Making Health Reform Work: State Consumer Assistance Programs
32 million Americans will soon begin enrolling in health insurance. Is your state ready?

To help ease the transition, the federal health reform legislation includes funding for outreach and enrollment assistance through independent consumer assistance programs. This report provides recommendations for policy makers considering how to best provide these essential services in their communities.

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The historic federal health care reform legislation of 2010, the Patient Protection and Affordable Care Act (PPACA), promises to provide health coverage to approximately 32 million people. Under this new law, the year 2014 will be one of extraordinary opportunities and challenges. Millions of people will enroll in health insurance in order to comply with the new law’s individual mandate, or coverage requirement. Many of these consumers, a significant number of whom live in diverse and vulnerable communities, will require help understanding their options, enrolling in private or public insurance, and using their new coverage. To smooth the transition, Congress included a provision to fund independent consumer assistance programs, or ombuds programs, starting in 2010. Beginning in 2014, these programs will be supplemented by state-based “Navigators,” which will work on a contractual basis with the state-based insurance Exchanges.

Consumer assistance programs provide a range of essential services to health care consumers who may have questions about choosing health insurance or accessing their health benefits. Most consumer assistance programs perform four basic functions: education; assistance with enrollment and renewal of coverage; navigation of coverage and benefits; and a “sentinel function,” reporting back to policy makers about problems with existing programs and regulations.

In this report, we review the history, structure, functions, and the policy successes of organizations that represent the four most common models of consumer assistance programs in use today: (1) nonprofit community-based organizations; (2) public-private hybrids; (3) government -run ombuds programs; and (4) private contractor/call-centers. Based on this analysis, we provide recommendations for states looking to create or replicate programs in order to draw down new funding during the initial phases of health reform implementation, or to simply comply with the new requirements of federal health law when fully implemented. We determined that consumer assistance programs are most effective when they feature the following characteristics:

- **Independence**: programs should be independent of state regulatory agencies, but have strong feedback relationships with these entities.
- **Breadth of services**: programs should serve consumers with all types of coverage.
- **Community presence**: programs should be based in the communities they serve, be culturally competent and have multiple language capacity, and should be able to reach consumers without internet access either by the telephone or through in-person assistance.
- **Professionalism and expertise**: programs should employ professional staff, emphasize training, and should have support from advocacy agencies.
- **Technological capacity**: programs should have or quickly acquire sophisticated data management programs to track trends and should employ online tools to serve consumers more quickly and effectively.
- **Sustainability**: programs should have a sustainable funding source.

As federal health reform is implemented, consumer assistance programs will act as an important bridge for health care consumers to help them better understand and take full advantage of the reformed health care system. Community-based nonprofit consumer assistance programs offer the most comprehensive, independent, and culturally appropriate services to consumers. These programs can be vital resources for states to build upon. States should consider the lessons learned from these existing models as they move forward with designing and funding a consumer assistance program that is right for their residents.
Federal Health Reform:
Challenges and Opportunities
The historic federal health reform legislation of 2010, the Patient Protection and Affordable Care Act (PPACA), holds the promise of providing health insurance coverage to 32 million more people in the United States.\(^1\) Under the new law, the year 2014 will be one of extraordinary opportunities and challenges. Millions of people will enroll in health insurance to comply with the new law’s individual mandate provision. No other law has contemplated enrolling so many people in health coverage, so fast.

In 2014, the Congressional Budget Office estimates that 16 million people will enroll in public coverage through expanded Medicaid programs or State Children’s Health Insurance Programs. Many of these people live in diverse and vulnerable low- and moderate-income communities.\(^2\) Another 24 million people will purchase coverage through the newly formed state insurance Exchanges.\(^3\)

While the law makes great effort to simplify and streamline enrollment into health insurance, many intractable challenges exist. For example, how will the Exchanges ensure that individuals and families enroll in the right coverage? How will consumers be evaluated for and access subsidies? How will they use their coverage once enrolled? Moreover, despite the historic nature of this law, current public opinion research reveals that many Americans remain deeply confused and even skeptical about what the new law will do to help them and their families. In many communities, suspicion of government-run services is widespread.

Congress, recognizing these concerns, included a provision to help prepare individuals and families for these sweeping changes to our health care delivery system by establishing a funding stream to support independent consumer assistance programs (CAPs), or ombuds programs. The law allocates $30 million in funding for such programs in 2010, with authority to allocate additional funds in the coming years.\(^4\) In July 2010, the Department of Health and Human Services issued the first solicitation to the states to apply for federal funding to establish independent CAPs, which indicated that programs grants will start as early as October 2010.\(^5\) By 2014, the law shifts much of the outreach and enrollment tasks for some consumers to the state insurance Exchanges, which are required to contract with local “Navigators.”\(^6\) These entities are similarly charged with the mission to educate consumers about their health care options and assist them with their enrollment and navigational needs and, in many cases, may be the logical expansion of existing consumer assistance programs.

Federal and state policy makers can immediately begin leveraging the opportunity presented in PPACA by either establishing or funding existing CAPs to help meet the demand for information about health reform. Many consumers already are seeking assistance with an array of new changes in public and private insurance coverage, the introduction of “high risk” programs for patients with pre-existing conditions, and new policies concerning young adults, to name just a few. Moreover, investing in CAPs now will help states lay the groundwork for more significant changes down the road. For example, the recent state reform experience in Massachusetts illustrates how an

About this Report

The Community Service Society and Community Catalyst identified a universe of more than 100 consumer assistance programs active in the United States—tailored to different payors and populations. We conducted a qualitative analysis in order to determine the most representative program designs and primary functions of consumer assistance programs.

We identified four common models of consumer assistance programs: (1) nonprofit community-based organizations; (2) nonprofit/government hybrids; (3) government-run offices or programs; and (4) private call centers. We selected eight representative programs and evaluated their history, population served, organizational structure, and effectiveness at performing the primary functions of CAPs. Descriptions are based upon a literature survey, review of annual reports from the selected programs, and interviews with directors and staff.
established program can quickly mobilize to help consumers contending with major changes in the health care system. There, the CAP operated by Health Care For All experienced a 400 percent increase in call volume in the months after health reform took effect.

