From Concern to Action:
A Look at Consumer Engagement to Advance Quality Health Care

Analysis and Recommendations for Increasing Capacity and Infrastructure for Advocacy

The Praxis Project
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ABOUT THE PROJECT

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Our thanks to The California Endowment for the opportunity to examine this rich legacy of work. We believe there are many lessons here that will provide effective compass points for future efforts.

About The Praxis Project

The Praxis Project is a non-profit organization based in Washington, DC. We are an intermediary working to support local policy advocacy as part of a comprehensive strategy for change. Our emphasis is on developing fields of work in ways that encourage multi-level, trans-disciplinary learning and collaboration. We work to identify “fulcrum” points, approaches that help lift and advance a wide range of issues like meta-messaging – communication strategies that cut across campaigns and issues for greater “echo” and impact.

For more information, please contact us at (202) 234-5921 or visit us on the web at www.thepraxisproject.org:

The Praxis Project
1750 Columbia Rd, NW
Second Floor
Washington, DC 20009
Background

The polls are virtually unanimous. Health care is a burning issue and in every city and every state, people are deeply concerned about it. Yet, advocacy to change the conditions is not as widespread as the numbers would indicate. Even in California where, thanks to dedicated health funders like The California Endowment and The California Wellness Foundation, there is extensive health advocacy infrastructure, we are still faced with the challenge Dr. Martin Luther King, Jr. posed more than 40 years ago: to undertake the “nettlesome task of organizing our strength into compelling power.”

The intent of this report is to explore the potential for creating a compelling, multi sector movement for quality care. The report examines lessons learned and emerging practice to support future grant making in the area of consumer engagement – especially as it relates to building demand and accountability for culturally competent, patient-centered care.

The paths of inquiry focused on four areas:

1. What has gone on before? Using a social movements “lens”, we conducted a retrospective scan that examines a breadth of relevant, diverse health related “movements.” In collaboration with the Endowment staff, we prioritized five of these “movements” – the environmental justice movement, the community health center movement, the disability rights movement, HIV-AIDS advocacy, and the fight to save public hospitals.

   Key questions guiding this area of inquiry were: How do movements make the transition from local to state to regional and to national impact? Are there common themes with regard to success and pitfalls? Are there certain competencies/capacities necessary to advance this work effectively? What kind of partnerships and intermediaries are important to build the necessary infrastructure, capacity and power to advance this work?

2. What is going on now? What are current examples of consumer engagement efforts in these areas of work and what are the key strategies, promising practice, potential leverage points and lessons for future efforts? In this case we looked at five organizations:

   • Tenant and Workers United in Alexandria, Virginia because of their unique combination of direct service, promotora style outreach with direct action organizing and policy change on quality care issues at the local and regional level

   • Community Coalition of Los Angeles because of their extensive capacity and base building work on local health issues in South Los Angeles
• PICO California because of a statewide approach to policy advocacy that has strong local, grassroots organizing at its foundation

• Chinese Progressive Association because of its focus on organizing low wage, mostly immigrant residents and their strategic combination of worker and health organizing

• Women’s Economic Agenda Project because of its unique approach to statewide and federal advocacy, strong partnerships with labor and base organizing of low wage women.

3. What is the emerging change model for this work and where are California efforts in this context? Based on the information collected using Praxis’ modeling framework (below), we developed a picture of the emerging model for this area of work to identify assets, potential partners and gaps in moving this work forward at statewide scale. There is also as a set of findings that we believe will be helpful in guiding future work in the area, titled Looking Ahead: Key Implications for Work in California, which can be found in the Summary of Key Findings.
Project Methodology

Our approach to identifying movement capacity and emerging change models in an area of work is grounded in our sense of what is required to sustain comprehensive change at scale. Ideally, well functioning, connected organizing efforts or “social movements” require at least the following six components in order to advance effective work over time:

- An active, engaged base that extends beyond professional advocates: community organizing, leadership development and capacity building initiatives that increase the power and numbers of those most affected to advocate in their own interests;

- Captured space on the public agenda and capacity to effectively communicate within the “ranks”: strategic communications that helps build consensus, strengthen networks and influences the public conversation through mass media, the web, etc.;

