

# Progress Despite Barriers

Public demand spurs expansion of health coverage

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## About Community Catalyst

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

**State Consumer Health Advocacy Program (SCHAP)**, a program of Community Catalyst, provides a broad range of support to build local consumer advocacy and change state health policy and work for national health reform. Through SCHAP, Community Catalyst identifies emerging health policy issues ripe for intervention and works with local and state advocacy groups to achieve policy change. Two special units of SCHAP are Consumer Voices for Coverage, a joint initiative of Community Catalyst and the Robert Wood Johnson Foundation designed to boost advocacy in 18 states, and Southern Health Partners, a group of 11 states funded by the Public Welfare Foundation that works toward proactive, regional health care reform. Both programs work to strengthen the capacities of state consumer advocates to advance state-level health policy change and promote federal coverage expansions.

For more information about Community Catalyst projects and publications, visit [www.communitycatalyst.org](http://www.communitycatalyst.org).

## Executive Summary

Many states expanded health care coverage in 2008, despite the economic crisis that exacerbated the burden of health costs on state budgets and forced states to make drastic spending cuts, according to two nationwide surveys. Drawing on public demand for quality, affordable health care, consumer advocates provided much of the impetus for these expansions.

This report draws on findings from two surveys: 1) a Community Catalyst-generated database of all state laws passed in 2008 that affected eligibility for health insurance; and 2) an online survey completed in fall 2008 by consumer advocates in 49 states plus the District of Columbia about state health policy environments and the priorities of the consumer health advocacy community.

Three significant trends emerge from these two nationwide surveys:

- **Twenty four states increased access to health insurance in 2008.** Eleven states enacted private insurance laws that are likely to increase coverage, and over one-third of states expanded public programs during a historic budget crisis. This progress clearly demonstrates that policymakers across the country faced intense pressure from the public to expand coverage.
- **The scope and frequency of health reforms have slowed significantly since 2007.** For example, the number of states improving access to private insurance dropped from 15 to 11 between 2007 and 2008, and many of the 2008 reforms targeted small populations, such as adult dependents. While the economic climate played a large part in this slowdown, a weak relationship between the states and federal government was also a barrier to comprehensive state-level reform.
- **Most states did *not* cut Medicaid and SCHIP eligibility in 2008.** This surprising trend demonstrates the effectiveness of state health advocacy organizations, which mobilized the public in support of safety-net programs. Many states considered Medicaid cuts, but only four reduced eligibility. Although the federal government has since passed enhanced Medicaid matching rates and added incentives for states to preserve Medicaid eligibility, these provisions were not yet enacted and did not influence state activities during 2008 legislative sessions.

These trends reveal two critical factors for advancing health reform in upcoming years:

- **To expand access on the state and national levels, consumer advocacy organizations must continue giving voice to the public demand for quality affordable health care.** These grassroots efforts are essential for maintaining momentum for reform in the face of budget crises, political opposition, and other barriers. Philanthropic organizations' continued funding of that work enables advocates to launch timely and effective campaigns for reform.
- **To facilitate future state expansions, national health reform must include provisions that will create a more productive partnership between the states and the federal government.** For example, as part of a comprehensive national health reform law, the federal government can streamline the process for expanding Medicaid, give states additional incentives to engage in cost containment efforts, set minimum insurance regulations, and provide states with assistance in transitioning to stricter insurance market rules.

## **Introduction**

Despite a historic economic crisis, 24 states and the District of Columbia expanded health care coverage in 2008. By organizing the public's demand for quality affordable health care, state consumer advocates provided much of the impetus for these expansions.

In 2008, the most promising outlet for this public demand was state-level health reform. But the election of President Obama, who campaigned on the promise of universal health care, has made comprehensive reform on the national level a real possibility. This paper draws lessons from two nationwide surveys of state experiences and consumer advocates' activities in 2008 to determine some of the factors necessary for achieving comprehensive reform on the state and federal levels in upcoming years.

