIV/AIDS incidence per 100,000	3.3	37.4	11.5
Asthma mortality rate per 100,000	1.2	4.5	No data
Uninsured rate (non-elderly)	11%	18%	22%

- > There are no legislative or regulatory provisions with respect to free care.
- > MI's cigarette tax is the 3<sup>rd</sup> highest in the nation at \$2.00 per pack, and it is more than double the tax in any of the neighboring states. The state spends only \$3.6 million on smoking prevention, using none of the funds from the state tobacco settlement or the cigarette tax for that purpose. It ranks 51<sup>st</sup> in CDC smoking prevention compliance, with a smoking rate of 23.4%. It has the 37<sup>th</sup> highest adult smoking rate among the 50 US states.
- > It is estimated that the annual health cost directly caused by smoking is \$3.1 billion, of which \$1B is paid by Medicaid.
- > State and local taxes account for 6.4% of Gross State Product (GSP), above the national average of 5.0%. MI is ranked 11<sup>th</sup> highest in total taxes relative to personal income.

**POLITICAL ENVIRONMENT**

- > Governor Granholm is a Democrat, but Republicans have majorities in both houses of the legislature. MI's current Governor inherited a state that many feel was reshaped by her conservative predecessor who served for 12 years. During his term, 31 tax cuts were enacted. Republican control of the Governor's office and both houses resulted in redistricting that has further strengthened Republican dominance in the state legislature.
- > People interviewed believe that term limits and redistricting have resulted in a more ideologically Conservative, and often less informed, legislature. Advocates report that it has become much harder for them to influence legislators. Term limits create a loss of historical knowledge, and key leadership positions are filled by inexperienced legislators. This is particularly problematic when complex health policy issues are being addressed. Term limits have also weakened an important coalition between Detroit legislators, who represent many people of color, and legislators from low-income rural areas with inadequate access and resources.

MI

Michigan *(Continued)*

## KEY ADVOCACY ISSUES

- > **Medicaid:** Proposals to generate savings in the FY2007 budget included higher co-pays and premiums and reductions in long-term care funding based. The House also proposed elimination of coverage of young adults, and of “caretaker relative” coverage. Provider rates have been cut, and physician participation in Medicaid has fallen 23% between 1998 and 2005.
- **Tax and revenue issues:** According to people interviewed, structural deficits in the state budget place enormous pressures on the Medicaid budget. Though the current administration is more committed to health care initiatives, severe budget constraints continue to threaten public health and benefits programs. The new state budget process introduced for FY2006 lumps together all expenditures (except K-12 education and capital spending for state facilities) into one Omnibus Bill, which makes it more difficult for health advocates to influence budget decisions. Despite a poll showing that residents favor a tax increase to close the Medicaid shortfall and keep prescription drugs available, legislators are loathe to raise taxes.
- **Resource and health disparities:** Rural areas and the Detroit/Wayne County area have severe service shortages. Resources have been leaving the Detroit/Wayne County area for more affluent parts of the region. Clinics and family doctors have left the Detroit area; there are only three health centers, with nine sites, in Detroit. Oakland County, the richest in MI, has the lowest White and highest Black infant mortality rates in the state (2002 data).

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“THERE IS A LACK OF MEDICAL HOMES FOR CHILDREN OF COLOR, MOST OF WHOM  
ARE ENROLLED IN MEDICAID; THEY HAVE COVERAGE BUT NO CARE.”

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## ADVOCACY CAPACITY

- > A variety of organizations, some focusing exclusively on health issues and others focusing on a range of human services and other social issues, play leading roles in consumer health advocacy. The state does not, however, have a single statewide, membership-based health advocacy organization focusing on the full range of health access issues, such as Medicaid and SCHIP reform and expansion, administrative advocacy, hospital charity care, children’s health, and other access issues.
- > Advocates credit the Michigan League for Human Services with providing leadership on policy-oriented advocacy. It has also taken the lead in addressing state revenue issues.
- > Staff from the Michigan Poverty Law Program and Michigan Legal Services provide important staffing for efforts around long-term care, Medicaid defense, and universal coverage. The Long Term Care Commission – with a broad range of consumer, provider, and policy representatives – is seen as an effective collaboration that is moving policy forward in this area.

Michigan *(Continued)*

- > The Service Employees International Union [SEIU] builds coalitions of the long-term care employees whom it represents, providers, and consumers in order to fund long-term care and promote care in community settings. SEIU makes use of up-to-date electronic systems to successfully mobilize members and supporters to educate elected officials on issues of concern, such as nursing home staffing, mandatory overtime, and patient safety.
- > MichUHCAN has made a concerted effort to build the “business case” for universal coverage and has gathered support for a set of principles related to universal coverage from business leaders, municipal governments, elected officials, and a range of organizations and individuals throughout the state. The organization has also been actively involved in the HRSA-funded planning process that is informing Governor Granholm’s proposals to cover MI’s uninsured.
- > Several organizations and coalitions address health care as part of their focus on children and family issues. Some groups are dedicated to particular constituencies such as children with special needs, the elderly, or people requiring mental health services. Though a few are well resourced, many are wholly volunteer efforts with minimal budgets or are dependent on staffing and other resources contributed by large organizations or agencies. Organizations representing seniors and people with disabilities have been most effective in mobilizing their members. Advocates note that there is strong constituent support for long-term care issues, but there is less active support for the majority of Medicaid recipients, who are children.
- > There are a number of congregation-based or community-based organizations – such as MOSES in Wayne County and the Michigan Organizing Project in western MI – whose members have identified health care as a key issue. Grassroots organizations have had positive results and some of their efforts are linked to state or regional initiatives. Increasing and strengthening grassroots organizing and bringing it together with policy advocates to forge effective, sustainable coalitions is seen as a priority.
- > The Detroit/Wayne County Health Authority is a relatively new entity that brings together elected officials, community-based agencies, business, and providers to harness resources for preventive, primary, and secondary care.
- > Many advocacy organizations are located in either in Wayne County or Lansing, with smaller representation in the rest of the state.
- > Advocacy on Medicaid and public benefit programs has been defensive for more than a decade. Continuing state fiscal constraints have made advocacy more difficult.
- > Organizations report that they are taking on more projects and issues but facing stagnant or declining budgets.

## FUNDING

- > It is difficult to obtain funding for advocacy-related work. Few state or local foundations fund policy, community organizing, or public policy advocacy.
- > Cuts in state funding have made it more difficult to get resources for advocacy, as funders are shifting their priorities toward filling the service delivery gap resulting from reduced public funding.

NM

New Mexico<sup>11</sup>

## HEADLINES

- > NM has one of the lowest per capita incomes in the nation combined with one of the highest tax rates relative to personal income. NM ranked 47<sup>th</sup> out of 50 states in per capita income – \$24,995 compared with \$31,472 nationally – and had the 5<sup>th</sup> highest state and local taxes as a percent of personal income.
- > Its Governor, Bill Richardson, is a Democrat who won the 2002 race by the largest margin since 1964. Democrats have majorities in both houses of the legislature.
- > Uninsurance among non-elderly residents fell 3.6 percentage points in NM from 2000 to 2004 while it rose 2.7% for the nation as a whole. This resulted from a combination of factors. Individually purchased insurance coverage increased and employer-sponsored insurance declined at a significantly lower rate than in the nation as a whole – a 1.1 percentage point decrease, compared with 4.8 points nationwide. In addition, the number of people covered through Medicaid increased more than the national average – 1.9 percentage points, compared with 1.5 points.
- > NM's health indicators generally are better than those in the nation as a whole. It has a higher infant mortality rate and asthma mortality rate among Whites. It has a higher prostate cancer mortality rate among Hispanics and a lower rate among Blacks. Its rate of HIV/AIDS is lower among all racial and ethnic groups, and significantly lower among Blacks and Hispanics, than the national average. Diabetes rates among Native Americans are especially high.

## KEY DATA

- > NM's population is approximately 1.9 million. Whites make up 43% of the population, well below the national rate of 68%. Blacks make up only 2% of the population, significantly lower than the national rate of 12%. But the Hispanic population is substantial – 45%, compared with 14% nationally. Native Americans account for 8.7% of the population compared with a national rate of 0.5%.
- > NM is approximately 75% urban and 25% rural.
- > NM's per capita income is one of the lowest in the nation, ranking 47<sup>th</sup> out of 50 states – \$24,995, compared with \$31,472 nationally.
- > NM's poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 23%, significantly higher than the national poverty rate of 17%. Thirteen percent of Whites live in poverty, compared with 12% nationally; 29% of Hispanics, compared with 29% nationally, live in poverty; and 29% of Blacks live in poverty, compared with 33% nationally. Thirty-seven percent of “others” live in poverty, almost double the national rate of 20%; most of these are Native Americans.

<sup>11</sup> The NM report utilizes additional data so as to reflect the state's substantial American Indian population. Those data sources include the Centers for Disease Control and the state's own website.

New Mexico *(Continued)*



> Health coverage status of the NM population, relative to the US population as a whole, is as follows:

Type of Coverage	NM	US
Private Insurance	46%	59%
Medicaid	18%	13%
Medicare	12%	12%
Uninsured	22%	16%

- > About 22% of NM residents – slightly more than 400,000 people – are uninsured, well above the national rate of 16%. Eleven percent of Whites are uninsured, compared with 13% nationally; 23% of Hispanics are uninsured, compared with 34% nationally. Twenty-eight percent of American Indians/Alaskan Natives are uninsured.
- > Uninsurance among residents fell 3.6 percentage points in NM from 2000 to 2004 while it rose 2.7% for the nation as a whole. This resulted from a combination of factors: employer-sponsored insurance declined at a rate of 1.1, a significantly lower rate than the 4.8 points nationwide; and NM’s Medicaid population increased more than the national average – 1.9 percentage points, compared with 1.5 points nationally.
- > NM has a 71% federal Medicaid matching rate, one of the highest in the US. It ranks 24<sup>th</sup> in spending state resources for Medicaid, and spending accounts for 0.80% of its GSP, which is below the national rate of 0.87%. The eligibility standard for all children is at 235% FPL. NM ranks 27<sup>th</sup> in parent eligibility for working parents at 69% FPL, and 40<sup>th</sup> for non-working parents at 30% FPL.
- > Dual eligibles account for 8% of Medicaid recipients (US, 14%) and account for 24% of Medicaid spending (US average is 40%).
- > Thirty-two of the 33 counties have federally designated “medically underserved” areas. About 56.3% of NM’s residents live in poor counties, which make up 29 of the state’s 33 counties. Twenty-seven of the poor counties have health centers, and two do not.



New Mexico *(Continued)*

> Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic	American Indian/ Alaskan Native
Infant mortality rate per 1,000 births	6.2	15.6	6.3	6.8
Prostate cancer mortality per 100,000	29.8	62.5	29.8	20.5
HIV/AIDS incidence per 100,000	5.9	17.3	8.0	9.1
Asthma mortality rate per 100,000	1.8	No data	No data	No data
Uninsured rate (non-elderly)	11%	No data	23%	28%

- > For free care, NM has a county-based system: the counties reimburse hospitals and other providers (including ambulances) for the care they provide to indigent patients. Hospitals are also responsible for implementing their own charity care policies and determining income eligibility levels independently. Free care is overseen by the County Board of Commissioners and the County Indigent Hospital and County Health Care Board.
- > NM ranked 20<sup>th</sup> in compliance with the CDC tobacco prevention standard, spending \$5M or 36.4% of the CDC’s recommended minimum standards. NM also has the 22<sup>nd</sup> highest tobacco tax rate. The annual health cost caused directly by smoking is estimated at \$425 million, of which \$170 million is covered by Medicaid. NM charges 91 cents per pack (ranked 22<sup>nd</sup> lowest out of 50).
- > Adult smoking rate in NM is 22% and ranked the 23<sup>rd</sup> lowest adult smoking rate among the 50 US states.
- > State and local taxes, about \$4.0 billion, account for 6.5% of Gross State Product (GSP), well above the national rate of 5.0%. NM ranks 5<sup>th</sup> highest in total taxes as a percent of personal income. This means that the state has a stronger revenue stream than would be expected given its low per capita income.

**POLITICAL ENVIRONMENT**

- > NM’s Governor, Bill Richardson, is a Democrat who won the 2002 race by the largest margin since 1964. Democrats have majorities in both houses of the legislature.
- > The Governor has said that health access improvement is a priority and has appointed a council to develop ideas. This creates potential for incremental change and represents a marked change from the previous “libertarian” administration, when health advocates had to focus on defensive advocacy.



## New Mexico *(Continued)*



- > Free care is implemented, funded, and overseen at the county level. This means that county-level advocacy can have a concrete impact on health care access for uninsured people.
- > Policymakers are generally accessible, but NM is a geographically large state where many areas are physically isolated from Albuquerque and Santa Fe. This makes statewide advocacy challenging.
- > There are large rural and frontier areas and very conservative rural pockets.
- > The legislative sessions are short and intense. People interviewed indicate that this can provide an advantage to industry lobbyists during the legislative decision-making process.

### KEY ADVOCACY ISSUES

- > **Medicaid:** There have been Medicaid policy changes that have hurt enrollment (22,000 recipients have left the rolls), including the governor's new six-month recertification requirement. There is recognition that full coverage will take a long time, but there could be forward movement through Medicaid expansion by eliminating the six-month recertification process, and moving to 100% of the poverty level for eligibility.
- > **Free care:** NM has a county-based free care system in which the counties reimburse hospitals and other providers, including ambulances, for the care they provide to indigent patients. Free care is overseen by the County Board of Commissioners and the County Indigent Hospital and County Health Care Board of each county. Hospitals are also responsible for implementing their own charity care policies and determining income eligibility independently.
- > **Hospital access:** Health access barriers at University Hospital in Albuquerque have received a great deal of attention. Key issues include requiring a 50% deposit from uninsured people, transparency in financial assistance, steep charges for uninsured care, and interpreter services. A broad-based community coalition has successfully worked to improve policies at the hospital and to begin a broader dialogue about health reform.
- > **Increasing access:** The governor has appointed a council to develop strategies to improve access. Diverse approaches have been mentioned, including tax credits, an expanded insurance pool, and stripping away mandates and utilizing catastrophic/deductible plans. This latter is a concern for access advocates who note that many mandates cover important preventive services and that the insurance department says that mandates don't cost much. Uninsurance is a serious and growing problem. Many people are forced to go without care, use emergency rooms, or seek care in Mexico. There is a significant lack of accessible specialty and tertiary care, with only a single tertiary care hospital in a state. This presents substantial geographic and transportation barriers.
- > **Universal health care:** There has been a campaign to push for universal health care modeled on a single-payer system. While this has fostered discussion, there is an emerging consensus that the campaign is not moving forward and does not provide a vehicle for reform.
- > **Access to care:** Rural access and poverty, which are often associated with transportation problems, are significant problems for American Indians and others living in rural areas. There is a need to address the health delivery system side. Broader coverage would be a significant help to many of the



NM

New Mexico *(Continued)*

underserved, and there is a need to address provider supply in rural areas, which may involve greater use of physician assistants. Urban American Indians face particular health access problems and cultural barriers in mainstream urban health delivery systems.

**ADVOCACY CAPACITY**

- > Medicaid defense has been an important focus for advocates. This advocacy work has been done in coalitions composed of children's organizations, disability organizations, grassroots organizations, and providers such as pediatricians. These include Health Action New Mexico, Human Needs Coordinating Council, Voices for Children, the Center for Law and Poverty, and others.
- > The Community Coalition for Health Care Access (CCHCA) is a very active and broad coalition that raised issues about requiring 50% deposits from uninsured residents, transparency in financial assistance, and language interpretation problems. The ensuing negotiations produced policy changes and ongoing collaboration on health policy. Although technically a local advocacy campaign, this effort has statewide impact and state policy implications because University Hospital is the publicly funded hospital in the state's major population center and the only tertiary facility in the entire state.
- > Health Action New Mexico is the fiscal agent and facilitator of the Health Care for All (HCFA) Campaign, a highly collaborative effort to build consensus on policy and political options for attaining universal coverage in New Mexico. The HCFA effort is intentionally *not* tied to a specific policy solution, and HCFA expects to build political strength through active organizing of the uninsured. Its goal is to craft and achieve a plan to provide universal coverage by 2009.
- > The New Mexico Health Security Campaign has been a lead advocate for a single-payer system that has engaged in public education, outreach, and legislative advocacy for the past seven years. Many people interviewed believe that this effort is becoming less relevant to consumer health advocacy in the state.
- > Advocacy organizations work with community-based organizations and faith-based groups, especially on Medicaid defense and CCHCA efforts. There had also been community engagement focused on advocacy related to the Blue Cross nonprofit conversion.
- > There is a significant level of grassroots local and county organizing, some of which engages on health care access advocacy but much of which does not.

**FUNDING**

- > The need for advocacy and organizing resources was mentioned consistently. Some local foundations that fund organizing have shifted from funding health and social services to funding economic development. There is some grant funding from a local community foundation. The state community foundation is perceived as placing more emphasis on its own programs, including community health outreach, than on work initiated and carried out by other organizations.

**New Mexico** *(Continued)*



- > Con Alma, created from the Blue Cross conversion, is the largest health foundation in the state. Advocates indicate that the bulk of its funds support services and that funding for advocacy is provided in smaller increments. The foundation staff has played a role in fostering greater collaboration among advocates, including its multiyear funding of Health Action New Mexico and the HCFA effort.
- > In general, advocacy and grassroots organizations report that they primarily receive project-specific and year-to-year funding that does not support institution building.