- Concrete handles for participation and a clear set of demands: power analysis informed advocacy that changes policy and the environment and moves decisionmakers to act;

- Connection to good information that guides the work: research and analytical resources that evaluate and identify promising practice, generate solutions and critique current and proposed policies/practices;

- Time and space to connect, build, regroup and respond to changing conditions: well facilitated reflective space for strategic planning, priority setting, and relationship building;

- Adequate resources: staffing, knowledge, materials, technology, etc., to implement the work outlined above
Assessing Supportive Infrastructure
By Component

These components provide a baseline for our analysis. However, we understand that efforts can pose unique challenges and surface new strategies and approaches. As a result, actual change models at work often look different than the “ideal” above.

Using this framework as an “ideal,” the scan looked at specific aspects of movement work in their real world context. In short, this scan does not judge or evaluate this work. It only lifts up particular “stories” or lessons from these movements that examined work in a component area. Rarely are funding, staffing and infrastructure sustained to the point where any effort has adequate infrastructure in every component area. One of these rare examples is found in the tobacco control movement where, thanks to sustained public and private funding over nearly two decades, the field was able to develop extensive member networks, a multi million dollar strategic communications infrastructure that penetrated nearly every household, high levels of intermediary development, strong cross sector networks and extensive training and leadership development capacity.
Most movements are not as fortunate. And it is not the intent of our work to
discount the hard work of the many other advocates who achieve so much
in spite of limited resources. We look forward to the day when resources are
available in a sustained way and at scale, to build the kind of infrastructure
needed for comprehensive, multi issue social change in every community and
geographic area of need.

**Scan Methodology**
We examined case studies, organizational websites, previous interviews,
analysis and other secondary sources in the development of movement
profiles and assessments. Informant interviews were conducted in the
development of movement profiles, which are directly attributed unless the
informant requested anonymity. This happened with only one informant and
in only one profile, the profile on environmental justice organizing.

We also had conversations with a number of intermediaries and base building
groups in order to gain better insight into their efforts (or potential interest)
in work around quality care. We prioritized groups based on previous work
on health care or related health justice issues. The scan looked at some
intermediaries located outside of California but with significant work in the
state. Base building and member based groups were all located in the state
Results and findings from the scan do not list individual organizations but
categories of groups with examples of organizations that exemplify these
categories. We wanted to avoid the appearance of providing a comprehensive
listing where groups might feel concern if they were omitted.

Five groups were singled out for short case studies that highlight specific
practices that warrant further examination and, in most cases, replication.
These case studies, as with the profiles and other analysis, reflect only a
small sample of the rich work going on. Unfortunately, time did not permit
a more comprehensive analysis, which could have certainly filled volumes.
Hopefully, these initial findings can help structure more in depth investigation
in the future.
Summary of Key Findings

Looking Back: Key Findings from Movement Profiles

- Movements need networks that focus on building movement infrastructure, education, leadership development, and collective strategizing around local, national, and even global issues.

- Learning communities are critical in moving the work forward – especially opportunities that allow advocates to get out of the United States and explore alternative visions of what’s “possible.”

- Base building is critical to success; it takes years of investing before there are significant returns, but it is certainly worth it.

- Communities are animated by efforts that allow them to address root causes of health issues. It is important that their work results in concrete change where they live.

- Intermediaries have a critical role to play in field development. Virtually all successful efforts had a body of supportive organizations that facilitated networking, alliance building and collaborative learning.

Looking Ahead: Key Implications For Work in California

- With its extensive intermediary and organizing networks and diverse patient base, California is uniquely positioned to build a diverse consumer base for quality care.

- Many base building groups working at the neighborhood level and those organizing key constituencies have some aspect of health work already on their agenda.

- Although there are many strong health focused intermediaries to support policy development and strategic communications, intermediaries supporting organizing are primarily multi issue, multi sector.

- Organized labor and other worker formations are engaged in aspects of this work and under the right conditions, could play a pivotal role in base building and policy advocacy.