Community Catalyst developed both of the surveys used for this report. First, Community Catalyst staff researched and created a database of all state laws that were passed in 2008 that affected eligibility for health insurance coverage. Community Catalyst then distributed an eight-question survey in November 2008 to consumer advocates in each state and the District of Columbia; the survey asked respondents about the health policy environment in their state and about 2008 and 2009 priorities of consumer health advocates. Advocates in the District of Columbia and all states except Montana responded.

## **Expanding Access**

The economy's freefall and the imminent federal debate on health care reform slowed state action in 2008. But the failing economy also increased the urgency for health reform, as hundreds of thousands of American families lost their insurance,<sup>1</sup> and countless others worried about becoming uninsured. In 2008, health care advocates responded to this increased urgency by successfully mobilizing support for expanding public programs and improving private health insurance at the state level.

### **Public programs**

Despite budget shortfalls, seventeen states and the District of Columbia expanded access to public programs in 2008. Eleven states expanded eligibility for children through Medicaid or SCHIP programs. Changes ranged from those targeting small groups, such as young adults who had been in foster care in Louisiana, to broad expansions, such as increasing eligibility from 200 percent of the Federal Poverty Level (FPL) to 250 percent FPL for all children in South Carolina. Two states created buy-in programs, allowing families above income limits to buy SCHIP coverage at full cost.

Nine states and the District of Columbia enacted adult expansions. Five of these states expanded Medicaid or SCHIP eligibility, including for pregnant women. Additionally, four states and the District of Columbia created or expanded subsidized insurance programs funded solely by the state for all low-income adults or for low-income workers at small businesses. The District of Columbia, for example, created a subsidized insurance program for residents earning between 200 percent and 400 percent FPL, and did this without federal matching funds.

That more than one-third of states expanded public programs during a historic budget crisis clearly demonstrates that policymakers across the country were feeling immense pressure from the public to expand affordable coverage for low- and moderate-income families. Successful consumer advocacy campaigns are a major reason that policymakers heard the public's voice so clearly.

In Washington state, for example, advocates were instrumental in securing funds for the Health Insurance Partnership (HIP), an exchange designed to help employees in small businesses access health coverage.<sup>2</sup> Advocates provided policy advice to legislative leaders, created lobbying strategies and organized small business owners to testify at hearings. In addition, advocates generated media about the HIP's benefit to small businesses and demonstrated grassroots support through e-mail, phone calls, handwritten letters and constituent meetings with lawmakers. Finally, advocates published research on the impact of the health care crisis on small businesses and their perspectives on reform. These activities led to the creation of subsidies to help employees of small businesses obtain insurance through the HIP.

Despite this progress, these expansions represent a slowdown in state action from 2007, when 35 states expanded access to public programs for children or adults.<sup>3</sup> This slowing is due in part to the worsening economic environment. But federal restrictions in 2007, known as the August 17 directive, also contributed to the decline in expansions, especially for children's coverage. Specifically, the directive limited states' efforts to expand SCHIP for families above 250 percent FPL.<sup>4</sup>

For example, Louisiana passed legislation in 2007 to expand SCHIP to children in families earning up to 300 percent FPL. However, the federal government refused to support that full expansion, approving a waiver that only allowed Louisiana to expand eligibility to 250 percent FPL. The directive hurt SCHIP programs in at least seven other states,<sup>5</sup> and many other states may have been deterred from expanding coverage.

Although the Obama administration has since repealed the August 17 directive, the experience confirmed states' need for a productive partnership with the federal government to continue improving coverage, especially in the current economic environment. The federal government could take concrete steps to improve this partnership as part of broader national health reform.

For example, states must apply for a federal waiver to expand Medicaid or SCHIP to new populations. Currently, this process is burdensome and time consuming for states, and difficult for the public to understand. As part of national health reform, the federal government could streamline the process, create greater transparency, and increase funding to states to encourage expansions.

The federal government could also help states save Medicaid funds by improving health care quality, rather than making cuts. Specifically, the Centers for Medicare & Medicaid Services (CMS) could jumpstart state Medicaid cost-containment initiatives, such as care management programs for people with chronic illnesses, by giving states financial credit for savings to Medicare from people enrolled in both programs (dual eligibles). The federal government could also create standards to integrate care for dual eligibles and promote payment reforms across all public payers.