**HEADLINES**

- > OH’s per capita income is ranked 24<sup>th</sup> in the nation at \$30,129, close to the national average of \$31,472. In 2001, the state ranked 34<sup>th</sup> in state and local taxes per person, and 28<sup>th</sup> in total taxes as a percent of personal wealth.
- > OH’s Governor is Republican, and there are substantial Republican majorities in both houses of the legislature, continuing a historic trend of Republican control of all branches of state government. Administration and legislative support for limiting taxes is an obstacle to health reform proposals that increase government spending.
- > Employer-sponsored insurance coverage decreased less in OH than in the nation as a whole from 2000 to 2004, as did total private insurance coverage. Increase in Medicaid enrollment was higher than the national average. As a result, uninsurance rose in OH at about half the national rate.
- > OH’s health indicators generally are similar to those in the nation as a whole. It has a higher infant mortality rate among both Black and White mothers but a significantly lower HIV/AIDS among Blacks, Whites, and Hispanics than the nation as a whole.

**KEY DATA**

- > OH’s population is approximately 11.1 million. The White population is substantial—83%, compared with 67% nationally. Blacks make up 11.5% of the population, compared with the national average of 12%. Only 2% of the population is Hispanic, compared with 14% nationally.
- > OH is 77% urban and 23% rural.
- > OH’s per capita income is ranked 24<sup>th</sup> in the nation at \$30,129, close to the national average of \$31,472.
- > Despite a per capita income close to the national average, OH’s poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 15%, which is below the national rate of 17%. Thirty percent of the state’s Black population lives in poverty, compared with 33% nationally; 12% of its White population lives in poverty, compared with 12% nationally; and 29% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the OH population, relative to the US population as a whole, is as follows:

Type of Coverage	OH	US
Private Insurance	64%	59%
Medicaid	11%	13%
Medicare	12%	12%
Uninsured	12%	16%

Ohio *(Continued)*



- > About 12% of OH residents—over 1.3 million people—are uninsured, compared with a national rate of 16%. Eleven percent of Whites are uninsured, compared with 13% nationally; 18% of Blacks are uninsured, compared with 21% nationally; and 34% of Hispanics are uninsured, equal to the national average.
- > Employer-sponsored insurance coverage decreased less in OH than the nation as a whole from 2000 to 2004 – a 3.3 percentage point decline, compared with 4.8 points nationally – whereas the increase in Medicaid enrollment was higher than the national average – 2.1 percentage points, compared with 1.5 points. As a result, uninsurance rose in OH at about half the national rate – a 1.5 percentage point increase in OH, compared with 2.7 points for the nation as a whole.
- > OH has a Medicaid matching rate of nearly 60%. Medicaid spending accounts for 1% of its GSP, significantly higher than the national rate of 0.87%. It ranks 6<sup>th</sup> in spending state resources for Medicaid. The state ranks 6<sup>th</sup> in eligibility standards for infants and 7<sup>th</sup> for children under 19, both at 200% FPL. The state ranks 17<sup>th</sup> for working parents and 14<sup>th</sup> for non-working parents, both at 90% FPL.
- > Dual eligibles make up 11% of Medicaid recipients, close to the US average of 14%, but they account for 46% of Medicaid costs (US average is 40%).
- > Fifty-five of OH’s 88 counties have federally designated “medically underserved” areas, and 1.3 million people live in these counties. Only 5% of the population lives in the state’s 16 poor counties, of which 10 have health centers and six do not.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	6.4	15.5	7.6
Prostate cancer mortality per 100,000	28.8	79.2	No data
HIV/AIDS incidence per 100,000	4.0	27.5	20.7
Asthma mortality rate per 100,000	1.2	3.1	No data
Uninsured rate (non-elderly)	11%	18%	34%

- > All hospitals are required to provide medically necessary care for uninsured people with incomes at or below the FPL. Interviewees report that demand for free care has increased while reimbursement rates for managed care payers, Medicare, and Medicaid have declined.
- > OH spends about 76% of the recommended CDC tobacco prevention standard, 10<sup>th</sup> in the nation. The estimated annual direct health cost of smoking is \$4 billion, about \$1.3 billion of which is covered by Medicaid. OH has a tobacco tax of \$1.25 per pack, 13<sup>th</sup> in the nation. It has an adult smoking rate of 25.9%, ranked 47<sup>th</sup> (1 = low rates) in the US.
- > State and local taxes in OH, about \$22.5B, account for 5.4% of Gross State Product (GSP), are slightly above the national average of 5%. OH ranks 28<sup>th</sup> in total taxes as a percent of personal income.

OH

Ohio *(Continued)*

## POLITICAL ENVIRONMENT

- > OH's Governor is Republican and there are substantial Republican majorities in both houses of the legislature. Republicans have controlled the governor's office and both houses of the legislature since the mid-1990s.
- > Term limits have decreased institutional knowledge about key health issues and programs. Frequent turnover of legislators requires health advocates to ensure that new legislators become knowledgeable about health care issues. Advocates believe that legislators exhibit little interest in long-term solutions because of their short horizon in the legislature.

## KEY ADVOCACY ISSUES

- > **Medicaid:** Medicaid has been the defining issue for health advocates, who have focused extensively on increasing Medicaid eligibility and defending against proposed cuts in access. Now, advocates are looking for ways to blend Medicaid with employer and employee contributions.
- > **Taxpayer Expenditure Limitation Amendment:** The legislature recently enacted a cap on state spending (which can be overturned by a simple majority) after a proposed constitutional amendment to cap government spending was blocked.
- > **Health care costs:** The increasing cost of health care is being discussed by all sectors of the community. Businesses are questioning their continued ability to provide affordable coverage for their workers. As premiums increase, more workers are unable to enroll in employer-sponsored insurance.
- > **Local and county access:** There is increasing interest among advocates and stakeholders for exploring the development of local and county solutions for expansion of health care access. A number of advocates believe that it may be difficult to make significant policy change on the state level, and it may be up to local communities and counties to address access to care.
- > **Health reform:** Although there is great interest in developing a proactive reform agenda and some initial steps have been taken in that direction, advocates have had to focus primarily on program preservation.

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**"WE ARE BECOMING MORE AND MORE SOPHISTICATED IN OUR DEFENSIVE WORK, BUT THERE IS NOT LEADERSHIP FOR PUTTING OUT AN AGENDA FOR BIG HEALTH SYSTEM CHANGE."**

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## ADVOCACY CAPACITY

- > Multi-issue coalitions play a lead role in consumer health advocacy in OH. Memberships of these coalitions are multisectoral and multidisciplinary, involving providers and advocacy and service organizations.

Ohio *(Continued)*

OH

- > Two groups are working to achieve statewide policy solutions to inadequate health care access. The Single Payer Action Network (SPAN) is focusing on getting a single-payer ballot initiative on the ballot in 2007. The Coalition for Affordable Healthcare in Ohio (CAHO) organized by Universal Health Care Action Network Ohio (UHCAN Ohio) is a long-range effort dedicated to building a statewide process to develop a health care reform proposal that is expected to take five years or more to achieve.
- > Three coalitions have played important roles in state health policy debates. The Campaign to Protect Ohio's Future, Have a Heart Ohio, and Family Coverage Coalition have been instrumental in shaping the strategies and tactics of individual organizations that are part of their coalitions. The Campaign to Protect Ohio's Future advocates for adequate revenues to avoid cuts in basic services, from health care to local government. According one of the convening organizations of the Family Coverage Coalition, "We work in coalition with other organizations and provide leadership to the coalition—our work is based on the decisions of the coalition. State budget decisions don't get made at our organization; they get made at the coalition level." The Family Coverage Coalition works to preserve Medicaid coverage for working parents and other groups. Both coalitions have large broad-based membership including human service organizations, advocacy organizations, unions, and consumer groups.
- > Alliances with multi-issue organizations involved in human service and budget issues have played an important role in consumer health advocacy.

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**"A KEY MILESTONE OF THE FAMILY COVERAGE COALITION WAS OUR JOINING FORCES SUCCESSFULLY WITH A BROAD-BASED COALITION THAT ADDRESSED A WIDE RANGE OF HUMAN SERVICE ISSUES AS WELL AS REVENUE ISSUES IN THE 2003 BUDGET SESSION, WHICH ULTIMATELY RESULTED IN A SUCCESSFUL EFFORT TO PRESERVE MEDICAID ELIGIBILITY AT 100% OF POVERTY IN THE FACE OF THE GOVERNOR'S PROPOSAL TO ELIMINATE THE EXPANSION ENTIRELY. THAT SESSION WAS IN SOME WAYS THE HIGH WATER MARK OF OUR COLLECTIVE POWER; WE COULD NOT REPEAT THAT SUCCESS STORY IN THE 2005 SESSION."**

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- > In 2005, the leadership group that had been the backbone of health advocacy in OH convened to develop a long-term strategy for increasing health care access. Approximately 30 people representing 21 organizations participated in examining the political or policy changes needed to improve health care access. These included legal services organizations, health care providers, health advocacy organizations, children's advocacy organizations, and funders.
- > Many advocates value local grassroots organizing as a key to success in state health advocacy, but they noted it is a labor-intensive process. Interviewees indicate they often don't have the resources needed to support it over the long term. State advocacy organizations and coalitions rely primarily on local partners to mobilize their constituents to impact state policies. Those local organizations need to have ongoing support for their work in local communities; support is also needed to build and maintain connections between local organizing and state policy advocacy.

OH

Ohio *(Continued)*

- > A number of local organizations that have been working on hospital accountability issues to ensure that hospitals provide free and low-cost care for eligible patients have been successful in helping patients get access to care. They recognize, though, that hospital systems cannot care for all of the uninsured and underinsured people. As a result, they see a need for stronger allies in the broader health care reform debate. Interviewees believe that organizations working on local health access issues have been successful in increasing access to care for vulnerable communities because they have been able to mobilize community members. For example, the multi-issue organization BREAD, with policy advocacy and support from UHCAN Ohio, achieved a \$1.1 million commitment from the county to provide primary care through the federally qualified health center in Columbus.

## FUNDING

- > A number of advocates noted that lack of adequate financial resources hampers the ability of advocacy organizations to have a significant impact on health care access, and they spoke about the lack of funder support for advocacy and organizing in the state. As a result, they say, advocacy organizations move from project to project and often do not have the flexibility to move on emerging issues that general operating support would make possible.
- > Service providers indicated an interest in moving an advocacy agenda and empowering their clients to get their voices heard, but limited resources hampers their ability to be active in their health care access arena.

# Oregon



## HEADLINES

- > OR had been a national leader in Medicaid and health access state policy, establishing the Oregon Health Plan (OHP) with one of the first Medicaid waivers. Over time though, a strong anti-tax environment and budget shortfalls led to program and policy changes that have resulted in significant reductions in enrollment of low-income adults and large increases in uninsurance.
- > OR's uninsurance rate increased 6.8 percentage points from 2000 to 2004, more than double the national rate of 2.7 points. Private insurance coverage fell 5 points, the same as the national average. But Medicaid coverage in the state fell 2.3 points, compared with a 1.5 point national increase.
- > Tax and budget shortfall issues dominate the political environment. A tax package was passed that provided resources for OHP access, but voters rejected continuation of the taxes in a ballot initiative.

## KEY DATA

- > OR's population is approximately 3.5 million: 80% of the population is White, compared with 67% nationally; 2% is Black, compared with 12% nationally; and 11% is Hispanic, compared with 14% nationally.
- > OR is 79% urban and 21% rural.
- > OR has a per capita income of \$28,734, 34<sup>th</sup> in the nation, compared with \$31,472 nationally. Its poverty rate – i.e. those with incomes below 100% of the Federal Poverty Level (FPL) – is 16%, slightly below the national average of 17%. Twenty-four percent of the state's Black population lives in poverty, compared with 33% nationally; 13% of its White population lives in poverty, compared with 12% nationally; and 34% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the Oregon population, relative to the US population as a whole, is as follows:

Type of Coverage	OR	US
Private Insurance	59%	59%
Medicaid	11%	13%
Medicare	12%	12%
Uninsured	17%	16%

- > About 17% of OR residents – over 560,000 people – are uninsured, compared with a national rate of 16%. Sixteen percent of Whites are uninsured, compared with 13% nationally, and 41% of Hispanics lack insurance, well above the 34% national average. No data were available for the Black population.
- > OR has experienced a 4 percentage point decline in employer-sponsored insurance since 2004, compared with of 4.8 percentage point decline nationally. Coverage trends among the non-elderly



who have Medicaid coverage in OR decreased by 2.3 percentage points from 2000 to 2004, compared with a 1.5 point increase nationally. As a result of a slightly lower-than-average loss of employer-sponsored insurance and a large decrease in Medicaid coverage, uninsurance grew at a higher rate than the national average from 2000 to 2004, 6.8 percentage points, compared with a 2.7 point increase for the nation as a whole.

- > OR has a Medicaid matching rate of 61%. It ranks 14<sup>th</sup> in state resources spent on Medicaid. Medicaid spending in OR accounts for 0.91% of its GSP, slightly above the national rate of 0.87%.
- > Medicaid eligibility standards are as follows: children ages 0-1 are eligible for Medicaid up to 133% FPL (ranked 43<sup>rd</sup> in the US); children ages 1-6 are eligible up to 133% FPL (ranked 28<sup>th</sup> in the US); and children ages 6-19 are eligible up to 100% of FPL (ranked 31<sup>st</sup> in the US). OR ranks 17<sup>th</sup> in income eligibility standards for working parents and 14<sup>th</sup> for non-working parents, both at 100% of FPL.
- > Dual eligibles make up 11% of Medicaid recipients (US, 14%) but account for 36% of Medicaid costs, below the national average of 40%.
- > Thirty-one of OR's 36 counties have areas that are considered "medically underserved." Slightly less than 20% of the people live in the 18 counties that are considered poor counties; 10 of the poor counties do not have a health center.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	5.5	10.3	5.1
Prostate cancer mortality per 100,000	32.5	56.7	18.4
HIV/AIDS incidence per 100,000	7.5	30.6	11.7
Asthma mortality rate per 100,000	1.8	No data	No data
Uninsured rate (non-elderly)	16%	No data	41%

- > There are no statutory or regulatory provisions that address free care in OR.
- > OR has a smoking rate similar to the national average and ranks 38<sup>th</sup> in compliance with recommended CDC tobacco prevention standards. The annual health cost directly related to smoking is estimated at \$1 billion, of which \$264 is covered by Medicaid. The tobacco tax rate is \$1.18 per pack, ranking OR 13<sup>th</sup> out of 50 states. The adult smoking rate in OR is 20%, with a smoking rank of 13<sup>th</sup> in the US (1 = low).
- > Total taxes, about \$6.1 billion, account for 4.7% of Gross State Product (GSP), slightly below the national average of 5.0%. OR ranks 42<sup>nd</sup> in total taxes relative to personal income.
- > The combination of a lower-than-average per capita income (34<sup>th</sup> in the nation); and low tax revenues as a percent of personal income (30<sup>th</sup> in the nation) means that OR's public sector is greatly constrained by lack of revenue.

Oregon *(Continued)*



**POLITICAL ENVIRONMENT**

- > OR’s governor, Ted Kulongoski, is a Democrat. There is a Republican majority in the House, and the Senate is under Democratic leadership with membership evenly balanced between the two parties.
- > The general perception among the people interviewed is that there is a lack of political leadership on health care. Part-time legislators who meet every other year are less able to develop substantive leadership on health policy issues or develop coalitions among various interests. A reduction in professional legislative staff exacerbates this dilemma. As a result, many issues end up on initiative ballots.
- > A strong anti-tax movement shapes the political debate. A property tax limitation measure increased need for state funds to support public schools. Advocates had won passage of a tax package that provided resources to support OHP access, but the tax package was repealed by voters, resulting in major cuts in coverage.
- > Almost all health care bills were held up in the House, which refused to hold hearings on them. In the face of ongoing budget shortfalls, political debate is about what benefits to cut. Raising revenue is not part of the debate.
- > The Portland area has raised local taxes to support health access by strengthening primary care and safety net capacity, and some counties are trying to craft local solutions to health problems. But they cannot meet the growing need created by state policy changes. One person interviewed said that state policies on Medicaid and coverage are critical to the ability of local efforts to meet demand.

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“YOU JUST CAN’T ADD SAFETY NET CAPACITY TO MEET THE HUGE GROWTH IN DEMAND.”

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**KEY ADVOCACY ISSUES**

- > **Medicaid access:** People interviewed said that “Medicaid overrides everything” and referred to the “demise of the Oregon Health Plan.” OR spends more of its own state revenues relative to resources on Medicaid, ranking 14<sup>th</sup> in state spending, but the need for public coverage is greater given its lower-than-average per capita income and decreases in private insurance. There have been significant cuts in eligibility and benefits for non-categorically eligible adults, and enrollment has decreased from 100,000 to 25,000. Administrative barriers and co-pays limit OHP enrollment: 67,000 of 105,000 uninsured children are eligible but not enrolled. One-year continuous enrollment for children was recently reinstated.
- > **Use of Medicaid funds for Family Health Insurance Assistance Program (FIHAP):** Public Medicaid funds are allocated to purchase expensive individual coverage and subsidize small group coverage through private insurers. A good portion of the SCHIP allotment goes toward FIHAP, which covers more adults than children. Many of those interviewed believe that more people could be covered if funds were used for regular Medicaid and SCHIP coverage.