- There is a great deal of ready infrastructure to support the work but this infrastructure must be expanded and better coordinated in order to effectively take this work to scale.
Power and Promise of a Fully Operational Change Model: The Environmental Justice Movement at Its Peak

By Kim Fellner

The Bottom Line
- Environmental justice movement pioneered modern efforts to bridge racial justice and health organizing.
- There are rich lessons in the care and feeding of networks and alliances across race and discipline.
- At its peak, the movement had every aspect of the change model in place. As the political context shifted and resources waned, key components were under funded and/or abandoned.
- Intermediaries made important contribution to field development. When they suffered cutbacks, the absence of sustained intermediary networks negatively affected the work – especially in the policy arena.
- There is still a strong base of support and expertise that has much to offer future work on quality health care.

Roots of Transformation
The history of environmental justice predates its emergence into the public eye. The environmental justice movement, forged at the intersection of the Civil Rights and Environmental Movements, began with a simmering sense of injustice. It bubbled up in many separate locations, especially African-American communities in the South, in response to environmental degradations that unfairly targeted communities of color.

A proliferation of studies and lawsuits in the 1970s exposed the disproportionate siting of environmental hazards in communities of color. Children were often the first to become sick, as industrial toxins leaked into the soil, polluted the water, and fouled the air; community health was the canary in the coal mine that signaled the deadly consequences and the urgent need for collective action.

A pivotal moment came in 1982, when African-American citizens of Warren County, North Carolina protested a landfill slated for their community. More
than 500 demonstrators were arrested, drawing national press attention and humanizing the issue for a larger public. The term “environmental racism,” attributed to civil rights leader Ben Chavis, described the phenomenon of unequal risk. This unequal risk grew increasingly apparent as communities around the country organized around local environmental injustices: Union Carbide chemical spills in West Virginia; hazardous waste dumps on Native American reservations; dangerous pollution along Cancer Alley in Louisiana; and the threat of an incinerator in East Los Angeles.

Slowly, clusters of organizations began to emerge. The Southwest Organizing Project convened a group of organizations that became the Southwest Network for Environmental and Economic Justice. Native Americans mobilized around nuclear waste dumping to form the Indigenous Environmental Network. In 1990, in a move that crystallized the struggle, environmental justice leaders of color confronted the ten most visible environmental NGOs, including the Sierra Club and the Audubon Society.

They sent a scathing letter calling the environmental establishment to account for its internal lack of diversity and its external myopia. The letter also noted that the established groups had failed to see, much less tackle, the racism inherent in the uneven impact of environmental abuses. The following year, those leaders of color hosted the First National People of Color Environmental Leadership Summit, officially birthing environmental justice as a full-fledged national movement and setting out “Principles of Environmental Justice” that have continued to guide its progress.

“The coining of two simple phases – environmental racism and environmental justice – changed the way thousands viewed their world and their ability to change it for the better.”

The Impact of the Environmental Justice Movement
The impact of the environmental justice movement has been profound. In less than 20 years, it has established a new locus of energy and awareness and publicly reframed issues of environmental health and sustainability. As Jeff Chang and Lucia Hwang wrote in ColorLines magazine in 2000, “The coining of two simple phases – environmental racism and environmental justice – changed the way thousands viewed their world and their ability to change it for the better.”
In the process, the environmental justice movement has expanded the definitions of the two movements that inspired its birth. The Civil Rights Movement expanded to include issues of environment and sustainability and extended beyond the black-white paradigm at its core to embrace a broad multiracial spectrum. Meanwhile, the Environmental Movement expanded to include urban landscapes and community well-being and broadened its vision and agenda beyond its comfortably white and privileged base. Those who most directly experienced the impacts of environmental exploitation were finally part of the process.

“The First National People of Color Environmental Leadership Summit provided a framework and vision that was much bigger,” said Roberto Rodriguez of the Southwest Organizing Project. “It’s about toxins in the community and people of color and poor people bearing the impact. It’s also about peoples’ livelihoods, economic rights, reproductive rights, human rights, access to good education and healthcare, aspects of sustainability and housing. For people who get involved in the sector today, environmental justice and environmental racism are their lenses. It’s really a vision for change, for living in balance with Mother Earth.”

**A New Movement Comes of Age**

The environmental justice movement has undergone at least two distinctive eras of development, one between the founding summit in 1991 and the second summit in 2002, the other extending from the second summit to the present.