### **Reforming Private Insurance**

Eleven states passed a total of 13 private market reforms that will improve access to health insurance. Many of these reforms were incremental and targeted. Four states enacted laws to expand the age dependents may remain on their parents' plans; Colorado and Washington passed rules for formal review of premium rate increases; and yet another state, Rhode Island, prohibited insurers from using health status in setting premium rates in the small group market.

These small changes lay a foundation for greater access to affordable health care. In addition, by keeping the inequities and inefficiencies of our health system in the news, these small successes

help build momentum for comprehensive reform at both the state and federal level. Advocates remained vital players in creating the necessary push to move policymakers on private market reforms.

In Kentucky, for example, a broad coalition of advocates successfully moved a bill to mandate that insurers offer coverage for dependents up to age 25. The coalition decided that this incremental change was winnable, even in a difficult political and fiscal time in their state. The coalition gathered many endorsements from other groups for this priority, and drew the attention of media and legislators to coverage gaps for young adults. The advocates met with other stakeholders, namely insurers and provider groups, to outline the effect of different solutions. Advocates also helped to negotiate a compromise bill with stakeholders. While the law was not as far-reaching as the advocates had hoped, they will assess its impact in the coming year and use the results to identify the need for additional reforms.<sup>6</sup>

In the current political and economic environment, states are finding it hard to make bold reforms in the private insurance market. For example, only five states allow all people to obtain coverage regardless of any health conditions (guaranteed issue),<sup>7</sup> and fewer than half of all states set limits on how insurers can price policies.<sup>8</sup> In addition, many states have high risk pools for people with chronic illnesses that function poorly and charge unaffordable premiums.<sup>9</sup>

States that implemented guaranteed issue and stricter premium regulations in the past did so in different political and health policy environments. Four of the five states with guaranteed issue had an insurer of last resort, such as Blue Cross, which was already shouldering the high costs of unhealthy enrollees while other insurers covered only the healthy. In these cases, the insurers of last resort provided important political support for the transition to guaranteed issue.

Today, to blunt insurer opposition to guaranteed issue, states often need to consider strategies that may be difficult to achieve, such as mandating that all people acquire insurance, providing significant subsidies for people with low and moderate incomes, or funding a reinsurance pool to help share the costs of people with chronic health needs. The federal government could ease the way for change by requiring guaranteed issue and by matching state funds for subsidies or reinsurance in a national health reform plan.

### **Looking ahead to 2009**

Advocates expect to continue advancing public expansions and market reforms on the state level in 2009. In 23 states, advocates plan to focus on expanding Medicaid and SCHIP eligibility as one of their top priorities, and advocates in 12 states report that promoting consumer-friendly private market reforms will be among their top goals for 2009. Targeted reforms include strengthening regulation of health premiums, establishing purchasing pools for small business, and expanding coverage for adult dependents.

Fourteen states have proposals for comprehensive reform on the table.<sup>10</sup> While anemic state budgets and state policymakers' hesitancy to take action prior to the national reform debate are obstacles to achieving comprehensive state-level reform this year, state advocates are trying to move forward in response to public demand.

An overwhelming majority of advocates surveyed - 40 of the 50 - reported that a top barrier to reform in their states is the weakening economy. Policy priorities for 2009 reflect that trend. In 11 states, up from eight in 2008, advocates say finding new revenue sources is necessary this session.

## **Medicaid Defense**

Many states significantly expanded Medicaid and SCHIP coverage over the past few years.<sup>11</sup> Undoing these creative and positive coverage expansions would be counterproductive as the country edges closer to national health reform.

Fortunately, the worst cuts to Medicaid and SCHIP programs were largely averted in 2008, despite states' immense fiscal pressures. This success was primarily due to advocacy campaigns that mobilized public support of critical safety net services.

### **Few eligibility cuts in 2008**

Only four states cut Medicaid or SCHIP eligibility in 2008. Hawaii and Rhode Island reduced eligibility for children's coverage. Rhode Island, Tennessee and Illinois restricted Medicaid for adults. Community Catalyst did not track other Medicaid cuts, such as those to provider rates, changes in benefit packages, or reductions in funds for outreach and enrollment, which occurred in some states.<sup>12</sup> Eligibility cuts pose the most severe threat to health access.