OR

Oregon *(Continued)*

- > **Safety net capacity:** There are no formal statutes or regulations governing free care in OR, and 31 of the 35 counties have medically underserved areas. A range of local and county advocacy efforts are focused on hospital charity care and expanding primary care and safety net systems. Safety net clinics in Portland are at capacity and take only walk-ins as new patients. At the same time, hospitals are undertaking significant capital expansions.
- > **Tax and revenue issues:** OR ranks 37<sup>th</sup> in the nation for both state and local taxes per capita and as a percent of personal income. Tax and budget shortfall issues are seen as dominating the political debate, and Medicaid coverage has been a major focus of cuts. People we interviewed talked about a “fundamental need to generate public support for state revenue and fair taxes in order to address health access and coverage.” Building public support is critical. Advocates were successful in winning a tax package to expand Medicaid coverage through the legislative process, but it was later overturned by a ballot initiative.

### ADVOCACY CAPACITY

- > The Oregon Health Action Campaign (OHAC) is recognized as the statewide consumer health advocacy organization. OHAC has a strong focus on Medicaid access as well as community benefits and charity care. It has a long history of work on expanding Medicaid, insurance reform, and nonprofit conversions. OHAC engages constituencies through a number of local organizing projects and through connections to grassroots organizations. It is a key support for information and strategy development and coordination.
- > Oregonians for Health Security (OHS), a relatively new advocacy project funded by organized labor, focuses on issues related to costs, particularly within the hospital and drug industries. OHS conducts door-to-door canvassing and has a major focus on electoral strategy.
- > Health care access is emerging as an important issue for a growing number of grassroots and community-based organizations. ACORN’s low and moderate income members are increasingly affected by health access issues such as Medicaid cuts, hospital charity care and medical debt, and lack of adequate primary care. There is a broad range of local and county advocacy, but it is largely not connected to state policy advocacy. Local provider and community coalitions focused on safety net issues see the critical connection between state policymaking and their own efforts.
- > Advocates identified expanding grassroots organizing capacity and building connections to state policy advocacy, expanding the base and leadership, stronger policy capacity, and acquiring more coalition support and infrastructure as priorities for improving their impact on policy outcomes. Increased grassroots organizing capacity will also require increased coalition capacity to connect local advocacy to statewide health policy advocacy.

**Oregon** *(Continued)*



**FUNDING**

- > Advocates who were interviewed noted that there was relatively little foundation support for public policy advocacy, including related health policy analysis. While there is some foundation support for public policy analysis in other issue areas, the use of national consulting firms for this work means that OR's own policy analysis infrastructure is not developed.
- > Project-based, short-term funding is the typical basis of foundation support, making it difficult for advocates to build organizational capacity and be strategic in their work.
- > A statewide community foundation reported that its board members are hearing more about health access issues in their communities.

CO

Colorado

## HEADLINES

- > CO has a higher-than-average rate of uninsured residents despite having the 7<sup>th</sup> highest per capita income in the nation. The state ranks only 43<sup>rd</sup> in the share of the state economy devoted to Medicaid. Only 8% of CO residents have Medicaid coverage, compared with the nationwide average of 13%. Bringing Medicaid spending up to the national average would have a significant impact on the state's high uninsurance rate.<sup>12</sup>
- > CO's political environment is dominated by tax limitation legislation (the so-called Taxpayers' Bill of Rights, or TABOR) passed in 1992 that restricts revenues and spending to population and inflation. State and local taxes are well below the national average – 3.5%, compared with 5% nationally. In 2004, CO ranked 49<sup>th</sup> out of 50 states in state and local taxes as a percent of personal income, and its per capita taxes are only \$50 per person higher than Mississippi's. Recognition that TABOR was harming the state's economy and infrastructure led to a successful 2005 ballot initiative that suspended the law for five years.
- > Advocates succeeded in passing a 2004 ballot initiative that raised tobacco taxes to expand Medicaid and CHIP+ eligibility and access to other health services despite a conservative political environment with strong anti-tax opposition.
- > The Governor, Bill Owens, is Republican. In 2004, Democrats gained control of the legislature for the first time in 44 years, with a one-vote majority in the Senate and a three-vote majority in the House.

## KEY DATA

- > CO has a population of 4.4 million. Its White population is slightly larger than the nation's as a whole (71%, compared with 67% nationally), its Black population is significantly smaller than the nation's as a whole (4%, compared with 12% nationally), and its Hispanic population is significantly larger than the nation's as a whole (21%, compared with 14% nationally).
- > CO is a largely urban state, with 84% of its population living in urban areas and 16% outside of metropolitan areas.
- > Its per capita income – \$34,561, compared with \$31,472 nationally – is the 7<sup>th</sup> highest in the nation. CO's poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 13%, while the poverty rate for the US as a whole is 17%. Sixteen percent of the state's Black population lives in poverty, compared with 33% nationally; 9% of its White population lives in poverty, compared with 12% nationally; and 27% of its Hispanic population lives in poverty, compared with 29% nationally.

<sup>12</sup> These and other data on Medicaid enrollment, state spending, and insurance do not take into account the effect of the Medicaid expansion enacted as a result of the 2005 ballot initiative that will raise eligibility for parents to 60% FPL.

Colorado *(Continued)*



> Health coverage status of the CO population, relative to the US population, is as follows:

Type of Coverage	CO	US
Private Insurance	64%	59%
Medicaid	8%	13%
Medicare	8%	12%
Uninsured	17%	16%

- > While CO has a higher-than-average employer-sponsored insurance rate, its overall uninsurance rate is above the national average because of its very low rate of Medicaid coverage. Seventeen percent of CO’s residents are uninsured—about 750,000 people. The national rate is 16%. Hispanics are 2.5 times more likely to be uninsured than Whites. About 14% of non-elderly Whites are uninsured, compared with 13% nationally, and 36% of Latinos are uninsured, compared with 34% for the nation as a whole.
- > CO has experienced a 6.4 percentage point decline in employer-sponsored insurance since 2004, compared with the US decrease of 4.8 points. From 2000 to 2004, Medicaid coverage among the non-elderly increased by 0.2, compared with the 1.5 increase in the US. As a result of a higher-than-average loss of employer-sponsored insurance and a smaller increase in Medicaid coverage, uninsurance grew at a faster rate than the national average from 2000-2004, a 3.6 percentage point increase, compared with a 2.7 point increase for the nation as a whole.
- > CO has a Medicaid matching rate of 50%. The state spends 0.57% of its GSP on Medicaid, substantially below the national rate of 0.87%. CO ranks 43<sup>rd</sup> in the amount of its own state resources for Medicaid.
- > CO’s investment in Medicaid is low compared with national standards. The eligibility threshold for working parents is only 39% FPL, and for non-working parents it is 32% FPL. The state ranks 37<sup>th</sup> for working parents and 41<sup>st</sup> for non-working parents.<sup>13</sup>
- > Medicaid eligibility standards are as follows: for children ages 0-1, it is 133% FPL (43<sup>rd</sup> in the US); for ages 1-6 it is 133% FPL (28<sup>th</sup> in the US); and for ages 6 and over it is 100% FPL (31<sup>st</sup> in the US). SCHIP expansion brought coverage for children up to 200% FPL.
- > Dual eligibles in CO account for 15% of Medicaid recipients (US, 14%) and account for 43% of Medicaid costs (US average is 40%).
- > Forty-seven of CO’s 63 counties have areas that are considered “medically underserved” by the federal government. Twenty-seven of the counties are considered poor, and 14 of those do not have a health center. About 9.1% of CO’s residents live in poor counties.

<sup>13</sup> See note above



Colorado *(Continued)*

- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	5.5	13.8	6.2
Prostate cancer mortality per 100,000	29.1	67.7	26.7
HIV/AIDS incidence per 100,000	8.0	40.1	11.7
Asthma mortality rate per 100,000	1.65	No data	2.9
Uninsured rate (non-elderly)	14.0	No data	36.0

- > For free care, Colorado’s Indigent Care Program provides partial reimbursement to participating providers for patients under 200% FPL<sup>14</sup>
- > CO ranks 34<sup>th</sup> in the nation for compliance with the Centers for Disease Control’s tobacco prevention standards. The annual health cost directly caused by smoking is estimated at \$1.2 billion, about \$300M of which is covered by Medicaid. The adult smoking rate for CO is 20.1% with an adult smoking rank of 6<sup>th</sup> in the US (1 = low). Tobacco tax rate is 84 cents a pack, and it is ranked the 24<sup>th</sup> highest in the US.
- > State and local taxes, about \$7.0B, equal 3.5% of the Gross State Product (GSP), significantly below the national average of 5%. CO is ranked 49<sup>th</sup> highest in the nation for total state and local taxes relative to personal income.

**POLITICAL ENVIRONMENT**

- > The Governor, Bill Owens, is Republican. In 2004, Democrats gained control of the legislature for the first time in 44 years, with a one-vote majority in the Senate and a three-vote majority in the House.
- > Tax revenues had been limited by the 1992 Taxpayers’ Bill of Rights (TABOR) legislation, but a successful 2005 ballot initiative suspended TABOR for five years. The initiative was supported by health care and other human services advocates. The suspension was also supported by the Governor and by the business community—many of whom had originally supported its adoption—because they believed that TABOR’s limits on state revenues threatened core government services and the state’s economy.
- > Medicaid is seen by many as a drain on the state budget; advocates have to be vigilant about efforts to cut coverage or change the program through a waiver process. Advocates see the importance of developing strategies to reduce Medicaid costs without reducing access to needed care.
- > Health care advocates have had a significant impact on policy outcomes in a very challenging political and economic environment. They must often build support for basic government services by citing economic impact rather than by promoting them as critical to meeting basic health needs.

<sup>14</sup> In 2006 the legislature voted to increase this to 250% FPL



Colorado *(Continued)*

## KEY ADVOCACY ISSUES

- > **Medicaid:** CO's investment in Medicaid relative to its available resources has been below the national average, although the situation is improving somewhat. Its very low eligibility standards for working and non-working parents are a serious problem that limits access. Medicaid is often seen as a drain on the state budget, making it a potential target for cuts in coverage or changes in the program through a waiver. In 2005, health advocates were able to prevent a Health Insurance Flexibility Act (HIFA) waiver that would have created a pared-down CHIP-like program for children and adults. A bill that would have facilitated the waiver was introduced in the 2006 legislative session, but it ultimately died because it would have had a negative budget impact. Many advocates feel that rising Medicaid costs need to be addressed, but that this should be done by looking for efficiencies rather than cutbacks in benefits and eligibility. They also note, however, that Medicaid costs are no greater than other health care costs, and the reason Medicaid is taking a bigger piece of the state budget is because of TABOR.
- > **Free care:** The Colorado for Health Care initiative of the Service Employees International Union (SEIU) is spearheading a hospital transparency project to ensure that hospitals are seeing their "fair share" of uninsured poorer patients. It is also addressing issues surrounding the number of Denver hospitals that are relocating out of the city, which puts additional stress on safety net capacity. Early research shows that Denver hospitals are showing profit margins that are significantly higher than the national average. The Colorado Consumer Health Initiative (CCHI) compiled data on the level of charity care provided by local hospitals. In 2004, uninsured patients, who are charged full retail cost, were charged four to five times what hospitals charge health plans, and up to 10 times what the federal government pays for the same care. There is some sentiment that hospitals should give uninsured patients the same discounts they give health plans. Several large hospitals that provide a significant share of safety net care have either placed a cap on the care they will provide to the uninsured or are considering doing so.
- > **Private insurance:** CCHI works to reduce the number of uninsured by expanding coverage in both private and public insurance. The coalition believes that you cannot effectively impact access in either sector without working on both. The goal is to make affordable insurance that provides adequate benefits available to more people. Because large numbers of uninsured are workers in small businesses, there is a focus on improving small group insurance. Key private insurance issues include community rating, elimination of balance billing, mandates that ensure consumer protections, network capacity, affordability for small businesses and the self-employed (as a business group of one), and guaranteed enrollment regardless of health status, age, or gender for health plans sold to small employers.
- > **Tax and revenue issues:** Tax and revenue issues are central to the ability of advocates to protect and improve health care access. State and local taxes are among the lowest in the country relative to personal wealth. Budget constraints are a serious barrier to expanding health care access, and they create pressures to cut Medicaid eligibility and benefits. As described above, advocates played an important role in a successful 2005 ballot initiative to suspend TABOR for five years, preserving about \$365 million of state revenue annually. While the revenues will be used for infrastructure improvement rather than health care, they will reduce pressures to cut Medicaid. Advocates were successful in increasing Medicaid and other health care access by raising the tobacco tax in 2004, which is not subject to TABOR limits.



- > **Immigrants' rights to access:** Immigrants' rights to access health care and other government services has become an important issue in the legislature and through the ballot. In 2003, the state legislature passed a bill that terminated Medicaid eligibility for many *legal* immigrants. Litigation delayed implementation, however, and the law never went into effect. In 2005, the legislature passed a bill that restores eligibility for several categories of legal immigrants—people who are qualified for SSI, who were in the US prior to August 1996, who are no longer subject to the five-year federal ban on receiving services, or who need prenatal care. The bill, however, also requires the state to recover costs of medical care from immigrants' sponsors, which will deter eligible immigrants from seeking care. Advocates are preparing to oppose a ballot initiative that would deny undocumented immigrants access to any public services and would allow anyone to sue an institution for providing such services.

### ADVOCACY CAPACITY

- > The CO health advocacy community includes a range of health care and multi-issue organizations that work collaboratively in broad coalitions to address health access and revenue issues. In combination, they are able to mobilize strong grassroots organizing, state policy advocacy, policy analysis and research, and coalition-building capacities to affect policy outcomes. Health and multi-issue organizations work collaboratively on multiple issues including health care access, tax and revenue policies, and access for immigrants to health care and other public services. Key organizations include the Colorado Consumer Health Initiative, Colorado Progressive Coalition, SEIU's Colorado for Health Care project, and the Colorado Center on Law and Policy.
- > Several things have led to a significant increase in advocacy capacity and impact in a very short period of time: (1) creation of several key organizations that have played increasingly effective roles in health advocacy over the past 10 years, (2) increased funding, and (3) more strategic funding support for advocacy. The successful 2004 campaign to raise the tobacco tax and expand Medicaid and other health care access programs served as a galvanizing event that brought people and organizations together and provided an impetus for a more proactive advocacy agenda.
- > There is a high level of collaboration between many different kinds of organizations. Examples include: the collaboration between grassroots community-based organizations and state policy advocacy organizations; and the collaboration between the advocacy community and funders. Organizations jointly apply for grant funding together, share funding leads, strategize on campaigns, and often pool resources in coordinated campaigns. In the charity care transparency project for example, five organizations co-funded a study that was important to the campaign.
- > Many grassroots and community-based organizations that serve low-income communities and communities of color are working on local health care issues such as access to free hospital care, and curbs on certain hospital billing practices. There are explicit efforts to build bridges between these organizations and state policy advocacy in order to build a base for policy change and to ensure that policy solutions are relevant.

## Colorado *(Continued)*




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**“HEALTH CARE IS COMING UP AS A TOP PRIORITY FOR COMMUNITY ORGANIZING GROUPS. THEIR CONSTITUENCIES ARE SAYING THAT HEALTH CARE IS VERY IMPORTANT. THE TIMING IS RIGHT FOR FIGURING OUT BRIDGES BETWEEN POLICY ADVOCATES AND COMMUNITY ORGANIZING GROUPS.”**

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- > CCHI, a statewide coalition begun only six years ago, plays a role in enabling people and organizations to come together and work strategically. The coalition, which operates by consensus, works on improving coverage through both private and public insurance. It uses relationships with employers (developed through work on improving private insurance) to talk about the importance of protecting and expanding Medicaid. The political environment has taught CCHI the importance of strategic partnerships and the importance of new messages that address the value of health care and how it affects the economy.
- > The Colorado Center on Law and Policy and the Colorado Health Institute provide research, policy analysis, and information on Medicaid, CHIP, and health insurance status.
- > The Colorado Progressive Coalition (CPC), a multi-issue coalition formed in 1996, engages in community organizing through door-to-door canvassing, community events, and skill-building clinics. It played an important role in the campaign to suspend the TABOR revenue limits by building a field operation and engaging people at the grassroots level. CPC works on four broad issues: quality health care for all, tax fairness, voter registration and education, and racial justice and civil rights. Its health care advocacy focuses on expanding access, reducing prescription drug costs, and reducing health disparities.
- > SEIU’s Colorado for Health Care project has a sophisticated voter identification project and is building a list of voters concerned about health care. It provides organizing capacity on issues of hospital accountability and transparency.

### FUNDING

- > The Rose Foundation, a community foundation, and Colorado Health Foundation (previously HealthOne Foundation), a conversion foundation, are the primary funders of consumer health advocacy in Colorado. The Colorado Health Foundation recently underwent a major change in direction, and it has significantly increased its level of support for advocacy.
- > Both foundations take a strategic approach to funding that focuses on ensuring that the necessary capacities are in place and that there is a high level of collaboration and coordination. Funders were key in the development of the CCHI, which plays an important role as a lead statewide health advocacy coalition organization, and the Colorado Health Institute, which provides policy analysis and research capacity. Funding strategies support collaboration between the two organizations, which work closely together in coalitions, on ad hoc committees, and on joint project work. Funders also support the Colorado Center on Law and Public Policy, which provides legal advocacy, policy analysis, and research. Funding is focused on supporting effective state advocacy capacity and building a collaborative infrastructure.