Most of the 11 years between the first and second summits were characterized by a fortunate convergence of several factors:

- The animation of its own possibilities and inspiration by its leadership;
- A political climate that was not generally hostile and was occasionally supportive;
- A relatively benign economic environment; and
- A funding community that, in response to all these factors, was willing to take some risks to subsidize more innovative organizing.
The results were impressive. Networks thrived. The Asian Pacific Environmental Network was formed, as were the National Black Environmental Justice Network and the Southern Organizing Committee for Economic and Social Justice. Farmworker organizations became a vibrant part of the mix.

As more organizations joined, the work advanced on both political and community fronts. African-American communities in Louisiana defeated plans for a uranium enrichment plant, forcing the company to withdraw its application from the Nuclear Regulatory Commission. These networks came together and added federal policy advocacy to already intense local agendas. They pushed for and won an executive order under President Clinton that placed pressure on the Environmental Protection Agency and the Department of Health and Human Services to factor in environmental justice criteria in federal policy decisions – including dedicated public funding for environmental justice research and advocacy. States including Florida, Texas, and Oregon set up new policies for citizen engagement on environmental justice issues. Organizations like Alternatives for Community and Environment in Boston and the Labor/Community Strategy Center in Los Angeles tackled issues of transportation and urban sprawl, expanding the range of issues to incorporate equitable, sustainable development.

In addition, environmental justice organizations in the U.S. forged ties with their counterparts in other countries. In 1992, representatives from the newly empowered movement participated in the UN Conference on Environment and Development in Rio de Janeiro. In 1994, the Environmental Justice Resource Center, housed at Clark Atlanta University, listed more than 600 environmental justice organizations in the U.S., Puerto Rico, Mexico, and Canada. And by the time the UN World Conference Against Racism happened in South Africa in 2001, there were international alliances around corporate malfeasance in the oil and waste industries. As former director of Asian Pacific Environmental Network Joselito Laudencia noted in 2002, “There’s been a real growth in analysis connecting local to global. We now talk about climate

“I think it’s important to separate the health of the movement from the health of the conference. There were close to 1,100 people there, representing an international movement with a broad base…If people come together and there is no vying for power and no contention, you don’t have a living movement.”
change as climate justice. We’ve gone from nimby-ism, not in my backyard to not in anyone’s backyard, not just, ‘you can’t do this in my country,’ but ‘you can’t do this in any country.’”

By the time the movement reconvened for the second Environmental Justice Leadership Summit in the fall of 2002, the climate had changed literally. In 2000, George W. Bush was elected president, ushering in an administration that was perceived to be openly hostile to virtually all the goals of the environmental justice community. Then the events of September 11 created new deterrents, as new surveillance and harsh policies targeted immigrant communities and chilled political protest of all kinds.

There were also challenges internal to the movement. Innovative principles and aspirations were extremely challenging to put into practice. Networks struggled to model a racially diverse movement with mutually shared power. There were tensions between academics, scientists, and policy people versus grassroots community organizations to control the direction of the movement. And the generational shifts in leadership and culture were starting to surface as the first of the baby boomers stared 60 in the face and young activists entered organizational life. These fault lines were all in evidence in 2002 as the Second Environmental Justice Leadership Summit got underway.

Most participants viewed the tensions that emerged at the second summit as a necessary part of the movement’s evolution. “I think it’s important to separate the health of the movement from the health of the conference,” noted one participant. “There were close to 1,100 people there, representing an international movement with a broad base...If people come together and there is no vying for power and no contention, you don’t have a living movement.”

The Role of Funding and Resources
In the wake of the summit, funding seemed to move toward specific, tangible projects with specific, measurable solutions. Meanwhile, funding for the networks, with their less calculable focus on building movement infrastructure and education, began to dry up. This created a double challenge for the grassroots organizations.

Changing politics dictated a move from a national strategy to a state and local focus, requiring a shift in organizing strategy and tactics. “The Bush Administration has had a pretty significant impact,” said one grassroots leader. “In much of the ’90s, the emphasis was on national or regional activity, even for locally-based groups like ours.” He noted that there had been some significant gains in state regulations, but it required a different type of organizing. “Most of us don’t have the capacity to do both the local and national work,” he added, “and the inability to move stuff on a national level
Just at the moment when collective strategizing, education, and reflection – components that the networks had offered – were badly needed, foundation support for the networks began to wane has forced us to swing the pendulum back to a more local and regional focus.”