In light of the economic crisis, it is surprising that more states did not cut public program eligibility. With pressure to find savings in state spending, the Medicaid program, accounting for 17 percent of the average state budget, is a tempting target.<sup>13</sup> However, by raising the consumer voice to support these important programs, advocates were successful in defending Medicaid against major cuts.

For example, California faced a \$17 billion deficit in 2008, which led the governor to propose Medicaid cuts that could have denied health coverage for more than one million Californians. Consumer advocates responded by uniting a broad-based coalition of health and human service organizations to defend Medicaid. Advocates developed fact sheets for legislators and the media that translated the cuts into the number of Californians who would lose health insurance.<sup>14</sup> Advocates also distributed papers that detailed the cuts' effects on private insurance premiums<sup>15</sup> and California's economy as a whole.<sup>16</sup> Consumer advocacy organizations also held rallies and earned significant media coverage.<sup>17</sup> By articulating the harm to consumers and the larger community, California advocates warded off the worst of the proposed Medicaid cuts in 2008. While the state cut reimbursement rates for providers and imposed greater reporting requirements for families, advocates helped to prevent 400,000 low-income parents from being cut, and preserved vision, dental and other vital services.<sup>18</sup>

This success story is not unique to California—advocates across the country achieved victories using similar tactics. In fact, advocates in 13 states reported working on some aspect of Medicaid defense (i.e. preventing benefit or eligibility cuts, or defending against burdensome enrollment or renewal practices) as a top priority in 2008, with 70 percent of advocates reporting they successfully prevented at least some of the proposed Medicaid or SCHIP cuts.

### **Prospects for 2009**

Defense of Medicaid and SCHIP will become even more essential in 2009 and 2010, as at least 47 states face budget shortfalls.<sup>19</sup> The recent federal stimulus provides a much-needed boost in Medicaid funds to states, and requires states to preserve eligibility. However, many states are pursuing cuts to benefits, provider rates, or outreach and enrollment support.<sup>20</sup> At the same time, public concern about access to affordable health care is rising as the recession continues to threaten families' access to employer-based insurance.

Advocates are responding to increased public concern by shifting resources toward Medicaid defense. The number of states in which advocates report that Medicaid defense will be one of their top policy priorities rose from 13 to 16 between 2008 and 2009.

For example, Utah now faces a budget deficit totaling more than 10 percent of its general fund.<sup>21</sup> Advocates are rolling out a sophisticated Medicaid defense campaign. At least 26 organizations, including provider groups and consumer advocates, formed the Utah Medicaid Partnership to protect the program. They have proposed cost-saving alternatives such as strengthening the state's preferred drug list and creating pilot programs to experiment with more effective payment systems in Medicaid.<sup>22</sup>

To emphasize the human impact of the proposed cuts, advocates in Utah created an online story bank of families covered by the Medicaid program.<sup>23</sup> Advocates also organized town hall meetings, summits with legislators, and press conferences for families to share their stories. The campaign has earned significant media coverage, including [a report](#) that highlights individuals whose lives would be devastated by proposed cuts to the Medicaid program.

Highly effective defense campaigns require significant resources, and consumer advocacy organizations are not immune to the effects of the recession. These groups typically rely on grants from foundations, as well as individual donors. Because foundations' assets have declined by 28 percent on average in the past year, many have reduced grant amounts.<sup>24</sup> The recession's toll on nonprofit organizations is becoming apparent as more are forced to lay off staff due to reduced resources.<sup>25</sup> But now the work of consumer advocacy organizations is most critical. As always, Philanthropic organizations' investments in state-level advocacy will continue to be essential to protecting safety net services and maintaining momentum for national reform.

## Conclusion

States' experiences moving health reform in 2008 reveal two important lessons about advancing health reform in the upcoming years.