CO

Colorado *(Continued)*

- > Funders provide explicit support for long-term capacity building, leadership development, coalition building, and collaboration. In some cases, funders support both grassroots (or community-based) organizations and state policy advocacy organizations, as well as collaborative planning and issue campaigns between the two. One foundation has hired a grants officer with experience in both grassroots organizing and public policy advocacy in order to link policy advocacy with grassroots involvement.
- > The board of one foundation is working to take advantage of emerging political opportunities such as the upcoming gubernatorial election to move consumer health advocacy forward. It is considering doing polling about how the public feels about health care issues going into the election, and developing strategies to get candidates to take positions on health care.

## Connecticut

CT

## HEADLINES

- > CT has the highest per capita income in the nation. Total state and local taxes account for a higher percentage of state gross wealth than the national average. This means that CT has a very strong tax base. Despite its very high per capita income, there is significant stratification of income and there are a number of poor towns. Hartford, for example, has the 2<sup>nd</sup> highest child poverty rate in the country.
- > CT enjoys a substantially higher rate of employer-sponsored insurance and only slightly lower Medicaid coverage, resulting in a significantly lower percentage of uninsured residents than in the nation as a whole.
- > Despite a low rate of Medicaid enrollment and high per capita income, CT's state spending for Medicaid relative to gross state product is more than double the national average, and it ranks 9<sup>th</sup> highest in the nation for use of state dollars for Medicaid. CT also has the highest spending on dual eligibles in the US.
- > Despite exceeding the national average for almost all indicators, there are significant racial and ethnic disparities: Blacks and Hispanics are three times more likely to be poor than Whites, and twice as likely to be uninsured. The infant mortality rate of Blacks is almost triple that of Whites, and the incidence of HIV/AIDS is more than six times higher for Blacks and more than nine times higher for Hispanics.
- > Health access problems appear to be geographically localized in towns and communities with lower incomes and larger numbers of people of color. There is a perception that these areas have a limited political voice in health care policy debates.

## KEY DATA

- > CT's population is approximately 2.8 million. The White population is substantial—77%, compared with 67% nationally. Both the Black population—9%, compared with 12% nationally—and the Hispanic population—10%, compared with 14% nationally—are slightly below the national average.
- > CT is 88% urban and only 8% rural.
- > Its per capita income is the highest in the US at \$42,972, compared with \$31,472 nationally.
- > CT's poverty rate – (i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 13%, while the poverty rate for the US as a whole is 17%. Twenty-six percent of the state's Black population lives in poverty, compared with 33% nationally; 8% of its White population lives in poverty, compared with 12% nationally; and 36% of its Hispanic population lives in poverty, compared with 29% nationally.

> Health coverage status of the CT population is as follows:

Type of Coverage	CT	US
Private Insurance	64%	59%
Medicaid	11%	13%
Medicare	13%	12%
Uninsured	11%	16%

> About 11% of CT residents—almost 340,000 people—are uninsured, compared with a national rate of 16%. The uninsurance rate for Hispanics is 24%, compared with 34% nationally; 11% of Whites are uninsured, compared with 13% nationally, and no data were available for Blacks.

> Employer-sponsored insurance fell 6.6 percentage points between 2000 and 2004, well above the national rate of 4.8 points. But Medicaid coverage increased at more than double the national rate—3.6 percentage points, compared with 1.5 points. Despite its higher-than-average loss of private insurance, CT’s uninsurance rate grew at a lower rate than that of the nation as a whole, 2.0, compared with 2.7 percentage points.

> CT has a Medicaid matching rate of 50%. State Medicaid spending accounts for 1.82% of its GSP, more than double the national average rate of 0.87%. CT spends more of its own resources on Medicaid than any other state in the nation.

> Medicaid eligibility standards are as follows: for children it’s 185% FPL; for working parents it is 157% (8<sup>th</sup> highest in the country); and for non-working parents it is 150% FPL (also 8<sup>th</sup> nationally). CT’s SCHIP program covers children up to 300% FPL.

> Dual eligibles account for 17% of Medicaid recipients (US, 14%) but account for 62% of Medicaid costs, the highest in the nation (US average is 40%).

> All of CT’s eight counties have areas designated as “medically underserved” by the federal government.

> Differences in health status, health outcomes and insurance status by race/ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	5.4	14.2	7.1
Prostate cancer mortality per 100,000	27.3	66.3	23.7
AID/HIV incidence per 100,000	11.4	71.8	107.8
Asthma mortality rate per 100,000	1.1	3.3	No data
Uninsured rate (non-elderly)	11%	No data	24%

## Connecticut *(Continued)*

CT

- > CT's free care requirement states that any person whose income is below 200% of the FPL and who has applied for and been denied health coverage under Medicaid or any other public program is eligible for free care. All hospitals must annually file their policies regarding free or reduced-cost care and debt collection with the state, as well as undergoing an independent audit of the amount of uncompensated care they provide.
- > CT ranks 45<sup>th</sup> in the nation for CDC standards for tobacco control spending. The annual health cost directly related to smoking accounts for \$1.5 billion, \$396 million of which is covered by Medicaid. CT's adult smoking rate is 18.1%, with an adult smoking rank of 5<sup>th</sup> in the US (1 = low). CT has the 8<sup>th</sup> highest tobacco tax, \$1.51 a pack.
- > Total state and local taxes account for 5.5% of the Gross State Product (GSP), which is above the national average of 5.0%. The state ranks 23<sup>rd</sup> in total taxes relative to personal income. The combination of having the highest per capita income in the nation and a roughly average tax rate means that CT government has a relatively strong revenue stream.

### POLITICAL ENVIRONMENT

- > CT's state government is divided between the two parties. The Governor is Republican, but the majority of legislators are Democrats.
- > Trust of public officials is low since the resignation of Governor Rowland in 2004, which resulted from state and federal corruption charges and subsequent investigations into the ethics of a number of state legislators. Indications of possible scandals attract media headlines.
- > Media coverage of health care issues is limited, particularly on issues within the state's jurisdiction. Ethical scandals and base closings, which play a key role in regional economies, have dominated the news.
- > Even though the insurance industry no longer dominates CT, the state still sees itself as the insurance capital of the world. The industry's continued political power plus the fear of more insurance companies leaving the state make the legislature reluctant to pass any legislation that would hurt the industry. The message that jobs must be preserved gives the pharmaceutical industry, which has a presence in the state, a similar degree of political power.
- > Advocates report that there are no clear legislative leaders on health care. Health care issues do not funnel through one single committee or legislator, and no legislator is seen as a "go-to person" on health access issues. Some advocates cite the need for campaign finance reform to effect significant change.
- > CT's urban and low-income communities, where uninsurance and underinsurance are primarily found, are to a large extent disenfranchised in state health care and other policy decisions. One interviewee indicated that increasing voter turnout in key urban and low-income areas has the potential to improve the political voice of these communities and strengthen demand for increased health access.

CT

Connecticut *(Continued)*

## KEY ADVOCACY ISSUES

- > **Medicaid:** Protection and expansion of Medicaid is identified by advocates as the most consistently important health care issue. Although CT has the highest per capita income, high private insurance coverage, and a lower-than-average poverty rate, the state's Medicaid coverage rate is slightly below the national average—11%, compared with 13% nationally. Medicaid participation of African Americans is slightly below the national average, but participation of Hispanics is well above the nation as a whole—30%, compared with 22%. Dual eligibles account for 60% of Medicaid costs, significantly above the national average even though there are only slight differences in the percentage of Medicaid recipients who are dual eligibles. CT ranks 2<sup>nd</sup> in the nation for long-term care spending but 50<sup>th</sup> in acute care services and 49<sup>th</sup> for prescription drug spending.
  - Advocates have been working for transparency in Medicaid-managed care spending, because \$625 million of Medicaid money was being spent without a publicly available contract. Advocates have applied for access to the contract through the Freedom of Information Act.
  - Connecticut was one of the first states to draft legislation to protect drug benefits for people eligible for both Medicare and Medicaid and the State Pharmacy Assistance Plan, serving as a model for other states. Advocates have been working with the legislature to protect dual eligibles and enrollees in the state's senior pharmacy program, and they were working to protect these enrollees during the transition to Medicare Part D.
  - Advocates were focusing on preventing increases in SCHIP premiums, reducing cost sharing for parents, opposing more frequent redetermination requirements, and protecting the state's federal Medicaid waiver.
  - Restoration and retention of Medicaid benefits for legal resident immigrants is an issue that has received advocates' attention. Immigrants whose benefits are not federally reimbursable were cut from the Medicaid program during the last economic downturn. Since then, there has been an annual struggle to restore or maintain benefits for this population during each budget cycle.
  - Advocates are also working to maintain and restore health benefits for economically needy childless adults in the state-administered and financed General Assistance program, another population that saw cuts during the last economic downturn.
- > **Hospital billing and collection practices:** In 2002, the Connecticut Center for a New Economy, a research arm of SEIU, conducted an investigation of Yale New Haven Hospital's billing and collection practices. The study found that the hospital had, at one time or another, held a lien on 75% of all the homes in New Haven. The hospital used wage garnishment, very high interest rates, and even home foreclosures as a means of collecting debts. A Freedom of Information request uncovered the hospital's misuse of free-bed funds and a routine failure to notify self-pay patients of the availability of free care. The partnership of legal, legislative, and grassroots advocates around the billing and collection practices of Yale New Haven Hospital led to the enactment of state legislation requiring fairer billing and collection practices.

## Connecticut *(Continued)*

CT

- > **Universal coverage:** Almost all of the people interviewed mentioned the need for universal coverage as a key policy change for improving access to care. Achieving universal coverage by 2007 has become the goal of a broad coalition. Advocates of universal coverage are no longer focused on creation of a single-payer system and are instead taking an incremental approach to universal coverage through multiple changes that expand public and private coverage.
- > **Racial and ethnic disparities:** The state has a very high per capita income and an overall low uninsurance rate, but it also has pockets of extreme poverty combined with high uninsurance rates among people of color. Yet advocates said surprisingly little about health disparities and, despite the fact that nearly 25% of the population is non-White, one interviewee even said, “There are very few minorities in Connecticut.” This may reflect the fact that people of color are to a large extent geographically concentrated.

### ADVOCACY CAPACITY

- > Educating the public to build broad public support for universal comprehensive health coverage is seen widely as a priority for advocacy.
- > Advocates emphasize the importance and efficacy of turning people out in large numbers to show grassroots support for an issue. All of the advocates interviewed highlighted the effectiveness of this strategy, and they noted that even think tanks and policy groups are moving to adopt a more grassroots approach. They report, however, that grassroots organizing is a costly and labor-intensive process and that there is limited funding available. Despite the widely acknowledged importance of grassroots organizing, interviewees indicated a greater emphasis on think tank and policy work because that is what funders are willing to support. There appears to be a lack of connection between local grassroots organizing, which is largely related to free care and billing issues, and state policy advocacy for expansion of access.
- > Three kinds of organizations are involved in health advocacy: multi-issue organizations that combine direct service, advocacy, and organizing; organizations whose primary work is grassroots organizing on a range of issues; and organizations that combine policy and advocacy, some of which focus solely on health care issues.
- > The Health Care for All coalition, a project of the Connecticut Citizen Action Group (CCAG), has organized a coalition of 40 organizations to come together to advocate for health care access. Their goal is achieving universal coverage by 2007.
- > Six of the nine organizations interviewed were 19 years or older, and three of them are devoted exclusively to health care.



CT

Connecticut *(Continued)***FUNDING**

- > The perception of many advocates is that funders are more willing to support think tank and policy work than grassroots organizing or capacity building.
- > There are two conversion foundations in the state, the Universal Health Care Foundation of Connecticut, and the Connecticut Health Foundation. They both fund a range of work including advocacy. The Universal Health Care Foundation is playing a major role in policy development related to its mission of achieving universal access to health care within the state.
- > Community foundations are perceived by advocates and funders as being overly cautious about supporting advocacy.

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**“ALL TOO OFTEN ADVOCACY IS ASSOCIATED WITH PEOPLE DOING EXTREME THINGS.  
WE NEED TO EQUATE ADVOCACY WITH MOTHERHOOD AND APPLE PIE.”**

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Illinois



HEADLINES

- > Health coverage expansion and universal access have become key political issues in IL. Concerns about these issues have contributed to a shift to a Democratic state Senate and a larger Democratic margin in the House, election of the first Democratic Governor in 26 years, and election of Barack Obama to the US Senate in 2004. These shifts, in turn, have fueled significant coverage gains and an energized exploration of universal coverage.
- > IL advocates have a strong sense of opportunity at the present time. They successfully promoted the All Kids program through which IL will offer subsidized coverage for all children regardless of income or immigration status. They also were successful in promoting an extension of coverage to an estimated 400,000 additional adults by raising the eligibility standard for low-income parents from 39% FPL to 185%, despite a state fiscal crisis.
- > Many of IL's health indicators are worse than those in the nation as a whole. It has a higher infant mortality rate among Black and White mothers, a higher prostate cancer mortality rate among Black and White men, and a higher asthma mortality rate for Blacks, Whites, and Hispanics. On the positive side, the prostate cancer mortality rate among Hispanic men is lower, and the rate of HIV/AIDS is lower for all racial and ethnic populations.

KEY DATA

- > IL's population is approximately 12.6 million, with a racial and ethnic makeup similar to that of the nation as a whole. Sixty-eight percent of the population is White, compared with 67% nationally. The Black population is substantial – 15%, compared with 12% nationally. The Hispanic population is below the national average – 12%, compared with 14% nationally.
- > IL is a largely urban state, with 88% of its population living in urban areas and 12% living outside of metropolitan areas.
- > IL's per capita income is 14<sup>th</sup> in the nation, \$32,965, compared with \$31,472 nationally.
- > IL's poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 18%, compared with 17% nationally. Thirty-nine percent of the state's Black population lives in poverty, compared with 33% nationally; 12% of its White population lives in poverty, compared with 12% nationally; and 24% of its Hispanic population lives in poverty, compared with 29% nationally.
- > Health coverage status of the IL population, relative to the US population as a whole, is as follows:

Type of Coverage	IL	US
Private Insurance	63%	59%
Medicaid	9%	13%
Medicare	12%	12%
Uninsured	14%	16%



Illinois (Continued)

- > About 14% of IL residents – almost 1.8 million people – are uninsured, compared with a national rate of 16%. Eleven percent of Whites are uninsured, compared with 13% nationally; 24% of Blacks are uninsured, compared with 21% nationally; and 30% of Hispanics are uninsured, compared with 34% nationally.
- > Employer-sponsored insurance declined at a much lower rate than for the nation as a whole from 2000 to 2004 – a 1.8% decrease, compared with a 4.8% decline nationwide. Medicaid coverage increased at a slightly higher rate than the national average – 1.7%, compared with 1.5%. As a result, uninsurance among residents was virtually unchanged in IL while it rose 2.7% for the nation as a whole.
- > IL has a Medicaid matching rate of 50%. The state ranks 12<sup>th</sup> in spending its own state resources on Medicaid. The state spends 0.95% of its GSP on Medicaid, substantially above the national rate of 0.87%.
- > Medicaid eligibility standards are as follows: for infants under age 1 it is 200% FPL; for children ages 1-19, it is 133% FPL. SCHIP expansion brought coverage for children up to 200% FPL. Eligibility standards for parents are well above national averages: IL is 12<sup>th</sup> in the nation for working parents at 140% FPL, and 12<sup>th</sup> in the nation for non-working parents at 133% FPL.
- > Dual eligibles in IL account for 10% of Medicaid recipients (US, 14%) but account for 28% of Medicaid costs (US average is 40%).
- > Less than 3% of the state’s residents live in poor counties, which make up 19 of the 102 counties in IL. Among the 19 poor counties, 12 have a health center and 7 do not. Eighty-one of the state’s 102 counties have federally designated “medically underserved” areas, including Cook County, where a large portion of the population lives.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Percent of population	68%	15%	13%
Infant mortality rate per 1,000 births	6.0	15.5	No data
Prostate cancer mortality per 100,000	30.3	69.7	17.1
HIV/AIDS incidence per 100,000	7.4	60.8	21.4
Asthma mortality rate per 100,000	1.3	6.1	1.7
Uninsured rate (non-elderly)	11%	24%	30%

- > There is no explicit policy for the provision of hospital “free care” or “charity care,” in statute or regulations. The availability of assistance depends on each facility’s policy.
- > IL ranks 37<sup>th</sup> in the country for compliance with CDC’s tobacco prevention standards, spending only 16.9% of CDC’s recommended minimum. The annual health cost directly related to smoking is estimated at \$3.1 billion, \$1 billion of which is paid by Medicaid. IL has an adult smoking rate of 22.2% and an adult smoking rank of 33<sup>rd</sup> in the US (1 = low). Its tobacco tax of 98 cents per pack is the 19<sup>th</sup> highest in the nation.

## Illinois *(Continued)*



- > State and local taxes, about \$25.5 billion, account for 4.8% of the IL Gross State Product (GSP), slightly below the national average of 5.0%. In 2001, IL ranked 36<sup>th</sup> in total taxes relative to personal income.

### POLITICAL ENVIRONMENT

- > Health advocates made health care access a major issue during the state elections in 2002, and they believe that health coverage issues played a role in transforming the Senate to a Democratic majority and the election of the first Democratic governor in 26 years. Governor Rod R. Blagojevich has made expanding health care access a high priority of his administration.
- > Former State Senator Barack Obama was the chief sponsor of the Health Care Justice Act, an accomplishment that was highlighted in his US Senate Campaign.