States seeking to design and implement consumer assistance programs appropriate to the needs of their constituencies have several models to choose from. This report seeks to explain the relative strengths and weaknesses of each model and provide practical considerations for policy makers.

We argue that nonprofit community-based consumer assistance programs, with their local knowledge, connections, and expertise, are best positioned to explain the new law to individuals and families in the neighborhoods in which they live and work. Whether helping a retired teacher in California or a low-waged immigrant worker in East Harlem, these locally-based programs know the unique needs of their constituents. Mature and effective CAPs, such as Community Health Advocates, operated by the Community Service Society (CSS) in New York, often work with a broad network of community partners to ensure the delivery of efficient, culturally competent health help to people in their own neighborhoods. These “trusted messengers” understand how to reach and assist diverse, low-income, and vulnerable populations—the people who will be most dramatically affected by health reform.

In addition, effective CAPs play an important “sentinel” function. They serve as the eyes and ears of policy makers, yet remain independent of changes in political administrations. Although independent, these programs work closely with government officials to alert them to emerging trends, issues, and challenges faced by their shared constituencies. CAPs perform this important reporting function by providing real-time, data-driven feedback and recommendations both when the best-laid plans go awry, and when health care programs positively change people’s lives.

The Federal Health Reform Law Lists Five Functions of Independent CAPs

The PPACA appropriates $30 million to support new or existing independent CAPs. To qualify for funding, programs must work with state health insurance regulators and consumer assistance organizations to help consumers navigate the new health care system. The required tasks go far beyond simply enrolling consumers. Section 1002 of the law details five functions of CAPs:

1. Help consumers enroll in coverage;
2. Educate consumers about their rights and responsibilities regarding their health insurance plans;
3. Help consumers file internal appeals and educate consumers about external appeals;
4. Report on problems that consumers experience by collecting and analyzing data to share with the Department of Health and Human Services; and
5. Help consumers obtain premium tax credits.

“Nonprofit community-based consumer assistance programs, with their local knowledge, connections, and expertise, are well positioned to explain the new law to individuals and families in the neighborhoods in which they live and work.”
Consumer assistance programs help people who have questions about health insurance, are trying to enroll in an insurance plan, or are having trouble accessing and using their health coverage. They may be housed in a variety of venues, from nonprofit community-based organizations to government-run agencies, and can serve any number of people, from single communities to entire states. Each program often targets a different set of needs. For example, certain CAPs may serve consumers with only one type of coverage, like Medicare or Medicaid; other broader “all-payer” programs are designed to help consumers navigate different kinds of health care coverage, such as hospital charity care programs for the uninsured, public programs, and private insurance.

Many CAPs were created or grew exponentially to help consumers adjust to major changes in state health policy. For example, the Medicare SHIPs started in the early 1970s and now exist in every state to help seniors use Medicare. In the 1990s, California’s Health Consumer Alliance (HCA) and New York’s Community Health Advocates (CHA) were founded to help Medicaid beneficiaries switch from Medicaid Fee-for-Service into Medicaid Managed Care plans.
While they may vary in size, type, and scope, most consumer assistance programs perform four basic functions:

- **Education;**
- **Assistance with enrollment and renewal of coverage;**
- **Navigation of coverage and benefits;** and
- **Reporting back to policy makers (the “sentinel” function).**

### Education

CAPs provide health education and information to consumers, which can include distributing informative materials to the public, as well as more intensive outreach, such as presentations to groups or free one-on-one counseling sessions. Each organization develops materials appropriate for the population they serve, often distributing information in multiple languages and for differing levels of accessibility. This targeted educational outreach is essential so that consumers are able to quickly and effectively use this information to obtain coverage.

### Enrollment and Renewal of Coverage

CAPs also help consumers apply for public health insurance programs and enroll in health plans. Applying for any kind of health coverage—private or public—can be a complicated and frustrating endeavor, particularly for consumers who may be low-literacy or have a limited proficiency in English. CAPs guide consumers step by step through the process, answering questions and explaining requirements.

Even after a consumer is enrolled in a health insurance program, help is often needed in order to make important decisions regarding coverage, or to facilitate coverage renewals. For example, nearly every state Medicaid program requires an annual renewal process in which beneficiaries must re-prove their eligibility for coverage. CAPs add significant value for consumers needing to maneuver through this process. For example, in 2009, the rate of Medicaid and Family Health Plus renewals in New York City hovered around 73 percent. Consumers who sought renewal assistance from CHA were able to successfully recertify 89 percent of the time.

### Navigation

CAPs also help consumers use, or navigate, their coverage once they are enrolled. Navigation assistance can include choosing the right primary care doctor, sorting out billing issues, and fighting insurance denials. CAPs often represent consumers directly with providers and insurers; in insurance appeals, Medicaid fair hearings, or federal Medicare hearings; and occasionally even in court. Even when consumers
are not eligible for public insurance programs or cannot afford private insurance, CAPs can often help by connecting them to sources of free or discounted health care.

**Sentinel Function**

Finally, CAPs are the health care system’s “first responders,” reporting back to policy makers on the trends and glitches with the health care system encountered at the ground level. Most CAPs maintain databases to record client data, which allows them to track trends in coverage, enrollment, and other outcomes. By collecting data on individual cases, CAPs are able to detect patterns relating to specific policies—often much faster than can be done at the state level. In this respect, CAPs serve as the eyes and ears of policy makers, identifying problems before they become headlines, and often working with state officials to identify appropriate policy changes.

For example, in June 2008, Health Care For All (HCFA), a CAP in Massachusetts, began to receive many calls to their HelpLine regarding termination notices from people they had helped enroll in the state-subsidized health insurance program, Commonwealth Care. HelpLine counselors determined that these enrollees had not been sent the appropriate recertification notices and promptly alerted state officials. Working together, HCFA and the State were able to solve the problem quickly and prevent thousands of consumers from accidentally losing their coverage.

By fulfilling these essential functions—education, enrollment, navigation, and reporting back to policy makers—CAPs fill the void that exists between the average consumer and the dauntingly complex world of insurance plans, public programs, and health providers. The help of a skilled CAP can make an enormous difference to a consumer struggling against the often murky web of administrative agencies and regulators, insurance laws and regulations, and confusing health care jargon. By helping to ensure that individuals and families understand their choices and can make effective use of their health plans, CAPs save consumers, providers, insurers, and the government millions of dollars every year.