- **To expand access on the state and national levels, consumer advocacy organizations must continue drawing upon public demand for quality affordable health care.** Support from philanthropic entities has enabled advocates to launch successful and targeted grassroots campaigns for expanded health care access. These campaigns have helped maintain the momentum for health reform in the face of budget crises, political opposition and other barriers. The campaigns have helped protect Medicaid and SCHIP, expand public programs, and promote a more responsive insurance market on the state level. Since federal reform will face many of the same barriers, effective consumer advocacy campaigns will be critical to the success of national reform efforts as well.
- **To facilitate future state expansions, the federal government must enhance its partnership with the states.** Specifically, as part of a comprehensive national health reform law, the federal government can streamline the process for expanding Medicaid, promote cost containment, and allow states to benefit from savings to Medicare. The federal government could also partner with states to enhance access to health insurance by requiring a minimum set of insurance rules, such as guaranteed issue and prohibition of preexisting condition exclusions and experience rating. Finally, federal reform could provide support to states transition to these insurance reforms by helping fund subsidies and reinsurance.



## State action on health coverage in 2008

Each square represents a state that passed legislation

- Eligibility expansion or policy likely to increase coverage
- Cut to eligibility or policy likely to reduce coverage

Children's eligibility public ■■■■■■■■■■■■ 11  
□□□ 3

Adult eligibility public ■■■■■■■■■■ 10  
□□□ 3

Private insurance reform ■■■■■■■■■■ 11  
□□ 2

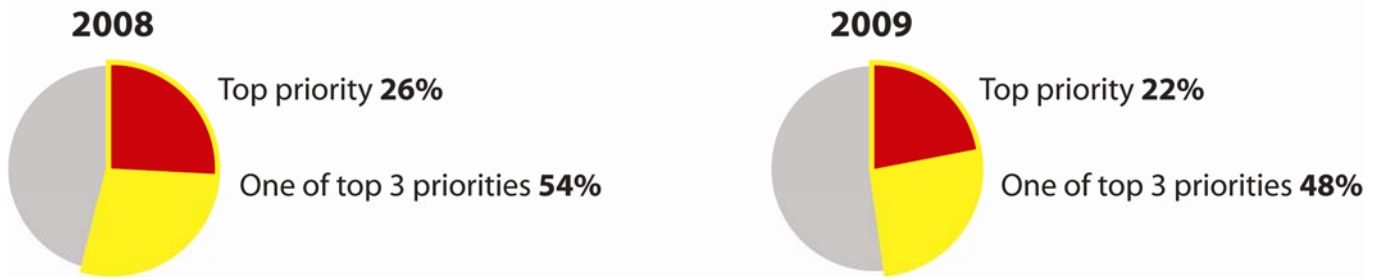
Employer mandate ■ 1

Individual mandate ■ 1

# Growing Focus on Medicaid

Little change in focus on children's issues, but significant increase in work on adult coverage

States listing **"Expansion or defense of Medicaid/SCHIP eligibility for children"** in their top three policy priorities



States listing **"Expansion or defense of Medicaid/SCHIP eligibility for adults"** in their top three policy priorities