### KEY ADVOCACY ISSUES

- > **Medicaid and SCHIP:** Coverage expansions for children, parents, and immigrants have been key concerns. There has also been significant concern that covered children are not receiving all of the screenings and services to which they are entitled under Medicaid.
- > **Private insurance coverage:** Small businesses, which employ many low-wage workers, and the self-employed have difficulty obtaining coverage because their premiums are significantly higher than those for large employers.
- > **Free care and hospital billing practices:** Hospital charges for uninsured patients are significantly higher than charges for patients covered by large insurers. High uninsurance rates are a particular problem for young adults and Hispanics. Hospital billing and collection practices are a key advocacy issue at the local level.
- > **Service delivery capacity:** There is a lack of access to primary and specialty care for people without coverage as well as for people covered by public programs, especially in Cook County and rural areas of the state. There are also relatively poor programs and services for uninsured and underinsured children with special health care needs. In some rural areas people have to drive three hours or more for medical visits. In some areas, there are very few, if any, providers who treat Medicaid patients.
- > **Tax and budget issues:** IL has what is characterized as an archaic tax system that relies on sales tax and a low (3%) flat income tax rate. This limits the growth of public revenues even when there is economic growth.
- > **Prescription drug costs:** Seniors and other advocates led successful efforts to establish a series of state-subsidized prescription drug programs. Most recently, IL developed wraparound programs to close the gaps in Medicare Part D.

- > **Universal coverage:** IL has achieved significant expansion of coverage for parents and universal coverage for children. Even when these Medicaid changes are fully in effect, however, large numbers of people will still be uninsured, including adults without dependents, working families above Medicaid eligibility levels who cannot access employer-sponsored insurance, and both legal and undocumented immigrants. Affordable comprehensive health care for all IL residents is a universal priority for health advocates. They are pursuing this goal through expansion of Medicaid and other public coverage, expansion of access to affordable private insurance, and expansion of service delivery capacity in medically underserved areas of the state. In addition, a statewide effort—mandated by legislation passed in 2004—is underway to develop a plan for universal coverage.

### ADVOCACY CAPACITY

- > Broad-based coalitions that bring together a wide range of state health policy advocacy organizations, grassroots and faith-based organizations, citizens' organizations, unions, and providers are the driving force for health advocacy in IL. Multiple coalitions, with some overlapping membership, have played major roles in advocacy on a broad range of issues, including: expansion of Medicaid access for children and parents; creation of a process to develop options for providing coverage to all state residents; making affordable private insurance more accessible for small business employees and the self-employed; and changing hospital free care and billing practices at the local level.
- > There is a strong culture of advocacy and organizing in IL, with a solid base and infrastructure. For example, senior organizations have the capacity to mobilize members. One statewide senior organization has almost 180,000 members, most of them union retirees, who are organized into clubs throughout the state. A statewide immigrant coalition has a strong community-organizing approach. After frustrating efforts to enact prescription drug programs, a coalition of citizens' groups, unions, and others held lobby days attended by well over 1,000 people and "closed down the Senate." They also made the drug program a key issue in the 2002 election, which they believe played a role in changing the state's political climate.
- > A unique collaborative partnership between the Sargeant Shriver National Poverty Law Center and United Power, a metropolitan-wide faith-based community organizing group, helped produce the successful proactive advocacy on Medicaid expansion that has led to universal coverage for children and significant expansion of coverage for parents. Their partnership made it possible to coordinate grassroots organizing, policy analysis and research, statewide advocacy strategy, and media and communications strategies into a coherent campaign for policy change.
- > The Health Justice Campaign is pressing to make progress toward accessible, affordable, quality health care for all IL residents. The Health Justice Campaign has been endorsed by over 100 organizations, largely through the efforts of the Campaign for Better Health Care—a 17-year-old grassroots coalition of more than 300 local and statewide organizations representing consumers, health care workers, providers, community organizations, seniors, and religious, labor, and disability rights organizations. Having succeeded in the passage of the Health Care Justice Act, they have been principally responsible for turning out more than 2,000 people to public hearings throughout the state held by the task force created by legislation to develop a plan for universal coverage in Illinois.

## Illinois *(Continued)*



- > Illinois Citizen Action, the Service Employees International Union (SEIU), and others are spearheading Healthy Illinois, an effort to create a statewide, comprehensive health insurance plan, available to small businesses and small municipalities with 2 to 50 employees as well as the self-employed and other uninsured individuals. Healthy Illinois will have affordable premiums and a sliding fee scale for those below 300% of the FPL. Inspired by Maine's Dirigo Health Plan, more than 1,000 endorsers to date include a significant number of municipalities and small businesses, as well as an array of community groups, unions, voluntary health organizations, health departments, and faith-based groups.
- > A range of advocates including labor unions, neighborhood-based organizations, faith-based groups, and others have caused local hospitals and hospital systems to adopt more generous charity care policies and communicate them to the public. They also influenced hospitals to adopt more consumer-friendly billing and collection practices. Through tenacious advocacy and national publicity, Champaign County Health Care Consumers convinced the local hospital to offer deeper discounts to the uninsured and to end its practice of arresting individuals for unpaid debts. The Chicago chapter of ACORN, a grassroots organization, used high-profile tactics to improve a hospital system's charity care policies and programs and require public disclosure. It was also instrumental in reducing the hospital system's litigation against uninsured people. In addition, community-based advocates have fought hospital closings and sought tertiary services in their communities. The American Federation of State, County and Municipal Employees (AFSCME) and SEIU both have active hospital financial accountability projects.
- > The Sargeant Shriver National Poverty Law Center, and Health and Disability Advocates, working with a private law firm, used litigation as a tool to enforce Medicaid Early Screening, Prevention, Diagnosis and Treatment (ESPDT) standards to ensure that children enrolled in Medicaid receive adequate, timely, well-child care. The litigation led to a landmark decision that is expected to provide an estimated \$50 to \$100 million in annual preventive and primary well-child care for children enrolled in Medicaid. The state's Medicaid program is currently implementing proactive, concrete approaches to ensure that children receive the full EPSDT services they are entitled to and need. The result of the Memisovski v. Maram case was described as a "huge sea change" by one policy advocate.

### FUNDING

- > Because there is a strong sense of opportunity in IL, some advocates feel that foundations are increasingly funding policy and advocacy. Organizations had mixed reports about private foundations' strategic directions. Some local organizers felt that foundations place a greater emphasis on statewide projects, which tends to overlook community-based grassroots organizing; others felt funding leans more toward the local than statewide efforts.
- > Because state government has been the target of advocacy and lawsuits, public funding may also be limited.
- > Some consumer organizations have present or historical ties to labor and have had difficulty overcoming the assumption that unions can and will offer financial support. Yet they report that even when some union funding has been available, it has not been stable or long term.

MD

Maryland

## HEADLINES

- > MD has the 4<sup>th</sup> highest per capita income in the nation but only ranks 41<sup>st</sup> in state and local taxes as a percentage of personal income.
- > Its Governor, Robert Ehrlich, is the first Republican to serve in the office in 36 years. There are large Democratic majorities in both houses of the legislature. Many of those interviewed do not expect Governor Ehrlich to be reelected in November 2006.
- > Advocates report that Governor Ehrlich's election has had a significant impact on consumer health advocacy. In prior administrations, they had access to executive branch agencies and staff. Now, the perception is that campaign contributors and corporate lobbyists, including some health industry interests, have access while consumer advocates have to fight to be heard.
- > Employer-sponsored insurance fell 7.9 percentage points from 2000 to 2004, well above the national average. Medicaid coverage was unchanged while increasing 1.5 percentage points nationally. As a result, the number of people without insurance grew at more than twice the national average during that period—6.8 percentage points, compared with a 2.7 point increase for the nation as a whole.
- > A recent poll of MD voters indicated that health care is the most important issue for many people. Middle-class consumers reported an erosion of coverage with higher out-of-pocket costs.
- > MD's rate of HIV/AIDS is lower among Whites and Hispanics than in the nation as a whole, but it is substantially higher among Blacks than nationally—106.9 per 100,000, compared with 73.9 nationally.

## KEY DATA

- > MD's population is approximately 5.5 million. The Black population is substantial—27%, compared with 12% nationally. Both the White and Hispanic populations are below the national average—60% of the population is White, compared with 67% nationally, and 7% of the population is Hispanic, compared with 14% nationally.
- > MD is 86% urban and 14% rural.
- > MD has the 4<sup>th</sup> highest per capita income in the nation, \$37,446, compared with \$31,472 nationally.
- > MD's poverty rate (i.e., those with incomes below 100% FPL) is 14%, well below the national average of 17%. The poverty rates of Blacks and Hispanics are below the national average but more than double the rate for Whites. Twenty-two percent of the state's Black population lives in poverty, compared with 33% nationally; 8% of its White population lives in poverty, compared with 12% nationally; and 22% of its Hispanic population lives in poverty, compared with 29% nationally.

Maryland *(Continued)*



> Health coverage status of the MD population, relative to the US population as a whole, is as follows:

Type of Coverage	MD	US
Private Insurance	65%	59%
Medicaid	8%	13%
Medicare	11%	12%
Uninsured	14%	16%

- > About 14% of MD residents—more than 760,000 people—are uninsured, compared with a national rate of 16%. Ten percent of Whites are uninsured, compared with 13% nationally; 20% of Blacks lack insurance, compared with 21% nationally; and 42% of Hispanics are uninsured, compared with 34% nationally.
- > Employer-sponsored insurance fell 7.9 percentage points from 2000-2004, well above the national average of 4.8. Medicaid coverage was unchanged while increasing 1.5 percentage points nationally. As a result of a higher-than-average loss of employer-sponsored insurance and no increase in Medicaid coverage, uninsurance grew at more than twice the national average from 2000-2004, 6.8 percentage points, compared with a 2.7 point increase for the nation as a whole.
- > MD’s Medicaid matching rate is 50%, among the lowest in the US. MD ranks 18<sup>th</sup> in the amount of its own state resources spent for Medicaid. Its eligibility standards for children are high compared with other states, but its standards for working and non-working parents are very low. Children qualify for Medicaid if household income is 200% FPL or less and for SCHIP with incomes of 300% FPL or less. But it only ranks 40<sup>th</sup> in eligibility for working parents, at 40% FPL, and 35<sup>th</sup> in eligibility for non-working parents, at 33% FPL. The state ranks 2<sup>nd</sup> in eligibility standards for pregnant women at 250% of FPL.
- > Dual eligibles in MD make up 11% of Medicaid recipients (US, 14%) but account for 30% of Medicaid costs (US average is 40%).
- > MD is the only state in the nation that still sets hospital rates. The rate setting mechanism builds in financing for uncompensated care, but there is very little monitoring to determine if hospitals are providing it. A law passed in the 2005 legislative session requires all hospitals to develop charity care/ financial assistance policies and publicize them to hospital patients and their families.
- > Nineteen of MD’s 24 counties are considered to have medically underserved areas and four of its counties, in which 15% of the people live, are considered poor counties. Among these four, one county does not have a health center.



MD

Maryland *(Continued)*

- > Differences in health status, health outcomes and insurance status by race/ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	5.3	12.6	5.7
Prostate cancer mortality per 100,000	28.1	71.7	No data
HIV/AIDS incidence per 100,000	7.2	106.9	17.4
Asthma mortality rate per 100,000	1.0	3.5	No data
Uninsured rate (non-elderly)	10%	20%	42%

- > In 2004, MD ranked 25<sup>th</sup> in compliance with CDC standards on tobacco prevention programs. It has the 12<sup>th</sup> lowest adult smoking rate in the nation, at 19.7%, and an adult smoking rank of 10<sup>th</sup> in the US (1 = low). The annual health cost directly related to smoking is an estimated \$1.8 billion, of which nearly \$450 million is covered by Medicaid. MD's tobacco tax is \$1.00 per pack, 16<sup>th</sup> highest in the US.
- > State and local taxes make up a higher percentage of MD's Gross State Product (GSP) than the nation as a whole—5.4%, compared with 5.0% nationally. In 2004, MD ranked 41<sup>st</sup> in total taxes as a percent of personal income.

**POLITICAL ENVIRONMENT**

- > Robert Ehrlich is the first Republican governor in 36 years. Both houses of the legislature are controlled by large Democratic majorities. MD has the nation's strongest executive branch. The legislature's power to amend the budget is limited—it has the power to reduce but not increase spending.
- > Many of those interviewed do not expect Governor Ehrlich to be reelected. At least one of the prospective Democratic candidates has a good record on health care access.
- > Advocates report that the election of Governor Ehrlich had a significant impact on their work. Under prior administrations, they had relatively easy access to executive branch agencies. The current perception is that campaign contributors and corporate lobbyists, including some health industry interests, have relatively easy access, whereas consumer advocates have to fight to be heard.
- > According to advocates, even legislators have had a difficult time getting important data, such as budget information, from the Executive branch.

**KEY ADVOCACY ISSUES**

- > **Medicaid coverage:**
  - MD has done a good job of covering children and pregnant women, but eligibility standards for both working and non-working parents are well below the national average. Coverage for non-parent disabled/chronically ill adults are some of the lowest in the country—their income must not exceed \$350 per month and they have to meet strict disability standards.

## Maryland *(Continued)*



- Under a Medicaid 1115 waiver approved in 2005, adult enrollees in the state's prescription drug assistance program will be enrolled in a primary care services program. Adults with incomes below 116% FPL will be eligible.
  - Mental health advocates expressed concern about consistent erosion of budget dollars for services. When MD received a waiver in 1996 to shift its Medicaid population into managed care, mental health services were not included. Advocates and providers believe the mental health system is piecemeal and uncoordinated.
  - A waiver that will move disabled people out of institutional care settings and into community-based settings is a significant issue for the disability community. When the waiver was initially granted, all planning was done within state agencies with virtually no input from the disability community or advocates. In addition, the state was planning to proceed with a full-scale program rather than initiating it on a pilot basis. Advocates were able to get legislation passed that mandated a public process as well as more attention to issues of quality of care, access to care, and patients' rights. The initial program was pulled back, and advocates and consumers have been actively engaged in the program's redesign.
- > **Immigrant health care access:** MD had been using state-only Medicaid funds to cover resident alien pregnant women and children who had been in the country less than 5 years. Last summer, though, the governor eliminated the program. Advocates were able to restore benefits to pregnant women who were already enrolled, but all children lost coverage, new enrollment was frozen, and enrolled women lost coverage after giving birth. Legislation supported by advocates in the 2006 session to restore the funding was unsuccessful, but advocates did succeed in getting funding for a small, time-limited, non-Medicaid program administered through local health departments, to increase primary care access for immigrants.
  - > **Tobacco tax:** Advocates have launched a tobacco tax campaign, proposing a \$1.00 per pack increase, the revenues from which would be used to fund expanded health access. The bill was sent to an existing legislative task force for additional study. Advocates are hopeful this signals a willingness to pass the bill in the session following the gubernatorial election.
  - > **Hospital charity care and financial assistance:** Because of its unique all-payer hospital financing system, MD has, in theory, provided for the cost of care allocated for the uninsured and those who are otherwise unable to pay all their bills. In practice though, many hospitals do not have clear, publicly accessible financial assistance policies, and there have been several high-profile cases where hospitals have refused to provide financial assistance. This issue was partially addressed in legislation that passed in 2005, which requires hospitals to develop and publicize financial assistance policies. The content of the policies is left to hospital discretion, including eligibility standards.
  - > **Community health centers:** A study of indigent care in Baltimore showed that some community health centers are not doing as much as they could for the uninsured, in part because of the competitive environment. They want to see more patients who have health coverage. Legislation passed in 2005 will expand funding/capital resources for community health centers, allowing many of them to expand services offered to patients.

MD

Maryland *(Continued)*

- > **Employer-sponsored insurance:** In 2005, consumer health advocates succeeded in passing the Fair Share Health Care bill—a law that requires employers with more than 10,000 employees to spend at least 8% of their payrolls for employee health insurance or pay the difference into a state Medicaid fund. The law, which has sparked similar advocacy efforts in 30 other states, was vetoed by the governor, but the legislature overrode the veto in early 2006. The law has been challenged in court by the retail industry, and a recent initial decision found that the law violated federal law. The case is currently on appeal.
- > **Small group insurance reform and high-risk pool efficiency:** There have been significant efforts at the state level to increase the number of businesses and insurers participating in the state's regulated small group market. In addition, the state's high-risk pool (i.e., the Maryland Health Insurance Plan) is operating at half its capacity, with a \$100 million surplus. Advocates have been working with lawmakers to come up with a solution to the problems in both programs.
- > **Revenue and tax issues:** Like many other states, MD anticipates a revenue surplus resulting from an economic turnaround. Advocates want to see revenues used to restore and expand health care access, but they expect the governor to use them as a basis for proposing tax cuts.

#### ADVOCACY CAPACITY

- > Maryland Health Care for All (MDHCFA) was generally identified as the principal health advocacy organization in the state. It has built a significant broad-based coalition of 1100+ groups—including physician associations, labor, faith-based groups, businesses, grassroots and constituency organizations, and health advocates—to support advocacy around a comprehensive health care reform agenda. It was a key player in the passage of the Fair Share legislation described above. The coalition's goal is to give all Marylanders access to quality, affordable health coverage. All coalition members have endorsed the MCHCFA plan, which includes multiple ways of expanding access to care, including an employer “pay or play” provision, an “individual mandate” for high income earners, a significant Medicaid eligibility expansion, a small group market expansion, a prescription drug buying pool, and the creation of a quasi-public insurer for those who have no other private sector option. The plan was developed after more than 4 years of input from 24 town meetings, multiple state and local organizations, and other health care stakeholders. One key aspect of the plan is to raise the tobacco tax to fund some of the program expansions. MDHCFA plans to make health access expansion a key voting issue in the 2006 state elections.
- > A relatively new coalition, Medicaid Matters! Maryland, which was convened by the Public Justice Center, Advocates for Children and Youth, and the Maryland Disability Law Center, has brought together a broad range of consumer advocates that work on Medicaid issues. The goal was to present a unified voice in policy discussions. Interviewees indicate that the coalition has already established a reputation as a credible voice on Medicaid policy issues within the legislative arena.