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**CAPs NAVIGATE:**

**Maine Program Wins Appeal in 24 Hours!**

Jane Bunyan, a caller to the Consumers for Affordable Health Care in Maine HelpLine, recalls the frustration she felt when her insurance company wouldn’t authorize a necessary procedure: “My husband needed a neuropsychological exam after a stroke to assess the nature of the damage. Our managed care company refused to authorize the exam and gave us one excuse after another. I needed legal assistance.” The HelpLine’s staff attorney contacted Ms. Bunyan’s doctor, and helped the doctor provide the additional information that was necessary to appeal the company’s decision. Ms. Bunyan marvels, “One day after receiving the attorney’s appeal letter, my husband’s exam was authorized.”

Source: Consumers for Affordable Health Care, Presentation at Consumer Voices for Coverage Annual Meeting (September 2009) (Consumer’s name has been changed to preserve confidentiality).
Consumer Assistance Programs in Action: A Closer Look at Representative Programs
There are many models of CAPs operating throughout the United States today. This report reviews four of the most common models: (1) nonprofit community-based organizations; (2) nonprofit/government hybrids or partnerships; (3) government-run programs; and (4) private call centers. Based on available information, we selected programs representing each of these models, with a close review of several distinct service models offered by community-based nonprofits. For each program reviewed, we highlighted defining program characteristics such as population served, types of insurance, methods of outreach, education, and assistance, and services provided. The programs described are:

**Model #1: Nonprofit Community-Based Organizations**
- The HelpLine Model: Health Care For All, Massachusetts
- The Community-Based Organization Model: Community Health Advocates, New York
- The Legal Services Model: Health Consumer Alliance, California

**Model #2: Nonprofit/Government Hybrids or Partnerships**
- The State Health Insurance Program Model, nationwide

**Model #3: Government-Run Programs**
- The Ombudsman Model: Office of the Governor, Consumer Health Assistance Office, Nevada

**Model #4: Private Call Centers**
- The Call Center Contractor model: The Medicare Hotline, nationwide
Model #1: Nonprofit Community-Based Organizations

The HelpLine Model: Health Care For All (HCFA), Massachusetts

- **Type of organization**: Nonprofit advocacy agency
- **Size of HelpLine**: Five staff members, plus interns and volunteers
- **Service area**: Statewide in Massachusetts
- **Target population**: All payors, all ages
- **Number of consumers served**: 36,842 calls in 2009
- **Budget and funding sources**: $554,275 from foundation and federal grants and individual donations

Source: Health Care for All, Massachusetts

History

Health Care For All (HCFA) was founded in Massachusetts in 1985 with a mission to advocate for comprehensive, affordable, accessible, culturally competent, high-quality health care and consumer education for everyone, especially the most vulnerable. The organization expanded to include a HelpLine in 1992, which for years served a small volume of consumers.

In 2006, Massachusetts passed a landmark health reform law that opened up new insurance options for hundreds of thousands state residents, and required all residents to get health insurance coverage. This sweeping reform prompted an immediate surge in the volume of HCFA’s HelpLine calls, from around 500 per month to more than 4,000. Many people had never had insurance before, and needed assistance with the complex application and eligibility process. As consumers became more aware of the new requirements and key deadlines approached, HCFA received as many as 2,000 calls per week.

With passage of health reform in Massachusetts, more than 400,000 residents became newly insured. Many observers have credited the enrollment assistance, outreach, and navigation services provided by programs such as HCFA’s HelpLine with helping to integrate these new consumers into the health care system. The success of HCFA and other similar groups has led to further capacity-building investments from the state, corporate sponsors, and foundations.

Helpline Call Volume, 2005-2009

![Helpline Call Volume, 2005-2009](chart.png)
Organizational Structure
HCFA is a nonprofit consumer advocacy organization that has provided policy analysis and advocacy on health care issues in Massachusetts since 1985—including participating extensively in the legislative process leading up to state health reform. HCFA staffs its HelpLine with four full-time, trained telephone counselors, a full-time manager, volunteers, and interns. HelpLine counselors are supported by HCFA's policy staff, who help to resolve difficult new consumer questions and identify systemic problems as they emerge.

Services Provided
Counselors take calls in English, Spanish, Portuguese, and Mandarin. Using a web-based technology called HelpEngen, staff help callers fill out applications for subsidized health coverage under the new law and guide them through the enrollment and renewal processes from start to finish. HelpLine counselors also help consumers navigate their coverage and resolve other health access issues.

In addition to helping consumers enroll in and navigate coverage, the HelpLine has provided critical information to state officials throughout the state health reform implementation process by identifying and documenting trouble spots, such as an early backlog in applications for the state’s subsidized insurance program, Commonwealth Care. This early feedback has enabled state officials to respond to such problems as they arise.

Lessons
- **Consumers need help in major health system transformations**—nonprofit Consumer Assistance Programs can rapidly respond to glitches and ease these transitions. Massachusetts’ sweeping reform of its health insurance system took place quickly and with relatively few glitches. Within two years, the state reduced the number of uninsured residents to less than 3 percent, the lowest rate in the nation. HCFA's HelpLine helped to ensure that this process ran smoothly and successfully.
- **Online tools can increase the efficiency of consumer assistance programs and reduce costs.** HCFA uses online software that allows counselors to screen and help consumers apply for coverage, often resolving problems on the spot, while reducing lag time for consumers, increasing accuracy, and saving the state administrative costs.

Health reform in Massachusetts gave Brenda and Daniel their first opportunity in years to secure health insurance. A call to the HCFA HelpLine connected them to a counselor, who helped them review their options and sign up for insurance. The timing was fortunate: shortly after gaining coverage, Daniel was diagnosed with a serious heart condition. Then Brenda and Daniel had a son, who spent a week in intensive care for respiratory problems.

“Health Care For All has been such a gift to our lives,” says Brenda. “If it wasn’t for our eligibility with the [State’s new health care reform] programs, we would probably have found out about his heart disease too late. And then came the unexpected surprise of having my son in neonatal care for a week.” Brenda and Daniel were relieved to have some of the financial burden lifted because, as Brenda describes, “both of these situations were hard enough to go through emotionally. We are just so amazed to be Massachusetts residents and able to count on the tremendous support we received from the HelpLine counselors.”