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- <sup>1</sup> California Healthline. Recession Drives Up Number of Californians Without Insurance. April 02 2009. <http://www.californiahealthline.org/Articles/2009/4/2/Recession-Has-Driven-Up-Number-of-Californians-Without-Insurance.aspx>
- <sup>2</sup> Due to 2009 budget cuts, the funds for these subsidies were suspended for the time being. See Senate Democrats Washington State. 2008. Breaking Issues: Governor's Budget. <http://sdc.leg.wa.gov/breakingissues/2008/12/govbudget.htm>
- <sup>3</sup> McDonough, John E, Michael Miller and Christine Barber. 2008. A Progress Report On State Health Access Reform. Health Affairs. 25(6): w420-w431.
- <sup>4</sup> The Obama Administration repealed the August 17 directive on February 2, 2009.
- <sup>5</sup> Georgetown Center for Children and Families. CMS August 17 Directive. <http://ccf.georgetown.edu/index/cmsdirective>
- <sup>6</sup> Seckel, Rich, Kentucky Equal Justice Center. 2009. Email to the author. March 27.
- <sup>7</sup> Kaiser Family Foundation. 2009. Individual Market Guaranteed Issue, 2008. <http://www.statehealthfacts.org/comparetable.jsp?ind=353&cat=7>
- <sup>8</sup> Kaiser Family Foundation. 2009. Individual Market Rate Restrictions, 2008. <http://www.statehealthfacts.org/comparetable.jsp?ind=354&cat=7>
- <sup>9</sup> See Pollitz, Karen and Eliza Bangit. 2005. Federal Aid to State High Risk Pools: Promoting Health Insurance Coverage or Providing Fiscal Relief? The Commonwealth Fund.
- <sup>10</sup> The Kaiser Commission on Medicaid and the Uninsured. 2008. States Moving Toward Comprehensive Health Care Reform. [http://www.kff.org/uninsured/kcmu\\_statehealthreform.cfm](http://www.kff.org/uninsured/kcmu_statehealthreform.cfm)
- <sup>11</sup> Heberlein, Martha, Cindy Mann, Jocelyn Guyer, and Dawn Horner. 2008. States Moving Forward: Children's Health Coverage in 2007-08 McDonough, John E, Michael Miller and Christine Barber. 2008. A Progress Report On State Health Access Reform. Health Affairs. 25(6): w420-w431.
- <sup>12</sup> Criteria for state health coverage changes were limited to eligibility for the purposes of this research. Community Catalyst did not track other changes to Medicaid and SCHIP that may indirectly affect access and coverage. See Appendix 1 for details on data and methods.
- <sup>13</sup> Selway, William. 2008. U.S. States Cut Spending for First Time Since 1983. Bloomberg, December 15. <http://www.bloomberg.com/apps/news?pid=newsarchive&sid=aSKM5LUshx4g>.
- <sup>14</sup> Health Access. 2008. Not Just a One-Time Cut: Permanent Policy Changes in Governor's Budget Would Deny Coverage to More Than One Million Californians. <http://www.health-access.org/preserving/Docs/HACoverageImpactReport06-25Final.pdf>
- <sup>15</sup> Health Access. 2008. Adverse Reaction: Proposed Health Budget Cuts Would Lead to Increased Health Insurance Premiums. <http://www.health-access.org/advocating/docs/CostShiftHAPaper2008FINAL081308.pdf>
- <sup>16</sup> Health Access. 2008. Significant Side Effects: The Economic Impacts of Health Care Cuts in California Communities. <http://www.health-access.org/advocating/docs/EconomicImpactHC08-14-08Final.pdf>
- <sup>17</sup> Rau, Jordan. 2008. Los Angeles Times. Gov. Loses Backing of Healthcare Groups. June 26.
- <sup>18</sup> Health Access Blog. 2008. Yearly Wrap Up: Budget. [www.health-access.org](http://www.health-access.org).
- <sup>19</sup> Lav, Iris J. and Elizabeth McNichol. 2009. State Budget Troubles Worsen. Center on Budget and Policy Priorities. <http://www.cbpp.org/9-8-08sfp.htm>. Accessed May 5 2009.
- <sup>20</sup> See for instance Miller, Andy. 2009. Possible cuts to Medicaid payments called 'devastating.' The Atlanta Journal-Constitution. March 30, and Kaiser Daily Health Policy Report. 2009. Kaiser Daily Health Policy Report Highlights Medicaid News in Louisiana, Massachusetts, Washington State. [http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=57835](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=57835).
- <sup>21</sup> Lav, Iris J. and Elizabeth McNichol. 2009. State Budget Troubles Worsen. Center on Budget and Policy Priorities. <http://www.cbpp.org/9-8-08sfp.htm>
- <sup>22</sup> Judi Hilman, Utah Health Policy Project. 2009. Email to the author, February 9.
- <sup>23</sup> Utah Health Policy Project. 2009. Storybank- Utahns speak up. <http://www.healthpolicyproject.org/Storybank.html>
- <sup>24</sup> Barton, Noelle and Ian Wilhelm. 2009. Taking a Big Hit. The Chronicle of Philanthropy. <http://philanthropy.com/premium/articles/v21/i08/08000601.htm>
- <sup>25</sup> Preston, Caroline. 2009. Letting Go. The Chronicle of Philanthropy. <http://philanthropy.com/premium/articles/v21/i08/08001301.htm>