## Maryland *(Continued)*



- > MD's disability community is well organized and was able to get the state to redraw its plan to move disabled people out of institutions into community-based settings. These advocacy organizations have the capacity to turn out constituents and their families when critical policy issues are under consideration. The MD Disability Forum and the MD Disability Law Center were cited as being particularly effective.
- > Grassroots consumers are mobilized primarily by labor-based organizations like the Service Employees International Union's (SEIU's) Marylanders for Health Care and Progressive Maryland, a multi-issue organization that engages in progressive issue advocacy and includes faith-based organizations, civil rights organizations, and the AFL-CIO. Both of these groups are pursuing electoral strategies focused on the next gubernatorial election. The Baltimore ACORN chapter has been able to mobilize grassroots organizations, but health care access is not currently a focus of its agenda.
- > A capacity gap identified by some of the funders who were interviewed is access to a trusted source of MD-specific health policy research. In their view, a key aspect of any advocacy work is the ability to produce data and information as part of the public education process. The MD Budget and Tax Policy Institute can provide analysis on the health aspects of the state budget and the impact of budget cuts on health programs, but its resources are relatively limited.
- > There is some legal backup through the Public Justice Center and the Maryland Legal Aid Bureau.

### FUNDING

- > Although resources are a challenge for many of the organizations interviewed, there are some progressive local and national funders that are investing in consumer advocacy. Some of the funders interviewed noted, however, that longer-term funding is often necessary to sustain advocacy efforts, and that is not how many foundations operate. In some cases, relatively small amounts of money would make a substantial difference in organizational effectiveness. For example, one very effective coalition that operates without staff is having difficulty raising resources for a half-time staff person who could manage the coordination, convening, and communications functions.
- > Several funders mentioned the importance of – and their interest in – collaborating with other funders, at the local and national levels.

MA

Massachusetts

## HEADLINES

- > In 2006, MA passed comprehensive health reform legislation that is intended to provide affordable new coverage for as many as 300,000 people with incomes up to 300% FPL through Medicaid, SCHIP, and subsidized private plans. As part of the package, Medicaid dental and vision benefits previously cut in 2002 were restored and enrollment caps expanded. New assessments on employers who do not provide coverage will help fund Medicaid and the state's Health Care Safety Net Trust Fund (the successor to the Uncompensated Care Pool, which will be phased out in 2007). Also in 2007, an individual mandate will require that all residents have coverage, but only if affordable insurance is available. This could cover an additional 225,000 people. The legislation represented a compromise among legislative leaders and major health care stakeholders, including the Affordable Care Today campaign (ACT/MassAct), led by Health Care for All (HCFA).
- > Consumer-based advocacy is highly developed. HCFA is the largest statewide consumer health advocacy organization in the country, with a staff of 25. It is a key leader in a sophisticated system of advocacy organized through overlapping campaigns and coalitions that involve numerous advocacy, community and interfaith groups, providers, health plans, and other allies.
- > Governor Mitt Romney is the fourth consecutive Republican Governor, but Democrats have a six-to-one margin in both houses of the legislature.
- > MA's per capita income, \$39,504, is the third highest in the nation.
- > There is a low uninsurance rate in the state—11%, compared with 16% nationally. Before health reform, estimates of the uninsured ranged from 530,000 to 730,000 people.

## KEY DATA

- > MA's population is approximately 6.4 million. Whites make up a substantial portion of the population—82% of residents, compared with 67% nationally; 6% of residents are Black, compared with 12% nationally; and 8% of residents are Hispanic, compared with 14% nationally.
- > MA is a largely urban state, with only 9% of its population living outside of metropolitan areas.
- > The per capita income is the third highest in the nation at \$39,504, compared with \$31,472 nationally.
- > MA's poverty rate – i.e., those with incomes below 100% of the Federal Poverty Level (FPL) – is 14%, whereas the poverty rate for the US as a whole is 17%. Twenty-nine percent of the state's Black population lives in poverty, compared with 33% nationally; 11% of its White population lives in poverty, compared with 12% nationally; and 34% of its Hispanic population lives in poverty, compared with 29% nationally.

Massachusetts *(Continued)*



- > The health coverage status of the MA population, relative to the US population as a whole, is as follows:

Type of Coverage	MA	US
Private Insurance	64%	59%
Medicaid	13%	13%
Medicare	12%	12%
Uninsured	11%	16%

- > Before health reform, the US Census reported that 11% of MA residents—almost 650,000 people—were uninsured, compared with a national rate of 16%. State surveys put the figure at 532,000. The low rate of uninsurance is caused primarily by the higher-than-average level of private coverage. Eleven percent of non-elderly Whites are uninsured, compared with 13% nationally, and 27% of Hispanics are uninsured, compared with 34% nationally. Uninsurance data were not available for Blacks.
- > Employer-sponsored insurance percentage fell 5.7 percentage points from 2000 to 2004, above the national average of 4.8. The Medicaid coverage rate rose less than the nation’s – 0.9%, compared with 1.5% from 2000 to 2004. As a result, uninsurance rose in MA rose at nearly double the national average – 4.7%, compared with 2.7% nationally during this period.
- > MA has a relatively low Medicaid matching rate of 50%, and the state ranks 19<sup>th</sup> in spending of state resources for Medicaid. Medicaid spending accounts for 0.85% of GSP, slightly below the national rate of 0.87%.
- > Medicaid eligibility standards are as follows: children ages 0-1 are covered up to 200% of the FPL (ranked 7<sup>th</sup> in the US); children ages 1-19 are covered up to 150% of the FPL (ranked 20<sup>th</sup> in the US). SCHIP coverage currently extends up to 200% FPL, and will increase to 300% FPL before the end of 2006. The Children’s Medical Security Program (CMSP), with limited, state-funded benefits, will continue to cover all other children, with a sliding scale premium. The state ranks 13<sup>th</sup> in Medicaid eligibility for working parents and 12<sup>th</sup> for non-working parents, both at 133% of FPL. It 4<sup>th</sup> in eligibility standards for pregnant women at 200% of FPL. Under health reform, Medicaid will also fund comprehensive plans at no cost to adults below 100% FPL and with subsidized premiums for those up to 300% of FPL. However, some potentially significant eligibility restrictions remain.
- > Dual eligibles in MA account for 17% of Medicaid recipients (US, 14%) but account for 52% of Medicaid costs (US average is 40%).
- > Only one of MA’s 14 counties is poor—11% of the state’s residents live in this county—but there are federally designated “medically underserved” areas in 11 of the 14 counties.
- > There are serious disparities in health outcomes and health status. HIV/AIDS rates among Blacks are 13 times higher than among Whites, and Hispanic rates are eight times higher. Asthma mortality rates are three times higher among Blacks and four times higher among Hispanics than among

Whites. The infant mortality rate among Blacks is about twice that of Whites, but both are among the lowest in the nation.

- > The prostate cancer mortality rate among both White and Hispanic men is slightly higher than the national average, but the rate for Blacks is substantially lower than that of the nation as a whole. The asthma mortality rate among Hispanics is almost four times higher than the national average. The rate of HIV/AIDS is lower among Whites than in the nation as a whole but substantially higher among Black and Hispanic residents than in the nation as a whole, and also relative to White MA residents.
- > Differences in health status, health outcomes and insurance status by race and ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	4.3	9.6	6
Prostate cancer mortality per 100,000	31.3	58.0	27.5
HIV/AIDS incidence per 100,000	6.6	84.6	54.1
Asthma mortality rate per 100,000	1.2	3.5	4.8
Uninsured rate (non-elderly)	11%	No data	27%

- > MA has an Uncompensated Care Pool that reimburses hospitals and health centers for most unpaid services for low-income people. Those under 200% of FPL are eligible for full free care, and those between 200% and 400% of FPL qualify for reduced cost care.
- > MA spends about 11% of the recommended CDC standards for tobacco prevention, ranking 40<sup>th</sup> in the nation. It is estimated that the annual health cost caused by smoking is almost \$3.3 billion, almost \$1 billion of which is covered by Medicaid. The state has the 6<sup>th</sup> highest tobacco tax in the nation at \$1.51 per pack.
- > The adult smoking rate in MA is 18.5%, which is the 6<sup>th</sup> lowest in the country.
- > State and local taxes account for 5.3% of the Gross State Product (GSP), slightly above the national average of 5.0%. MA ranked 31<sup>st</sup> in total taxes as a percent of personal income.

**POLITICAL ENVIRONMENT**

- > The Governor is a Republican, but both houses of the legislature are controlled by large Democratic majorities that are sufficient to override gubernatorial vetoes. There has been strong legislative support for health reform for many years, but public health and Medicaid cuts were initiated by conservatives from both parties during the 2002-2004 revenue crisis.
- > There has been a robust, effective, and growing consumer health advocacy movement spanning nearly two decades that has had significant access to the health policy decision-making process.
- > A strong anti-tax movement has led to significant cuts or limitations on both local property taxes and state income taxes for nearly two decades. This has created budget and revenue constraints.



## Massachusetts *(Continued)*

### KEY ADVOCACY ISSUES

- > **Medicaid:** In 1996 and 1997, advocates and their allies won coverage for all children through Medicaid, SCHIP, or the CMSP, as well as Medicaid expansions for adults and people with disabilities. Coupled with aggressive outreach, this led to a six-year expansion, and enrollment rose by 300,000 to over 1,000,000. Beginning with the 2002 fiscal crisis though, the state cut Medicaid, and enrollment dropped by over 80,000 through changes in eligibility, the reimposition of administrative barriers, the capping of enrollment, the reduction of outreach, and the institution of premiums. A MassHealth Defense campaign led to restored eligibility for 40,000 people in 2004; this newest health reform statute restores dental and vision benefits, and it increases enrollment caps for the long-term unemployed, the working disabled, and those with HIV/AIDS.
- > **Tobacco tax:** Tobacco taxes have been a critical source of funding for public coverage expansions. In 1996, a tobacco tax, along with federal matching funds, financed the MassHealth expansion and senior drug program. This initiative was the model for the national SCHIP program.
- > **Universal health care:** Lack of insurance has been a growing problem in the state, largely due to the loss of affordable private insurance. Immigrant workers (a rapidly growing population), workers in communities of color, and workers in small businesses are at particular risk. Universal health care remains a goal of HCFA and other health advocacy organizations, many grassroots organizations, and some public agencies such as the Boston Public Health Commission (BPHC). A coalition led by a group of physicians, nurses, and social workers is working to place a constitutional amendment on the 2006 ballot that would direct the legislature to establish universal, comprehensive coverage. Finally, there is an active effort to restore resources for public health, prevention, and outreach to complement health insurance coverage initiatives.
- > **Tax and revenue issues:** Tax and revenue issues and other human services budget needs created pressures to cut MassHealth in 2002 to 2004 and were a barrier to proposals for expansion of coverage. During this time two multi-issue grassroots organizations involved in state health advocacy were leaders in the “Stop the Cuts” coalition convened by tax policy and human services advocates, unions, and community organization groups to combat cuts, which had some success. Nevertheless, a strong anti-tax movement has, over the years, succeeded in significantly reducing local property taxes and state income and corporate taxes. As a result, MA is now close to the national average in state and local taxes relative to the state’s economy and average personal income. Despite this, many people still see MA as a “high tax state” and continue to oppose efforts to expand state revenues, which is a factor in any debate over public program expansions. Chapter 58, the recently passed health reform bill was able to generate a significant portion of its revenue from other sources---e.g. by reorganizing the use of Medicaid DSH funds and imposing an employer assessment on some employers that do not provide coverage.
- > **Employer coverage:** Employer coverage has become even more important as the state faces significant decreases in employer-sponsored insurance. Affordable coverage for low-wage public and private sector employees is a major issue. The state’s landmark 1988 employer mandate was never implemented because of business opposition. The MassACT ballot initiative proposed a 5% to 7%



MA

Massachusetts *(Continued)*

employer payroll assessment on companies that do not provide coverage, but the final compromise, adopted over a gubernatorial veto, was \$295/year per uninsured employee. In order to bring public attention to the issue, health advocates and unions passed a statute two years ago that requires the state to publish a report listing companies that had more than 50 workers enrolled in MassHealth or utilizing the Free Care Pool.

- > **Racial and ethnic disparities:** Disparities in health status, access, and outcomes related to race and ethnicity are seen as a major issue by urban health departments, by statewide health access advocates, and by the Critical Mass coalition, a policy group that is focused on racial and ethnic disparities that is composed of leaders from health care agencies and organizations from communities of color. A public policy initiative by advocates led to passage of a statewide Commission on Racial and Ethnic Disparities in Health to investigate issues related to coverage, barriers to care, and workforce diversity. The health reform bill includes provisions making that Commission permanent. The Boston Public Health Commission developed a blueprint for Boston city action to reduce disparities in access to appropriate care.
- > **Prescription drug coverage:** Senior and local health access groups see prescription drug costs as a major issue for their constituencies. For senior and disability advocates, the difficulties with Medicare Part D loom large.

## ADVOCACY CAPACITY

- > **Health Care for All**, the major health advocacy organization in MA, was founded in 1985 and has been instrumental in the passage of every major access expansion in the state, including programs for the unemployed, working disabled, children, seniors, and homeless people. It also has been instrumental in non-group, small-group, and managed care insurance reform, and it has recently become involved in racial/ethnic disparities in health, oral health, quality initiatives, and cost-effective delivery system innovations.
- > **Constituency-based groups** have significant impact, both on their priority issues and in broader campaigns. These include senior, disability, mental health, immigrant, public health, and disease-specific groups, as well as labor unions. Massachusetts Senior Action Council, founded in the early 1980s, can mobilize members throughout the state who belong to local chapters that are well known to local legislators. The local AARP is also influential, and both senior groups have focused on specific senior issues as well as initiatives with a broader impact, such as prescription drug reform. The National Alliance for the Mentally Ill has numerous chapters with active members, and the Independent Living Centers also have an active, experienced grassroots base. The Massachusetts Immigrant and Refugee Coalition, the Massachusetts Public Health Association, and the AIDS Action Coalition spearhead coalition efforts in their own areas and actively support Medicaid and health access. The American Cancer Society and the American Heart Association have been leaders in tobacco tax/health access campaigns. Two SEIU locals representing health care workers and janitors are in the ACT/MassACT coalition leadership group, along with the Massachusetts Building Trades Council.

## Massachusetts *(Continued)*



- > **Multi-issue community organizing and multi-ethnic interfaith groups** have in recent years brought a new depth of grassroots activism to health advocacy in the state. HCFA has built partnerships with several of these local and statewide organizing groups as part of its strategy to build a deeper base of grassroots support and leadership in health reform.
- > **Broad-based coalitions:** Statewide health advocacy is conducted largely through coalitions that were formed to address particular issues or broad initiatives. These coalitions focus the policy analysis, research, grassroots organizing, campaign implementation, communications, and statewide advocacy capacities across numerous organizations. In addition, an electoral strategy organized around health care and other low-income residents' issues, including revenue, has been spearheaded by Neighbor to Neighbor, a grassroots organization with a 501c4 component.
- > **Communities of color:** Leadership and engagement from communities of color in the health care debate has increased substantially with the involvement of three major grassroots organizing groups in the ACT/MassACT coalitions: the Greater Boston Interfaith Organization, Neighbor to Neighbor, and Coalition for Social Justice, all of which have deep roots in communities of color in Boston and 10 mid-size Massachusetts cities. Through them, people of color who have lost Medicaid coverage or are uninsured have gained a much stronger voice in the campaigns for expanded health access and Medicaid defense. They have also been a force in support of efforts to reduce racial and ethnic disparities in health.
- > **Stakeholder involvement:** There is a long history of wide-ranging stakeholder involvement in consumer health advocacy in MA. Most recently, the Blue Cross Blue Shield of Massachusetts Foundation and Partners HealthCare, the state's largest health care system, financed the development of policy options for health reform. They also periodically convene major stakeholders. Both organizations have been allies with consumer advocates in major public policy initiatives, along with a broad range of other health care stakeholders. The state's network of 53 community health centers, which are major recipients of MassHealth and Free Care Pool revenues, is represented by the Massachusetts League of Community Health Centers, which is another leader at the state, local, and federal levels.

### FUNDING

- > Local and statewide MA foundations provide significant support for consumer advocacy-oriented organizations, although primarily for the policy and programmatic work. Obtaining general operating support for community organizing and advocacy is seen as a continuing challenge.
- > Health advocacy organizations receive substantial support from the Blue Cross Blue Shield of Massachusetts Foundation, the Jessie B. Cox Charitable Trust, the Boston Foundation, other local and national foundations, and a number of non-profit hospitals and health insurers.