Source: Federal Register, December 10, 2009 at S12860.
The Community-Based Organization Model:
Community Health Advocates of New York

- **Type of organization:** Network of community-based nonprofit organizations
- **Size:** 10.5 staff members at a central support organization and 35–45 staff members at 25 community-based organizations
- **Service area:** New York City area
- **Target population:** all payors, all ages
- **Number of consumers served:** 10,000 consumers in 2009

**History**

Community Health Advocates of New York (CHA) [formerly the New York City Managed Care Consumer Assistance Program (NYC MCCAP)], was established in 1998 in response to enrollment problems that arose during the transition from Medicaid fee-for-service to managed care—especially for New York’s low-income, culturally and racially diverse populations. However, from the beginning, CHA has served consumers with all types of insurance and even those without any coverage at all.

**Organizational Structure**

CHA is based on a decentralized “hub-and-spokes” model. The Community Service Society (CSS)—an independent nonprofit advocacy group—plays the role of the central hub and fiscal conduit to a citywide network of 25 existing community-based organizations (CBOs). CSS maintains a central, password-protected database, which each CBO accesses over the internet. CSS staff work closely with each CBO to coordinate program work, provide technical assistance, training, individual case reviews, and data collection, and facilitate regular meetings for CBOs to jointly discuss emerging issues and unique cases. CSS develops program resources such as a website, an advocate’s guide, and informational brochures for advocates and consumers. CSS operates a helpline for consumers to call directly with questions or issues regarding their health insurance. CSS also employs a number of policy staff who work to bring systemic and community-level issues that arise to the attention of City and State officials.

CBOs are the heart of the CHA program. “You have to train peer and lay advocates in the communities you want to reach, so your services are accessible,” explains Christine Molnar, former CHA Director. These organizations bring an established sense of trust from the communities they serve.

**FY 2009 MCCAP Consumers by Insurance Type**

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Percent of Consumers</th>
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<tbody>
<tr>
<td>Medicaid</td>
<td>38%</td>
</tr>
<tr>
<td>Uninsured</td>
<td>27%</td>
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<tr>
<td>Dual Eligible</td>
<td>11%</td>
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<tr>
<td>Medicare</td>
<td>10%</td>
</tr>
<tr>
<td>FHP</td>
<td>8%</td>
</tr>
<tr>
<td>Commercial</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
</tr>
<tr>
<td>CHP</td>
<td>1%</td>
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*Others includes Union and Veteran’s coverage.*

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*12*
and have the capacity to communicate with consumers in 11 different languages. Through the CBOs, CHA is able to reach vulnerable communities, such as immigrant groups, people with disabilities, homeless people, low-income or low-literacy populations, and the formerly incarcerated. Two CHA agencies, the Medicare Rights Center and the Legal Aid Society, provide further technical assistance to advocates and clients. CHA’s funding has traditionally been based on a grant from the New York City Council, which leverages additional funds from the federal Medicaid program. Because these funds must be allocated annually by a vote of the City Council, CHA’s funding has a level of uncertainty.

**Services Provided**

In 2009, CHA provided individual assistance to nearly 10,000 health care consumers with all types of insurance. This included helping people determine eligibility for public programs, better understand how to effectively use their benefits, resolve billing problems, or find health care providers within their community. The program also helped uninsured consumers find ways to reduce their medical bills and find sources of free or low-cost care. CHA staff also conducted 400 trainings geared to advocates and consumers.

**Lessons**

- **Community-based organizations can serve hard-to-reach populations.** CHA’s diverse network of CBOs brings outreach, education, and counseling to the city’s most vulnerable neighborhoods. This includes the ability to provide linguistically and culturally appropriate services. CBO staff members provide face-to-face contact with consumers through a trusted presence in the communities they serve.

- **An online database helps keep program leaders ahead of systemic problems and trends on the ground level.** CHA’s web-based system enables CBO staff to record each interaction with consumers. The database allows CHA’s central managers to keep in touch with CBO counselors, helping to troubleshoot cases and ensure quality control. It also allows CHA to identify trends, document problems, and suggest policy changes before problems become widespread.

- **CAPs that are housed in nonprofit organizations are able to perform the sentinel function with a strong independent voice.** CHA’s central hub, the Community Service Society of New York (CSS), is an independent organization with a 160-year history of advocacy in the fight against poverty. CSS also has the expertise and capacity to analyze CHA data, research policy options, and write reports and other materials to support policy solutions for problems identified through the program.

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**CAPs EDUCATE:**

**Making COBRA Work**

In 2009, at the peak of the “Great Recession,” the federal government enacted a new premium subsidy to help laid-off workers pay for health insurance premiums under the Consolidated Omnibus Budget Reconciliation Act—better known as “COBRA.” In New York, State law was modified to extend COBRA eligibility from 18 to 36 months.

Immediately, Community Health Advocates (CHA) saw an increase in the number of consumers calling their helpline with COBRA questions. By the end of the third quarter of the year, the number of calls about COBRA grew three-fold. CHA embarked on an educational campaign about COBRA and the new premium subsidy, training its network of 25 community-based organizations and other groups, such as workforce agencies. CHA also learned that locally- and nationally-based employer benefit managers were unaware of the State’s COBRA extension and were prematurely terminating out-of-work consumers’ coverage. CHA collected representative cases and, working with the relevant government agencies, contacted the major out-of-state benefit managers, employers, and insurers to educate them about the new rules.
The Legal Services Model: Health Consumer Alliance, California

- **Type of organization:** Network of legal services and support organizations
- **Size:** Seven staff members at two support organizations and 59 staff members at nine community-based organizations
- **Service area:** 13 counties in California across the state
- **Target population:** All payors, all ages
- **Number of consumers served:** 12,798 in 2009
- **Budget and funding sources:** $10 million in grants from foundations, state agencies, counties, cities, and health plans

Source: Health Consumer Alliance, California.