Just at the moment when collective strategizing, education, and reflection – components that the networks had offered – were badly needed, foundation support for the networks began to wane. “There was a deliberate effort to move away from funding the networks,” said one California veteran organizer. “A funder actually asked me, ‘Why should I do this, if I don’t know what the outcome is, when I could fund an organization in Oregon to do a specific clean-up?’ The networks bring together a lot of grassroots communities to learn about laws, go through case studies, and ask questions. And they do it in many languages, English, Spanish, Korean, Chinese. The networks integrate the local situations into something bigger.”

Movement-Building in the Decades Ahead
The environmental justice movement’s success is not just in its very significant local, regional, and national victories, but in that “something bigger.” Reaching beyond the existing paradigms, the environmental justice community has established some of the components critical for movement-building in the decades ahead.

- **Multiracial Organizing**
  It has provided perhaps the first multiracial formation imagined and led by people of color. It inspired African-American, Asian-Pacific, Native-American, and Latino organizations to band together to form networks that, in turn, banded together to form a broad, diverse movement. It wasn’t easy and it remains contentious, but the breakthrough development signaled the new philosophy and politics of race in the struggle for social justice.

- **Connecting Academics and Activists**
  From the outset, this movement melded the efforts of academics and activists, with scholarly research fueling, championing, and advancing community activism. “Toxic Waste and Race,” a 1987 study by the United Church of Christ, provided demographic evidence correlating race with the siting of waste facilities. Dr. Robert Bullard and Dr. Beverly Wright were among the early scholarly voices. Bullard’s book, *Dumping in Dixie: Race, Class, and Environmental Quality*, came out in 1990, providing an academic
reinforcement of on-the-ground experiences. Although the evolution of the relationship between academics and activists has had its share of conflict, the symbiosis has been crucial to achieving substantive gains. It also created new opportunities on an unprecedented scale for community-based research.

- **New Narratives of Community Health**
  It has woven together a sophisticated new narrative of community health and sustainability with a comprehensive definition of environment that goes beyond wilderness, water, and air to embrace the urban landscape, housing, and employment. In doing so, it has provided a thread to connect rural and urban concerns.

- **Policy-Making and Political Institutions**
  The movement has offered a powerful framework to engage policy-making and political institutions. The confluence of scientific research, tangible evidence of harm, and the emotional weight of injustice provides a strong rationale for remedy. The issues raised are often subject to regulation by government agencies and legislation by local, state, and national jurisdictions. In 1994, President Clinton issued an executive order, “Federal Actions to Address Environmental Justice in Minority Populations and Low-Income Populations,” opening up new governmental avenues to redress inequities.

- **Wide-Ranging Alliance and Collaboration**
  The issues provide wide-ranging opportunities for alliance and collaboration – including health and housing activists, religious congregations, labor unions, artists, sympathetic officeholders within the regulating bodies and agencies, and sympathetic funders from a range of disciplines.

- **International Context**
  It has provided a vibrant international context that ties the struggles of people of color in the U.S. to the struggles of people in developing nations, and by extension, the environmental struggles in the U.S. with the global environmental crisis. The transnational corporations that endanger health and destroy habitat here at home are guilty of the same, or worse, violations abroad.

**California: Modeling the New Paradigm**
From the beginning of the environmental justice movement, California has played a unique role based on its environmental history, its demographics,
and the quality of its leadership.

The Civil Rights and social justice movements of the 1960s and 1970s dramatically changed the nature of California politics and created an infrastructure of community organizations within and across racial communities that became a springboard for the leaders and issues of the emerging environmental justice movement. Farmworkers had long organized around issues of pesticides and health. There was an active antinuclear movement. Native American organizations sprang up to defend native lands and sacred sites, emphasizing a traditional ethos of spiritual connection with Mother Earth. Asian and Latino activists from a panoply of countries brought new perspectives and new energy; indeed, by the 2000 census, non-whites comprised a majority – roughly 53 percent – of California’s 33.8 million people, with Latinos (32.4 percent) and Asians (10.8 percent) as the largest and fastest-growing populations. And, if the profusion of races and ethnicities provoked conflict, it also provided an opportunity to test out new alliances to advance a more equitable agenda.