NJ

New Jersey

## HEADLINES

- > NJ's per capita income is the 2<sup>nd</sup> highest in the nation, \$39,577, compared with \$31,472 nationally. While it has a strong tax base—10<sup>th</sup> in total taxes per person—state and local taxes are low relative to available resources. In 2004, state and local taxes in NJ were the 35<sup>th</sup> highest in the nation.
- > NJ has a significantly higher private insurance rate than the nation as a whole – 65% of non-elderly people, compared with 59% nationally – but a much lower Medicaid coverage rate – 8%, compared with 13% nationally. As a result, the state's uninsured rate for non-elderly residents is only slightly below the national average. The total number of uninsured is 1.2 million.
- > The Governor, elected in 2005, made health care coverage a priority issue during the campaign. He expressed support for expanding Medicaid eligibility levels, with an initial goal of ensuring that all children have coverage.
- > A number of major pharmaceutical manufacturers have corporate headquarters in NJ, and they are perceived as wielding significant influence in state politics.
- > There are significant racial and ethnic disparities in insurance status—81% of Whites have private insurance, well above the national average of 69%—compared with 51% of Blacks and 45% of Hispanics.
- > NJ's HIV/AIDS cases per 100,000 among Blacks is well above the national average—94.4 cases per 100,000 in NJ, compared with 73.9 nationally.

## KEY DATA

- > Total state population is approximately 8.6 million.
- > NJ's demographics are very similar to the national average. Sixty-five percent of the population is White, compared with 67% nationally. Thirteen percent is Black, compared with 12% nationally, and 14% is Hispanic, compared with 14% nationally.
- > NJ is a largely urban state, with only 6% of its population living outside of metropolitan areas.
- > Its per capita income is the 2<sup>nd</sup> highest in the nation, \$39,577, compared with \$31,472 nationally.
- > Its poverty rate (i.e., those with incomes below 100% FPL) is 13%, well below the national average of 17%. The poverty rates of Blacks and Hispanics are lower than the national average, but still well above that for Whites in the state. Twenty-nine percent of the state's Black population lives in poverty, compared with 33% nationally; 8% of its White population lives in poverty, compared with 11% nationally; and 23% of its Hispanic population lives in poverty, compared with 30% nationally.

New Jersey *(Continued)*



- > Health coverage status of the NJ population relative to the US population as a whole is as follows:

Type of Coverage	NJ	US
Private Insurance	65%	59%
Medicaid	8%	13%
Medicare	12%	12%
Uninsured	15%	16%

- > About 15% of NJ residents—almost 1.2 million people—are uninsured, compared with a national rate of 16%. While uninsured rates for Whites, Blacks, and Hispanics are similar to those for the nation as a whole, Blacks and Hispanics in NJ are two to three times more likely to be uninsured than Whites. Ten percent of Whites are uninsured, compared with 11% nationally, 25% of Blacks are uninsured, compared with 21% nationally, and 36% of Hispanics are uninsured, compared with 34% nationally.
- > Private insurance coverage fell 4.3 percentage points from 2000 to 2004, similar to the national average of 4.8, but Medicaid coverage grew by only 0.5, which is one third of the national rate of 1.5 points. As a result, the percentage of uninsured in NJ increased by 3.5 percentage points, compared with 2.7 points for the nation as a whole.
- > NJ has a Medicaid matching rate of 50%. Medicaid spending accounts for 0.90% of its GSP, slightly above the national rate of 0.87%. It ranks 16<sup>th</sup> in spending its own resources for Medicaid.
- > Medicaid eligibility standards are as follows: for children of ages 0-1 it is at 200% FPL (ranked 7<sup>th</sup> in the US); for children of ages 1-5, it is 133% FPL (ranked 28<sup>th</sup> in the US); and for children of ages 6-19, it is 133% FPL (ranked 27<sup>th</sup> in the US). Eligibility for working and non-working parents is very low, however. It ranks 30<sup>th</sup> in the nation for working parents, at 62% FPL, and 45<sup>th</sup> for non-working parents at only 23% FPL.
- > Dual eligibles in NJ account for 17% of Medicaid recipients (US, 14%) but account for 42% of Medicaid costs (national average is 40%).
- > None of NJ's 21 counties is classified as poor under federal standards, but 18 of its 21 counties have federally designated “medically underserved” areas.
- > Differences in health status, health outcomes and insurance status by race/ethnicity are as follows:

	White	Black	Hispanic
Infant mortality rate per 1,000 births	4.8	13.1	6.3
Prostate cancer mortality per 100,000	28.9	67.3	18.8
HIV/AIDS incidence per 100,000	6.6	94.4	30.8
Asthma mortality rate per 100,000	0.8	4.0	2.0
Uninsured rate (non-elderly)	10%	25%	36%

NJ

New Jersey *(Continued)*

- > NJ has a hospital uncompensated care pool that is used to provide charity care to the uninsured. Full charity care is available for those with incomes less than or equal to 200% of FPL. Households between 200% and 300% of FPL are eligible for assistance using a sliding fee scale. Hospitals that provide disproportionate amounts of charity care are reimbursed through a fund that consists of revenues from various taxes, including the tobacco tax.
- > NJ's tobacco tax is the 2<sup>nd</sup> highest in the nation at \$2.40 per pack, significantly higher than surrounding states. It ranks 31<sup>st</sup> for CDC compliance with smoking prevention standards. The annual health costs directly related to smoking are estimated to be \$2.9 billion, of which \$890 million is covered by Medicaid. Adult smoking rate in NJ is 18.9%, with an adult smoking rank of 8<sup>th</sup> in the US (1 = low).
- > Total state and local taxes, about \$20.9 billion, account for 5.0% of state GSP, which is the same as the national average. NJ ranks 35<sup>th</sup> in total taxes relative to personal income.

## POLITICAL ENVIRONMENT

- > The NJ Governor, elected in 2005, is Jon Corzine, a Democrat. Democrats have a majority in both the Senate and the Assembly.
- > During the 2005 campaign, Governor Corzine made health care coverage a priority issue and expressed support for expanding Medicaid eligibility levels, with an initial goal of ensuring that all children have coverage.

## KEY ADVOCACY ISSUES

- > **Medicaid access:** Medicaid is a key advocacy priority. NJ is one of a few states in which there was a significant restoration of benefits in 2005 *despite* a budget deficit. Enrollment in the Family Care program, which had been frozen under the previous administration, was reopened and eligibility levels were raised. The new enrollment will be phased in over three years. Despite the Family Care victory, some advocates have expressed concern that the revenues to pay for program expansion may not materialize because they come primarily from anticipation of increased efficiencies in Medicaid. There are commitments from the state that efficiencies will not translate into barriers to enrollment, but at least one advocate was skeptical. A recent concern is a proposal by the new Governor to institute co-payments for prescription drugs and for non-emergency use of emergency rooms. Co-payments have been proposed in the past, but to date, advocates have succeeded in fending them off.
- > **Tax and revenue issues:** NJ is grappling with a significant budget deficit. Several interviewees felt that it reflects a structural problem that will get worse before it gets better. There is also a concern that meeting the budgetary needs of programs like Medicaid will become secondary to politically popular budget decisions like property tax relief. While NJ has a strong tax base, 10<sup>th</sup> in total taxes per person, state and local taxes are low considering the resources that are available. In 2001, the state ranked 39<sup>th</sup> in the nation in total local and state taxes relative to personal wealth. The Governor's fiscal 2007

New Jersey *(Continued)*

NJ

budget proposal includes an assessment on non-Medicare hospital revenue. Half of the proceeds would go into the state's general fund, and the other half would be used to leverage federal matching funds to increase hospital Medicaid reimbursement and to fund charity care.

- > **Blue Cross and Blue Shield conversion:** The possibility that Horizon Blue Cross and Blue Shield might convert from non-profit to for-profit status has received significant attention from advocates. Conversion legislation was passed a few years ago, and although it is not as strong as consumer advocates had wanted, it establishes a conversion process with opportunities for public input. Horizon has filed and then withdrawn several conversion applications, largely because advocates were able to generate sufficient public opposition. Advocates do not believe that Horizon has abandoned its interest in converting, and they expect this to become an issue again. A related issue is the substantial amount of surplus Horizon has accumulated. A concern among advocates is that the governor and/or the legislature will encourage a conversion, or "raid" the surplus, and use the funds to balance the state budget.
- > **Prescription drug issues:** A recent concern for many advocates was the impact of the new Medicare drug benefit on so-called dual eligibles and on lower-income beneficiaries generally. Advocates were successful in preserving some of the state savings that are anticipated to result from the shift to federal financial responsibility, and those funds will be used to provide assistance with out-of-pocket drug costs for low-income Medicare beneficiaries. There also have been efforts to maximize the state's prescription drug purchasing power by creating a purchasing pool that would purchase drugs for Medicaid recipients, state employees, and community health center clients. The pharmaceutical industry is opposing these efforts and has convinced the state to rely for now on drug company discount programs to reduce costs.

## ADVOCACY CAPACITY

- > There are no broad-based consumer advocacy organizations in NJ that focus exclusively on health or health access. Most advocacy organizations have multiple issues on their agenda or focus on a broad spectrum of issues related to a particular population such as children, mentally ill people, or disabled people.
- > Despite this, there have been several successful efforts to pull together organizations working on the same health issues, such as expansion of the Family Care program or Blue Cross/Blue Shield conversion, so they can work together in coalitions at critical times.
- > Legal Services of New Jersey provided leadership on advocacy to expand the Family Care program. It played an important role in convening a broad coalition that included, among others, a small group of provider organizations. The coalition played a critical role in working directly with legislators and their staff to educate them on the issues and the various policy alternatives. The Association for Children of New Jersey was also cited as influential in the effort. New Jersey Appleseed and New Jersey Citizen Action have been involved in issues related to the Horizon conversion, along with other groups like the Hemophilia Society and AARP, which were concerned that premiums for their constituents would increase significantly if the conversion took place. NJ Citizen Action is a coalition

organization, and many of its member organizations represent consumer interests. It is able to mobilize consumers on its issues. New Jersey PIRG, a citizen-funded public interest advocacy organization that does organizing and lobbying, anticipates becoming more engaged in health care issues in the coming year.

- > ACORN has been effective in organizing at the local level in several of NJ's larger urban areas such as Newark. It is working to develop a statewide presence. Its agenda is set by its membership, and some of the health-related issues it has worked on include hospital billing and collection practices, interpreter services in hospitals, and lead paint abatement.
- > Priorities that were identified for strengthening health advocacy include more grassroots organizing, stronger connections between local organizing and state policy advocacy, and more in-depth health policy resources. Multi-issue organizations lack deep—and broad—health policy knowledge, and there is no centralized source for in-depth policy analysis and research.
- > Although individuals and organizations engaged in consumer health advocacy are familiar with each other's efforts and work collaboratively—or otherwise provide support—on a range of issues, there appears to be some bifurcation. One cluster of organizations focuses on public coverage programs and the interests of low-income people. Another group of organizations is more focused on issues that are relevant to middle-class consumers such as the Horizon conversion and insurance market reform.

## FUNDING

- > Resources for advocacy work come from a variety of sources, including organizational dues, door-to-door collections, support from the private bar (in the case of Appleseed and Legal Services), state contracts, and foundations.
- > State-based philanthropic resources present a mixed picture. In general, funders articulate a willingness to fund advocacy, but despite this there seems to be a preference for funding services. A problem with respect to funding health access work is that the Robert Wood Johnson Foundation is perceived by other funders as filling that niche. At the same time, though, the perception is that it only funds those projects/programs that are consistent with its own models.
- > Funders who were interviewed expressed an interest in collaborating with other funders—both state and national—and, in some cases, have a track record for doing so.



## Appendix A: Study Methodology

The information used in developing our report was obtained through analysis of demographic, economic and health data, interviews with people knowledgeable about health care issues and advocacy, and in-depth surveys of leading advocacy organizations. We developed a set of templates and tools for gathering and organization this information, which enabled us to assess advocacy strategies, capacities, and impacts in a broad range of health care and political contexts.

At the outset, we selected a sample of 16 states using four screens: geographic diversity, racial diversity, political balance, and consumer-based advocacy. For geographical diversity we used the four regional clusters developed by the U.S. Census Bureau. We then determined the total population for all of the states in each region and weighted them based on the total population of all 50 states. We chose the number of states from each region based on each regional cluster’s percentage of the total population in 15 states. We excluded Texas, New York, California both because of their size, and we also eliminated Hawaii and Alaska because of their distance. In addition, although the Census Bureau places Maryland and Delaware within the South cluster, we placed them in the Northeast region because we believe they are more aligned with the Northeast both historically and economically. Categorizing those two states as Southern would, in combination with our other screens, have led to an overweighting of states from the Southeast, and an over-representation of so-called “red” states.

Because of the critical relationship between health issues and race, as a second screen we used the racial diversity index contained in the 2002 U.S. Census. Within each region, the states identified had the highest percentages of residents who did not identify themselves as white. Due to the interest of our funder, Arkansas was included in the scan even though that state is not as diverse as others in the South.

We wanted all the selected states to have a minimum level of consumer-based advocacy activity. We tallied representation of consumer groups among attendees at both the Families USA Health Action conference and meetings of health care advocacy organization grantees of the Public Welfare Foundation in 2004 and 2005. If the states had at least one organization attending either or both conferences, we retained them in a regional cluster. Since all of the states have at least a minimum level of advocacy capacity, this is not a study of how the initial “spark” gets lit. Rather, it provides a foundation for looking at strategies for developing higher levels of health advocacy capacity and impact.

For political balance we wanted a sample that was roughly evenly split between “red” and “blue” states. The final sample included 9 states that voted Republican in the Presidential election and 7 that voted Democratic.

### States Included in the Study

Arkansas	Georgia	Maryland	New Jersey
Colorado	Illinois	Massachusetts	New Mexico
Connecticut	Kansas	Michigan	Ohio
Florida	Louisiana	Mississippi	Oregon



In each state we identified organizations working on health issues that are important to vulnerable constituencies and low- and moderate-income communities. Key issues were selected based on three screens, and the issues identified through this process were used to help determine which groups within each state would be interviewed.<sup>15</sup> Key issues included Medicaid; Medicare and Medicaid dual eligibility; expanding access toward coverage for everyone; safety net and hospital accountability; and racial and ethnic disparities in access and health outcomes.

Data and information were gathered through a review of published health care, political, and economic data; interviews with advocates and other experts on each state's political and health policy environment; interviews with funders with a demonstrated interest in state and local health care issues, including those who funded health advocacy; and in-depth surveys of key advocacy and organizing groups identified through the interview process. (See **Appendix B** for a list of national organizational contacts, **Appendix C** for a list of state-based interview subjects, **Appendix D** for the interview protocol, and **Appendix E** for the survey instrument.)

With respect to the interviews, initial information was gathered from people in national and state-based organizations who were asked to identify any and all consumer- and community-based advocacy organizations they knew of that address priority health issues in each state. All interviewees were asked a series of questions about the health care environment and the roles and capabilities of advocacy organizations in their state. Organizations were also asked a series of questions to identify organizing and advocacy groups for more in-depth study using a survey about organizational capacity.

Organizations selected for in-depth study responded to detailed surveys about organizational capacity. Survey responses were used to identify priority opportunities for strengthening organizational capacity and building a stronger institutional consumer voice and impact in health care policies and systems.

Using the information we gathered from the interviews, surveys, and our other research, we developed an in-depth report on each of the study states. Those reports were then circulated to several readers – advocates and, where possible, funders – within each state to assure their accuracy and confirm our characterization of the state political environment.<sup>16</sup> Changes were made to reflect this feedback.

We interviewed a total of 206 people, about 13 people in each state. Individuals interviewed included: leaders of consumer advocacy; grassroots and constituency organizations; legislators and other political leaders; policy experts; funders; and stakeholders. More than 70 organizations completed in-depth organizational surveys.

<sup>15</sup> Issues featured at Families USA's 2005 annual health conference; surveys conducted for the Public Welfare Foundation's annual convenings of leaders from state and local consumer health advocacy organizations; and 3) Community Catalyst's own experience providing policy and technical assistance to state and local health advocacy groups.

<sup>16</sup> We received feedback on the state-specific reports from 14 of the 16 states. Although the Arkansas report was sent to several readers in that state, they did not respond with any feedback. Also, the Louisiana report was not sent to any readers in that state because the post-Katrina challenges made it impossible to reach those interviewees.

## Appendix B: National Organizations

The following national organizations provided contact information for their local contacts and/or affiliates. This was one method that Community Catalyst used in identifying advocacy organizations in each state working on health access issues.

### **The Access Project**

Contact: Mark Rukavina  
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### **ACORN**

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*National Research Director*  
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Dallas, TX 75235  
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### **American Medical Student Association**

Contact: Kao-Ping Chua  
*Jack Rutledge Fellow*  
1902 Association Drive  
Reston, VA 20191  
(703) 620-6600

### **Campaign for Tobacco-Free**

Kids Contact: Letetia Daniels  
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Washington, DC 20005  
(202) 296-5469

### **Center for Community Change**

Contact: Seth Borgos  
*Director for Research and Development*  
1536 U Street NW  
Washington, DC 20009  
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### **Family Voices**

Contact: Nora Wells  
*Data Project Director*  
1135 Tremont Street, Suite 420  
Boston, MA 02120  
(617) 399-8324

### **Joint Center for Political and Economic Studies**

Contact: Carla Y. Gullatt  
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### **NAACP**

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### **National Council of La Raza**

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*and*

Jennifer Ng'andu  
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### **National Health Law Program**

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*and*  
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### **The Praxis Project**

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### **Service Employees International Union**

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### **Universal Health Care Action Network**

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### **Voices for America's Children**

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## Appendix C: State Contacts

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## Appendix C: State Contacts *(Continued)*

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## Appendix C: State Contacts *(Continued)*

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## Appendix C: State Contacts *(Continued)*

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## Appendix C: State Contacts *(Continued)*

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## Appendix D: Interview Questions

### TARGET CRITERIA

1. What is the mission of your organization?
2. What kinds of health care issues do you work on?
3. Who belongs to your organizations? How do they play a role in decision-making?
4. Who do you serve? How do they play a role in decision-making?
5. Does your organization focus on changing local, state and/or national policies? Which ones?
6. Is the organization involved in organizing the community, if so in what way?
7. Is the organization involved in advocacy, if so how?
8. What would you say are the key milestones in the history of your organization?
9. What are the key factors that are limiting the organization's development?
10. What do you think are the major assets of your organization?