**History**

California’s Health Consumer Alliance (HCA) was developed in 1998, when some Medicaid beneficiaries were transitioning into managed care plans and others were experiencing Medicaid terminations as a result of the implementation of the 1996 welfare reform law. Legal services groups saw an increase in questions from clients about how to access health services. The HCA grew out of a proposal by six legal organizations to address the problems they were seeing. “The program designers wanted to bring together a mix of organizations that served communities that were urban and rural, small and big, conservative and liberal, and balanced to work in partnership and collaboration,” says Mabel Ponce-Koch, Project Director of the Health Consumer Alliance.19 Another legal services model—Vermont Legal Aid’s Office of Health Care Ombudsprogram—is authorized under State statute and funded by the Government of Vermont.20

**Organizational Structure**

The Health Consumer Alliance serves consumers in 13 counties through a network of nine community-based legal services organizations called Health Consumer Centers.21 The National Health Law Program (NHeLP) serves as the lead organization and provides legal and policy support at the state and national level, maintains HCA’s database, develops educational materials for advocates and consumers, and coordinates partnership activities.22 Another partner, the Western Center on Law and Poverty (WCLP) provides similar support, focusing on state and local issues.23 The Health Consumer Centers work to solve health access problems and provide trainings and other services directly to consumers.24

**Services Provided**

While each Health Consumer Center works independently, HCA maximizes their impact and ensures consistency of service. A centralized database maintained by NHeLP tracks demographics, stories, and case trends across the partner agencies.24 Issues found in multiple locations become priorities for policy analysis and advocacy. HCA’s
advocates meet regularly to discuss emerging issues and develop policy recommendations. HCA also holds in-person, web, and telephone-based staff trainings at partner agencies on statewide and local issues.

HCA’s legal services providers have the capacity to litigate issues when advocates are unable to resolve a problem otherwise. For example, WCLP developed a class action lawsuit against one California County, representing 20 consumers who had been denied medical assistance because of the county’s low and inflexible income limits. In a decision by the State Supreme Court, WCLP was able to get the income limit increased by more than 30 percent.

Lessons

- **Program flexibility helps serve a diverse population.** HCA recognizes that diverse communities often prefer to turn to trusted local community-based groups. HCA’s network found unique ways to serve their communities, “almost organically,” according to HCA Project Director Mabel Ponce-Koch. “It is important to address the various needs of individual communities with approaches that respond to their particular needs. In some communities, setting up a hotline doesn’t work,” she explained. “People want to go in and talk to someone in person.”

- **Having legal resources at your disposal is a powerful tool.** While HCA’s advocates do not begin each case with plans to file a lawsuit, insurers and others are well aware that litigation is a possible outcome. The ability to translate the terms of an insurance contract, the regulations, or the law for their clients is an important asset, and can achieve systemic changes when necessary.

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**CAPs NAVIGATE:**

Appealing the Denial of a Child’s Asthma Medication

Abigail Walters’ son, Michael, was diagnosed with severe asthma when he was just two years old. Michael was first prescribed inhaled steroids. A few years later, he was approved for asthma step therapy management treatment, which stabilized his condition. Suddenly, when Michael was six years old, the family’s new Medi-Cal managed care plan refused to pay for Michael’s asthma medication unless he went back on inhaled steroids.

Abigail submitted her son’s Patient Prescription Record to the plan’s Pharmacy Department in an effort to document that he had already used this medication. Once again, she received a denial letter stating, “consider inhaled steroids.” Without the appropriate medications, Michael had to use his rescue inhaler more often, and his asthma-induced eczema worsened.

Abigail contacted the Kern Health Consumer Center (KHCC), one of HCA’s Health Consumer Centers. The consumer advocate submitted a grievance and materials explaining Michael’s treatment history and documenting his needs to the Medi-Cal managed care plan. Two days later, the medication was approved.

Source: HCA, California (The names in this story have been changed to preserve client confidentiality.)
History
The creation of Medicare in 1965 significantly increased access to health care for older Americans but also engendered a host of new questions and issues for seniors. The first State Health Insurance Programs (SHIPs) were created by individual state governments to help seniors navigate this new health care system. With the growth in Medicare supplemental insurance (or Medigap) plans, health care options for seniors became even more complex. In 1990, Congress responded by instituting a national SHIP program to provide health advisory services for people with Medicare through grants to the states.29

Organizational Structure
Two early SHIP programs, Washington’s Statewide Health Insurance Benefits Advisors (SHIBA), founded in 1976, and North Carolina’s Seniors’ Health Insurance Information Program (SHIIP), founded in 1986, were created and housed in their respective State Departments of Insurance. Some states have followed this trend, though many have opted instead for their State Department of Aging. These first SHIP agencies relied entirely on volunteers to counsel seniors about their choices. Over the years, many SHIPs have grown and now hire staff or make arrangements for “in-kind” volunteer relationships with local agencies. Each SHIP uses local experiences, agencies, and resources to design a unique model that works best in that area.

In addition to receiving technical assistance from the national Centers for Medicare and Medicaid Services (CMS), the SHIP network has historically received training, technical assistance, and advocacy support from the Health Assistance Partnership of Families USA that helped build SHIP programs and capacity at both the state and the local level.30

Services Provided
Expansions in Medicare coverage, including the creation of Medicare Part D prescription drug coverage, have spurred growth in the scope of assistance that SHIP staff and volunteers provide. While counselors still keep information about Medicare and related insurance programs in their repertoire, many also now provide enrollment assistance, help with billing and claims problems, and other services.31

Today, SHIP counselors help millions of seniors under-
stand, enroll into, and best utilize their Medicare, Medicaid, Medigap, Medicare Advantage, and Medicare Part D plans, and the many programs that help low-income seniors pay for care that basic Medicare does not.

Lessons

- **Relationships with consumer assistance programs can strengthen the impact of state agencies.** State SHIP programs are funded through state Departments of Aging or Departments of Insurance. These relationships allow SHIPs to both serve their clients and provide their agency with a strong feedback loop for consumer protection. As Deputy Commissioner of North Carolina’s SHIIP Carla Obiol said, “SHIIP folks have a direct line with the Department of Insurance, so we have a lot of eyes and ears out there to watch what is going on.”32

- **Trainings and other forms of staff support are important investments for consumer assistance programs with limited funds.** SHIP staff members agree that comprehensive training and staff guidance have played a critical role in the success of their programs. Correspondingly, a recent survey of SHIP directors found that they devote a significant amount of time and resources to training volunteers and staff.33

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**CAPs REPORT:**

Taking on medical debt and its many causes

The Health Insurance Counseling Project (HICP), a SHIP located in Washington, D.C., is a clinical program of the George Washington University Law School providing information, individual counseling, and advocacy for Medicare beneficiaries. HICP discovered that only around 10 percent of the eligible population was actually enrolled in the District’s Qualified Medicare Beneficiary (QMB) program for low-income seniors. HICP interviewed more than 500 Medicare beneficiaries and discovered an overly complicated enrollment process, difficulties in accessing benefits once enrolled, an asset test that was too high, and a lack of public information about the program.

HICP took its results and recommendations to the city council, which tripled the income level for the QMB program in 2006, and eliminated the asset test and simplified the application in 2008 (more than doubling the number of eligible residents). In 2009, HICP convinced the city council to authorize identification cards to QMB beneficiaries, making it easier for them to access their benefits and learn about HICP’s helpline number. As new QMB beneficiaries began to seek assistance in using their benefits, HICP’s caseload increased, from 180 cases per month in 2008 to 350 per month in 2009.

Model #3: Government-Run Programs

The Ombudsman Model: Office of the Governor, Consumer Health Assistance Office, Nevada.

- **Type of organization:** Government agency
- **Size:** Eight staff
- **Service area:** Statewide
- **Target population:** all payors, all ages
- **Numbers served:** 4,317 new cases and 5,124 other contacts in 2009
- **Funding amount, source:** $823,646, funded with workers compensation assessments, general fund authorizations, assessments on hospitals, and Medicaid


- **Type of organization:** Independent governmental agency
- **Size:** Nine staff
- **Service area:** Statewide
- **Target population:** all payors, all ages
- **Numbers served:** 2,613 closed complaints in 2009
- **Funding amount, source:** $981,577, funded by industry surcharges outside the general fund

History, Structure, and Services

The two governmental models reviewed in this report—Nevada’s Office of the Governor Consumer Health Assistance (GovCHA) and the Connecticut’s Office of the Healthcare Advocate (OHA)—were both created in 1999 to help consumers navigate their increasingly complicated health coverage options. Both agencies assist consumers with a range of services, including education, enrollment, navigation of coverage, appeals, and billing. They serve consumers with all forms of health insurance as well as uninsured consumers. They also provide a sentinel function, and participate in legislative and administrative advocacy.

The strength of these programs is their inherent authority as the government to investigate problems and enforce rules when they are broken. Nevada’s GovCHA works closely with State regulators like the Attorney General and the Board of Medical Examiners. These relationships give GovCHA staff extra authority when working out consumer issues. “We have a great rapport with the providers and insurers in the state,” explains Paulette Gromniak, GovCHA Quality Assurance Specialist. “So most of the time, when we call, we get cooperation right away. But on the rare occasions when we don’t, being able to say that I’m calling from an Executive Office of the State helps get results.” Similarly, in 2009, Connecticut’s OHA, working closely with the State Attorney General, obtained intervener status—a role unavailable to a nonprofit—in a premium increase hearing before the Connecticut Insurance Department (see box on page 20). In that role, OHA brought consumers to the hearing who would have been affected by the rate increase, raised questions about Anthem’s arguments, and brought public attention to the case. Under this pressure, the CID granted a much smaller increase than Anthem had requested.

“To ensure that a governmental program is effective, the designers must include features that guarantee its independence.”

While all consumer assistance programs face budget challenges, governmental programs sometimes additionally face political challenges from elected officials who do not support their mission. To ensure that a governmental program is effective, the designers must include features that guarantee its independence. For example, Connecticut’s OHA is headed by an independent Healthcare Advocate, appointed to a four-year term by the Governor with the approval of the General Assembly. The Governor chooses the appointee from a list of qualified candidates provided by an advisory committee, if no choice is made within 60 days, the highest-ranked candidate is sent to the General Assembly for approval. Allowing the committee to nominate the Advocate prevents a governor opposed to consumer advocacy from blocking an appointment. And the four-year term gives the Advocate some time to fight for consumer protections, including controversial measures.

Diversifying the source of a governmental program’s funding can insulate it from political pressure, as well. If a program is funded solely by annual votes of the state legislature, it will be much more vulnerable to budget cuts. While GovCHA receives some money from the state general fund, it is also funded by workers compensation assessments, hospital assessments, and funding from Medicaid. Connecticut’s OHA is funded by assessments on insurance companies, which helps ensure its independence.
Lessons

Governmental programs must be designed carefully to ensure their independence and authority. Government-run advocate programs are often at odds with state elected officials, state agencies that oversee health care programs, and other government agencies charged with regulating the insurance industry. To avoid conflicts of interest, it is critical that they are made as independent of these agencies as possible. Steps can be taken to avoid some of these pitfalls. Government advocate programs can be designed to structurally insulate them from political pressure. Finding sources of funding, such as assessments on insurers, that are not reliant on allocations from the state general fund help maintain their independence.

Governmental programs may have the authority to perform functions that nonprofit organizations cannot perform. Independent governmental health care advocates can be vested with statutory authority to intervene and represent health consumers in administrative proceedings, government councils and commissions, court proceedings, and as the voice of health care consumers in the policymaking role of state legislatures.

CAPs ADVOCATE:
Preventing Unreasonable Premium Hikes

In 2009, Anthem Blue Cross and Blue Shield of Connecticut sought to increase their individual insurance rates from 23 to 32 percent. Kevin Lembo (shown right), the Healthcare Advocate, immediately called on Anthem to withdraw the filing, and further asked the Insurance Commissioner, Thomas Sullivan, to reject the rate hike and the Governor to freeze insurance rates.

Even though the Connecticut Insurance Department (CID) is not required to hold public hearings for premium increases, and typically approves most rate increases, it held a public hearing at Lembo’s request. Lembo and the state Attorney General, Richard Blumenthal, intervened. They challenged Anthem’s justification for the increases and brought real consumers to testify about how the rate hikes would affect them. Lembo and Blumenthal argued that the CID should consider affordability as a factor in approving the rate increase and that given Anthem’s healthy profit margin in Connecticut, such exorbitant increases were unwarranted. While the CID disagreed, stating that the only factor they could consider was whether it was excessive, they approved a more modest increase from 13 to 20 percent—nearly half of what had been originally requested.