### ENVIRONMENT

1. What would you say are the "headlines" regarding access to health care in your \_\_\_\_\_? (state).
  - > Probe: Which population groups and communities are most negatively affected by these developments?
2. What recent or pending policy changes are affecting access to care in \_\_\_\_\_?
3. Looking to the future, what political or policy change are needed to improve access to health care for vulnerable populations and communities in \_\_\_\_\_?
4. In general, what are advocacy organizations doing differently or thinking about doing to respond to all the changes that you are seeing in the environment?
5. In your view, how effective are advocacy organizations for vulnerable communities in influencing state and local policies?  

Very Effective	Effective	Not Effective	Don't Know
----------------	-----------	---------------	------------
6. In your view, what are the gaps in the impact they are having—what else needs to be addressed by them or others?
7. What are some of the barriers to filling these gaps?

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## Appendix D: Interview Questions *(Continued)*

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### CONSUMER AND COMMUNITY ADVOCACY ORGANIZATIONS: ROLES AND CAPABILITIES

Now we would like to ask you some questions about consumer and community advocacy organizations in \_\_\_\_\_.

1. a) Can you tell me which organizations and/or coalitions are working on policy change or organizing work on the following issues (please include any local or grassroots group that may also be working on these issues):
  - > Medicaid
  - > Racial and ethnic disparities
  - > Making prescription drugs more affordable
  - > Coverage expansion, universal coverage
  - > Safety net issues (hospital accountability, free care, community health centers, other?)
2. Which of these organizations really stand out as having an impact on health system change in \_\_\_\_\_. What impact are they having?
3. You have identified organizations that are actively involved in advocacy and health care reform. Now can you tell me if there are other organizations, groups and/or individuals (both grassroots and industry) that could be allies in supporting the work of these organizations?

## Appendix E: Environmental Scanning Survey

Thank you for taking part in the previous telephone interview and this follow up survey. As you are aware, Community Catalyst is a national advocacy organization that works with state and local consumer health advocacy groups on health access issues including Medicaid, hospital charity care, prescription drug prices, and physician diversity.

Community Catalyst is undertaking a project funded by the W.K. Kellogg Foundation that is focused on gaining an understanding of the consumer health advocacy movement in 16 states. We see this as an opportunity to highlight the importance of the work of community and consumer based organizations.

Community Catalyst (and Kellogg) expects that the findings will be useful to foundations, to the advocacy groups themselves (for use in their organizational and resource development activities), and to others such as organizations seeking to develop or expand state, regional and national health access coalitions.

This survey takes approximately 30-45 minutes. It explores your organization and the work you are involved with in the community/state in more depth than our interview.

The survey will ask for your name, the name of your organization your state; however no organization or person will be identified individually in the report that will be developed. Our reports will be focusing on themes and will share the information in an aggregate format.

### INSTRUCTIONS

Questions #1 and #2 have an asterisk. That means you **MUST** answer those questions before the survey will allow you to proceed.

Your responses for a page are saved when you move on to 'next' page; until you do that your responses for that page are not saved. If you cannot complete the survey in one sitting, you will be allowed to go back into the survey and pick up at the page you left off.

We appreciate you taking the time to fill out the survey. Each organization that completes the survey will be given \$100 on completion of the survey and the name of the individual that fills out the survey will be entered into a drawing for an Apple iPod.

Once again, thank you, and if you have any questions please contact Jacquie Anderson at Community Catalyst, 617.275.2803 or [anderson@communitycatalyst.org](mailto:anderson@communitycatalyst.org).



Appendix E: Environmental Scanning Survey *(Continued)*

**ORGANIZATIONAL INFRASTRUCTURE**

\* 1. Your State

- |                                      |  |
|--------------------------------------|--|
| <input type="checkbox"/> Arkansas    | <input type="checkbox"/> Maryland      |
| <input type="checkbox"/> Colorado    | <input type="checkbox"/> Massachusetts |
| <input type="checkbox"/> Connecticut | <input type="checkbox"/> Michigan      |
| <input type="checkbox"/> Florida     | <input type="checkbox"/> Mississippi   |
| <input type="checkbox"/> Georgia     | <input type="checkbox"/> New Jersey    |
| <input type="checkbox"/> Illinois    | <input type="checkbox"/> New Mexico    |
| <input type="checkbox"/> Kansas      | <input type="checkbox"/> Ohio          |
| <input type="checkbox"/> Louisiana   | <input type="checkbox"/> Oregon        |

\* 2. Please provide the name, organization and title for the person completing this survey.

Name: \_\_\_\_\_

Organization: \_\_\_\_\_

Title: \_\_\_\_\_

3. How long has your organization been in operation?

- |   |   |
|---|---|
| <input type="checkbox"/> Less than one year | <input type="checkbox"/> 13 to 15 years     |
| <input type="checkbox"/> 1 to 3 years       | <input type="checkbox"/> 16 to 18 years     |
| <input type="checkbox"/> 4 to 6 years       | <input type="checkbox"/> 19 to 21 years     |
| <input type="checkbox"/> 7 to 9 years       | <input type="checkbox"/> More than 21 years |
| <input type="checkbox"/> 10 to 12 years     |   |

4. What would you identify as the organization's top priority issue?  
(the issue the organization spends most of its time and resources on?)

## Appendix E: Environmental Scanning Survey *(Continued)*

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

- We have a volunteer staff
- 1-3
- 4-6
- 7-9
- 10-12
- 13-15
- More than 15

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

- |   |   |
|---|---|
| <input type="checkbox"/> Less than \$50,000               | <input type="checkbox"/> \$500,000 to less than \$700,000     |
| <input type="checkbox"/> \$50,000 to less than \$100,000  | <input type="checkbox"/> \$700,000 to less than \$900,000     |
| <input type="checkbox"/> \$100,000 to less than \$200,000 | <input type="checkbox"/> \$1 million to less than \$2 million |
| <input type="checkbox"/> \$200,000 to less than \$300,000 | <input type="checkbox"/> \$2 million to less than \$4 million |
| <input type="checkbox"/> \$300,000 to less than \$500,000 | <input type="checkbox"/> More than \$4 million                |

7. Please check which groups are a focus of your organization's work.

	Very much a focus	Somewhat a focus	Limited of focus	We do not work with this group
Low-income	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Racial and ethnic minorities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People with disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children with special needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seniors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uninsured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rural communities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Urban communities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E: Environmental Scanning Survey *(Continued)*

8. Approximately what percentage of your funding is from the following sources?

- Foundations: \_\_\_\_\_
- Individual Contributions: \_\_\_\_\_
- Corporate Giving: \_\_\_\_\_
- Special Events/High Donor: \_\_\_\_\_
- Organizational Dues: \_\_\_\_\_
- Government Contracts: \_\_\_\_\_
- Other Contracts: \_\_\_\_\_
- Other: \_\_\_\_\_

9. Please indicate how much change there has been in the last three years for each of the following areas.

	A great deal of decline	Some decline	No significant change	Some growth	A great deal of growth
Size of organization's staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Size of organization's budget	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of health projects, programs or issues you focus on	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E: Environmental Scanning Survey *(Continued)*

10. How would you rate your organization in the following areas?

	A weakness	Satisfactory	A real strength
Board of directors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Resource development and fundraising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communications capacity and infrastructure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Technology planning/acquisition and use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personnel systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial management systems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Program and project development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Program and project evaluation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff training and development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Membership/leadership development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staff knowledge and skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. How would you rate your organization in the following areas?

	A weakness	Satisfactory	A real strength
Community outreach capacity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to impact public and private policies to help achieve the organization's goals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Involving community members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability to build successful coalitions that can impact private and public policies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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## Appendix E: Environmental Scanning Survey *(Continued)*

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### RACIAL AND ETHNIC DISPARITIES

12. What racial and ethnic health disparity issues have received the most attention in your region?
13. In general, how effectively have local health advocates incorporated issues relating to racial and ethnic disparities in their on-going work?
- Generally, there is limited focus on this area
  - Not Effectively
  - Somewhat effectively
  - Effectively
  - Don't know
14. In general, how effective do you think the organizations working on racial and ethnic disparities are in achieving their goal of reducing or eliminating racial disparities.
- Not Effectively
  - Somewhat effectively
  - Effectively
  - Don't know
15. What are the opportunities and challenges organizations face in addressing racial and ethnic health disparities?

## Appendix E: Environmental Scanning Survey *(Continued)*

16. How connected do you think the organizations working on racial and ethnic disparities are with those working on larger health policy issues?

- Not connected
- Limited connections
- Connected
- Very Connected
- Don't know

17. Is your organization working on issues related to racial and ethnic disparities?  
If no, please skip to question #21.

- Yes
- No

18. If your organization is working on issues you believe are related to racial and ethnic disparities, what are those issues? Please be as specific as possible.

19. Of those issues identified in the question above, what is the top priority issue of the organization (the issues your organization spends the most time and resources addressing)?

Appendix E: Environmental Scanning Survey *(Continued)*

20. If your organization is working on issues related to racial and ethnic disparities, what is the focus of the work? Rate each category.

	Not a focus	Somewhat a focus	A great deal of focus
Individual service provision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Policy change (local, state)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Negotiations with agencies or private institutions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legislative lobbying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coalition building	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Media education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Applied policy research and development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community organizing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**COALITION BUILDING AND MAINTENANCE**

21. Are there permanent or ad hoc coalitions focused on the following issues?

	Yes	No	Don't Know
Medicaid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Access/Coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Racial and Ethnic Disparities (e.g. HIV/AIDS, asthma, prostate cancer, diabetes)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Safety net (e.g. free/charity care, community health centers, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Environmental Justice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Budget/Revenue Issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Appendix E: Environmental Scanning Survey *(Continued)*

22. For the organization's top priority issues that you identified in question #4, is the organization involved in any coalitions? If so, what role does your organization play in these coalitions?
- No, the organization is not involved in any coalitions
  - Convener
  - Co-Convener
  - Provide staff support
  - Provide financial support
  - Mobilize and/or organize my constituents
  - Attend the meetings
23. How effective is the coalition that works on your priority issues?
- No coalition that works on our priority issue
  - Not effective
  - Effective
  - Very effective
  - Other (please specify)



Appendix E: Environmental Scanning Survey *(Continued)*

24. Is your organization involved in relationships with the following groups?  
If so, how would you characterize the relationships?

	Relationship type	How would you characterize the relationship?
Hospital Association (local, regional, state)	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
Individual Hospital Leaders	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
Medical society	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
Primary Care Association/ Community health Centers	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
Faith-based organizations	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
National organizations of color (i.e. NAACP, LULAC, La Raza)	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
Other national organizations	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial
Local organizations of color	<input type="checkbox"/> Formal Alliance <input type="checkbox"/> Informal Alliance <input type="checkbox"/> Ad Hoc	<input type="checkbox"/> None <input type="checkbox"/> Positive <input type="checkbox"/> Neutral <input type="checkbox"/> Adversarial

## Appendix E: Environmental Scanning Survey *(Continued)*

### COMMUNICATIONS AND MARKETING

25. Who is responsible for the organization's communications work?
- Full-time communications staff
  - Part-time communications staff
  - Executive Director
  - Policy Director
  - Other staff as delegated
  - Other (please specify)
26. Generally how many (if any) press releases and/or press conferences do you have in one year?
- None
  - Less than 3
  - 3 to 6
  - 7 to 10
  - 11 to 15
  - More than 15
27. How would you describe your organization's relationship with the press?
- No relationship
  - Weak relationship
  - OK relationship
  - Strong relationship
28. Do you have an annual communications plan?
- Yes
  - No

Appendix E: Environmental Scanning Survey *(Continued)*

29. Do you use polling or focus group information to help shape and develop your organization's messages?

- Yes
- No

30. What types of media does the organization work with and try to engage? Please check all that apply.

	No relationship	OK relationship	Strong relationship	Don't Know
Ethnic press	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Major newspapers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TV stations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radio stations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Local TV station/cable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. Do you collect personal stories of your constituents concerns?

- Yes
- No
- Don't know

32. Check all the marketing materials your organization has produced or produces.

- Brochure(s)
- Web site
- Newsletter(s)
- Annual report
- Annual fundraising appeal
- Other (please specify)

Appendix E: Environmental Scanning Survey *(Continued)*

33. Check all the features of your website.

- Don't have one
- Description of your organization and programs
- "Take action" tools (such as Capwiz, constant contact, etc.)
- Community room (message board for members)
- Contact us feedback form
- Surveys
- Consumer stories collection feedback forms
- Blog of news stories, events, happenings in your state
- Press room for reporters, including press releases
- Back issues of newsletters, reports, annual reports

34. How do you track and communicate with your organization's contacts, donors, and legislative allies?

	Not at all	Very little	Somewhat	A lot	Don't know
Newsletters	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conference calls					
Door-to-Door	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-advocacy tools (e.g. Capwiz, Constant Contact)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Annual reports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mail alerts/updates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phone Bank	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E-mail alerts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E: Environmental Scanning Survey *(Continued)***GRASSROOTS ORGANIZING AND MOBILIZATION**

35. What methods does the organization use to identify community members and involve them in the work of the organization? Please check all that apply.
- Door-knocking
  - Leafleting
  - Working through churches or community organizations
  - Newspaper ads
  - Helplines
  - Storybanking
  - Other (please specify)
36. What is your organization's capacity to involve community members and mobilize them to support the organization's goals?
- Very strong
  - Acceptable
  - A challenge we are trying to address
  - Not a key objective for our organization
37. Which best describes the involvement of community members in your organization? (Please check all that apply)
- We have a community organizing component to involve grassroots community members.
  - We have close ties to organizations representing grassroots community members with whom we collaborate.
  - Our board, steering committee, and/or leadership include grassroots community members.
  - We maintain a helpline and/or story bank that is used to mobilize grassroots community members to support policy efforts.
  - We are able to directly mobilize grassroots community members to help achieve policy goals.

Appendix E: Environmental Scanning Survey *(Continued)*

38. How involved are the following groups in the work of the organization?

	No involvement	Almost no involvement	Somewhat involved	Very involved
Disabled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seniors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People of color	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Under and uninsured individuals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People on Medicaid or other government assistance programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**POLICY ANALYSIS**

39. What information do you provide to your members/constituents about proposals for policy change so that they can be informed and speak out on their concerns?

	Yes	No
Fact Sheets	<input type="checkbox"/>	<input type="checkbox"/>
Forums	<input type="checkbox"/>	<input type="checkbox"/>
Trainings	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>

40. Does the organization release reports that:

	Yes	No	Don't Know
Describe the problems you are concerned about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identify policy solutions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Critique and/or analyze proposals for change made by others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Make your own recommendation of how to address the problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E: Environmental Scanning Survey *(Continued)*

41. Who is your target audience for the reports you develop (if any)? Please check all that apply.

	Yes	No	Don't Know
Our membership	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Policy makers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Local and state media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ethnic media	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**POLITICAL ADVOCACY AND STRATEGY**

42. What methods does your organization use in addressing your priority issues?

	Never	Infrequently	Frequently
Organizing (community etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Litigation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Developing and releasing reports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Service provision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legislative advocacy/lobbying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coalition Building	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Candidate forums	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Voter registration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**RESOURCE DEVELOPMENT/FUNDRAISING**

43. How well do the foundations in your state support consumer and community based advocacy to increase health care access?

- Not very well
- Satisfactory
- Very well
- Don't know

## Appendix E: Environmental Scanning Survey *(Continued)*

44. Do the foundations in your state collaborate with other funders in your state or national funders in efforts to build consumer capacity for health advocacy?

- Yes
- No
- Don't know

45. In general, what are some of the roles that foundations in the state have played in the area of health access?

	Never	Infrequently	Sometimes	Frequently	Always	Don't Know
Fund policy advocacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fund grassroots organizing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support policy research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Convene advocates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Issue policy reports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Conduct press events regarding the state of health access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### SUPPORT FROM NATIONAL ORGANIZATIONS

46. What specific types of support do you get from state or national organizations?

	Rarely	Infrequently	Frequently
Policy information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Federal updates	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strategy development assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal analysis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fundraising assistance and support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Coalition building support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organizational development	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
State policy and strategy support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



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## Appendix E: Environmental Scanning Survey *(Continued)*

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47. What support(s) would you like to get more of? Please check all that apply.

- Policy Information
- Federal updates
- Legal analysis
- Strategy assistance
- Fundraising assistance and support
- Coalition-building support
- State policy and strategy support
- Organizational development
- Other (please specify)

48. Is there anything that you have not been asked in this survey that you would like to add?

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### THANK YOU

Thank you for taking the time to fill out this survey. As we mentioned at the outset, we are hoping that the reports that results from this process will be used to both strengthen and highlight the work of community and advocacy groups working towards system change.

If you have any further questions or comments please contact Jacquie Anderson at 617.275.2803.