Undaunted, Lembo and Blumenthal proposed a bill in the Legislature in 2010 that would require the CID to hold public hearings on rate increases and allow the OHA and the Attorney General to appear and examine witnesses at the hearings. The bill required the CID to consider specific factors in determining whether the proposed rate is “reasonable” and actuari ally sound. The bill would have given the Attorney General and OHA the right to appeal the CID’s decision in court. The CID opposed the bill, which passed the House, but stalled on the Senate floor under time constraints.

Model #4:
Private Call Centers

The Call Center Contractor Model: The Medicare Hotline, Nationwide.

- **Type of organization:** Private call center contracted by government agency
- **Size:** Unknown
- **Service area:** national
- **Target population:** Medicare beneficiaries
- **Numbers served:** 28.1 million calls*
- **Funding amount, source:** $265.4 million,* federal appropriation

* FY 2010 budget projection

History, Structure, and Services

In addition to the services it provides through the national SHIP network, the Centers for Medicare and Medicaid Services (CMS) contracts with a private organization to provide consumer assistance to Medicare beneficiaries through a toll-free hotline, 1-800-MEDICARE. This number was established in 1998 to answer questions for beneficiaries regarding the new Medicare Choice program.

During the six months after enactment of the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA), the law that created Medicare Part D, the volume of calls to the hotline tripled. The Government Accountability Office (GAO) tested the hotline to determine how accurately customer service representatives were answering questions. They found that only 61 percent of questions were answered accurately—a problem which stemmed directly from the improper training of staff and a lack of adherence to protocol. The GAO made recommendations to revise, monitor and test the scripts used by hotline staff, and to increase training where needed.

In 2006, the GAO again tested the hotline and found that accuracy had only improved to about 67 percent. Caller satisfaction studies by the Department of Health and Human Services found similar problems with the hotline. A 2007 survey of callers found that 21 percent of callers hung up before receiving responses; more than half of those who hung up did so because the wait time was too long. Thirty-one percent of callers reported difficulty using the hotline’s automated system. Despite CMS’s efforts to improve hotline services, problems persist.

Lessons

- **A large, automated system for consumer assistance often fails to meet consumers’ needs.** By relying on contracted customer service representatives, the Medicare Hotline operates at a significant disadvantage. Using an automated system can be useful for filtering calls to proper representatives, but can also discourage or further frustrate consumers who are seeking help or information. Unlike the mission-driven nonprofit community-based CAPs reviewed in this report, call center representatives receive limited training, rely on the use of scripts, and are often unable to explain the information in the script or put it in context.
In the past, consumer assistance programs have followed a scattered pattern of growth, sprouting up in response to the needs of specific populations or in areas most affected by changes in the health care system. However, the onset of federal health reform could mark a sea-change in this pattern—not only because of the magnitude of changes involved and the subsequent need for consumer assistance, but also because it marks the first large-scale, nationwide push to provide access to quality consumer assistance for every single person in America.

Decision makers around the country now have an unprecedented opportunity to build consumer assistance programs in their own communities. The program models reviewed in this report provide valuable insights into the best practices and pitfalls to avoid when designing and implementing these programs. As states prepare to invest new federal funds for consumer assistance, they should consider the following recommendations:

- **Consumer assistance programs should be both independent of—but have strong feedback systems to—state regulatory agencies.**

  Under the American multi-payor system of health insurance, consumers routinely encounter a daunting set of multiple regulators—including insurance departments for private coverage, state health departments for public coverage, and the federal government for Medicare. Nonprofit community-based organizations can help consumers sort through the bureaucracy and get the appropriate help. While state agencies that regulate insurance companies or administer public insurance programs at first blush appear to be logical homes for CAPs, often, as both payors and regulators, these agencies have inherent conflicts of interest with CAP functions. Well-run independent CAPs leverage strong relationships with regulatory agencies to efficiently get results for their clients, while also serving as the eyes and ears on the ground for government agencies. CAPs can identify the need to intervene when an insurance company is not following the law, or when a systemic problem arises in a public coverage program. To maximize this rapid-response capacity, state agencies and CAPs should be required to share the data they collect.

- **Consumer assistance programs should serve consumers with all types of coverage.**

  Programs that serve consumers with different kinds of insurance coverage are best equipped to serve their clients effectively. Given the current patchwork of coverage options, few consumers can count on staying with one source of insurance coverage for long. A consumer who has a trusting relationship established with a specific program would be loathe to find that they could no longer call on that program for help once their type of insurance coverage changes. In the same respect, family members are
often covered by different sources of insurance. Limiting service to only those with a specific type of coverage in turn limits the program’s ability to serve their clients’ needs.

- **Consumer assistance programs should be based in the communities they serve and must be culturally competent and have multiple language capacity.**

Nonprofit community-based organizations are trusted sources of information for diverse and vulnerable communities. Trust in many of these communities is hard won. Using established community-based groups helps each program tailor their outreach and services to each community’s need. Many new enrollees in coverage will be from vulnerable and underserved communities, including communities with cultural and linguistic barriers. Programs must develop strategies to reach out to these communities and provide services that are culturally and linguistically appropriate. New York’s CHA, for example, has a network of CBOs in diverse communities that ensure that consumer assistance services are available to consumers a language they understand. Moreover, consumer assistance programs should not simply rely on the internet to reach their clients. Telephone and/or in-person assistance is essential for consumers who do not have access to the internet, or who need extra help.

- **Consumer assistance programs should employ professional staff, emphasize training and have support from advocacy agencies.**

Consumer assistance program leaders universally cite ongoing training for their staff and volunteers as one of the most important aspects of their programs. Successful programs invest heavily in initial training for new staff and ongoing training to keep advocates abreast of developments in public insurance programs, regulation of private insurance, and health access for the uninsured. Programs that rely on volunteers must also invest in rigorous training and certification programs, and recruiting and retaining strong volunteers can be difficult. Commercial call centers that provide minimum training to their customer service representatives often have lower customer satisfaction rates than nonprofits. CAPs that have access to legal or policy staff—either directly or through formal partnerships—are better able to support their front-line staff and address difficult cases as they arise. For example, California’s Health Consumer Alliance brings legal expertise to difficult cases.

- **Consumer assistance programs should employ online tools to serve consumers more quickly and effectively.**

Consumer assistance programs increasingly are leveraging online information systems and other data management tools in order to build their capacity for service and increase program efficiency. For example, Massachusetts’ HCFA advocates use web-based technology to help consumers apply for coverage, reducing the time it takes for individuals to fill out their applications and increasing accuracy. The program also sends automatic alerts to HCFA advocates when it is time for the consumers they have enrolled to annually renew their eligibility. Consumers are also increasingly turning to the internet for information and have come to rely on it as an effective means of communication. However, personal assistance—whether over the phone or in-person—is essential to a well-run consumer assistance program.

- **Consumer assistance programs should have a sustainable funding source.**

Consumer assistance programs are often established at a time of crisis, with time-limited grants or funding that must be renewed annually. But the need for consumer assistance continues after these short-term funding opportunities end. Consumer assistance programs need stable, sustainable funding sources that do not require annual votes of a legislative body or applications to nonprofit foundations. For example, the Connecticut Office of the Healthcare Advocate (OHA) is funded through surcharges on the insurance industry. This allows the OHA both to maintain independence from the shifting priorities of elected officials and to avoid budget crunches caused by economic downturns.

23
Conclusion

**Health reform will cover 32 million more Americans and will bring major changes to the health care delivery system in the United States.** The need to help consumers in the neighborhoods where they live and work will become increasingly urgent. As federal and state agencies work together to implement the new systems, they should look to the models of consumer assistance programs described in this report to provide concrete examples about how health reform implementation can be successfully achieved. In particular, they should consider the success of nonprofit community-based programs in serving the needs of consumers most likely to be affected by health reform. Much of the work of implementing health care reform falls to the states. As state and federal officials and health care advocates decide on the best ways to implement these new programs, consumers are already searching for information about how the new law will impact them and are inundating existing resources: AARP, Families USA, and a House of Representatives health care hotline all reported tens of thousands of questions from consumers in the weeks following health reform. All states now have the option to accept federal funding for state-based independent consumer assistance programs. One of the most important decisions state officials will make this year is how to use this funding. Existing consumer assistance programs are ready to take on new responsibilities, and to provide guidance to newly forming programs.

“Successful implementation of federal health reform hinges on ensuring that individuals and their families have information about new programs, as well as help to enroll in and navigate the health care system as changes take effect.”

Successful implementation of federal health reform hinges on ensuring that individuals and their families have information about new programs, as well as help to enroll in and navigate the health care system as changes take effect. Consumer assistance programs will provide an important bridge for health care consumers to help them better understand and take full advantage of what the reformed health care system can provide. Some of the programs profiled in this report already serve the functions outlined in the law, as do other programs currently operating in other states. As our nation addresses this exciting new challenge, states should closely consider building upon and strengthening the vital resources provided by nonprofit community-based programs as they move forward to design or fund a consumer assistance program that meets the needs of their communities.
2 Id.
3 Id.
4 See The Patient Protection and Accountable Coverage Act of 2010, PL 111-148, § 1002, Office of Consumer Information and Insurance Oversight, Affordable Care Act (ACA) – Consumer Assistance Program Grants, Initial Announcement, Invitation
8 For more information about the wide variety of consumer assistance programs helping consumers with health care, long-term care, and other services, see Families USA, “Consumer Health Assistance Programs: Report on a National Survey, June 2001.
9 An average of 70 percent of enrollees in the city overall returned their renewal applications during the period; 95 percent of those who returned their applications were found eligible. Data obtained by the Community Service Society from the Medical Assistance Program, New York City Human Resources Administration, April 2010.
10 Community Health Advocates, May 2010.
11 Health Care For All, “Mission Statement,” available at:
12 Fawn Phelps, Director of Policy, Health Care For All, personal interview, April 14, 2010.
13 Id.
14 Stan Dorn, Ian Hill, Sara Hogan, “The Secrets of Massachusetts’ Success: Why 97
15 Fawn Phelps, supra, n.12.
16 New York City Managed Care Consumer Assistance Program, MCCAP Annual Program Assessment, August 2008.
17 New York City Managed Care Consumer Assistance Program Annual Report 2009.
18 Id.
19 Mabel Ponce Koch, Project Director of the Health Consumer Alliance, personal interview, April 9, 2010.
20 The State of Vermont contracts with Vermont Legal Aid to perform the functions of the health care ombudsman, including help with enrollment, appeals, and navigating the health system. See 8 V.S.A. § 4089w. More information about Vermont Legal Aid’s Office of Health Care Ombudsman is available at
21 Health Consumer Alliance, “Our Partners,”
22 Id.
23 Id.
24 Id.
26 Id.
27 Mabel Ponce Koch, supra, n.19.
28 Health Consumer Alliance, supra, n.21.
29 Centers for Medicare and Medicaid Services, “State Health Insurance and Assistance Programs,” http://www.cms.hhs.gov/Partnerships/10_ships.asp (accessed March 9, 2010). SHIP was formerly known as the Information, Counseling and Assistance (ICA) Grants Program.
31 Id.
33 Health Assistance Partnership, “State of the SHIPs, A Summary of Results from the 2009 SHIPS Needs Survey,” January 2010. Thirty-six SHIP Directors (67 per-
34 State of Nevada Office of the Governor for Consumer Health Assistance, 2009
36 Conn. Gen. Stat. § 38a-1042(a), (b).
37 Conn. Gen. Stat. § 38a-1042(b). The advisory committee consists of six members appointed one each by the president pro tempore of the Senate, the speaker of the House of Representatives, the majority leader of the Senate, the majority leader of the House of Representatives, the minority leader of the Senate and the minority leader of the House of Representatives. Conn. Gen. Stat. § 38a-1049.
38 Conn. Gen. Stat. § 38a-1042 (b).
40 Id. at 4.
41 Id. at 6.
44 Id.
The Community Service Society of New York (CSS) is an informed, independent, and unwavering voice for positive action that serves the needs of low-income New Yorkers. CSS draws on a 160-year history of excellence in addressing the root causes of economic disparity through research, advocacy, and innovative program models that strengthen and benefit all New Yorkers. CSS promotes health care reform as an essential strategy for alleviating barriers to employment and improving the economic security of our constituents.

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.