California has several key assets to advance environmental justice:

- **It has a strong, stable cadre of community leaders with racially and experientially diverse backgrounds and broad vision.** Anthony Thigpen at Strategic Concepts in Organizing and Public Education (SCOPE), Diane Takvorian at the Environmental Health Coalition, Antonio Díaz at People Organized in Defense of Earth and her Resources (PODER), Vivian Chang at Asian Pacific Environmental Network (APEN), and Penny Newman at Center for Community Action and Environmental Justice (CCAEJ) are only a small number of the many dedicated individuals with deep community and movement roots who have helped build a dynamic and ecumenical approach to environmental justice. Furthermore, these leaders have also inspired others to become involved, creating a deeper bench, and a next generation, of leadership.

- **The state not only has active community-based organizations in many diverse communities, it has the largest number of union members in the country** and a union density of roughly 60 percent in the public sector. Although labor unions are not always aligned with community organizations on environmental issues, unions provide critical political power on the issues they support. In addition, many key community organizers have moved back and forth between labor and community organizations, providing a conduit for communication and cooperation.
The California environmental justice community has been successful in identifying allies in the political, academic, and funding communities. In fact, there is significant overlap as community activists are elected to office and appointed to key government positions and become professors and foundation officers. Los Angeles Mayor Antonio Villaraigosa is a former organizer; APEN founder Peggy Saika heads the Asian Americans/Pacific Islanders in Philanthropy; Pam Tau Lee coordinates public programs at the UC Berkeley School of Public Health. This synergy has helped move and fund an environmental agenda on several fronts.

California has an unusual number of foundations, large and small, with a commitment to the environment, health, and social justice. The French American Charitable Trust, McKay Foundation, Solidago Foundation, California Endowment, and Liberty Hill are only a few of the foundations that have supported environmental justice work.

Despite hefty corporate opposition to environmental and health initiatives, public support is broad enough that Governor Schwarzenegger has moved to advance clean air standards and access to health care, despite the opposition of his national party leadership. These initiatives have provided an opportunity to push the debate, not just statewide, but on a national level.

Several years ago, a report compiled by Martha Matsuoka on behalf of five core environmental groups in California, Building Healthy Communities from the Ground Up: Environmental Justice in California, detailed the concentration of health and environmental hazards in poorer communities and communities of color and the negative consequences for the residents. The report identifies three key components to maximizing success: state-level advocacy capacity; increasing philanthropic resources; and building solidarity with social and economic justice movements. While gains have been made in all three areas, there is still insufficient infrastructure, money, and density of community engagement to meet the environmental justice challenge. But the proven capacity of environmental justice to bridge constituencies and issues presents an opportunity we cannot afford to waste.

Promise and Practice: Supporting the Next Wave
This is a pivotal moment for the environmental justice movement, as it stands poised to enter the next stage of its development. With the approach of the 2008 elections, we are about to witness another change in the political landscape. And regardless of the outcome, two issues integral to environmental justice –
health care and climate change – have come to the fore. To create sustainable solutions will require not just strong infrastructure and capacity, but breadth of vision.

The environmental justice movement, both in California and nationally, suggests some components required for success and provides a good base from which to advance these initiatives. The history of the movement and the on-the-ground experiences, many of which are reflected in the case studies that follow, suggest some avenues to build both healthy communities and environmental justice.

**Movement Strengths and Challenges**

The strength of the environmental justice framework is its ability to bridge across issues and diverse communities – a strength that the issue of health care potentially shares. However, this vision requires intense nurture of leadership and membership through education and connective spaces. Whether the divides are racial, economic, or cultural, the barriers to a common agenda are formidable. Overcoming these barriers requires strong support for organizational development, safe spaces for dialogue and leadership development and even some forms of experimentation that can be hard to measure.

Suggested recommendations include funding more opportunities for leaders and members of the base to interact across issues, geographies, and racial/ethnic communities and providing a funding stream for networks and associations that cross traditional boundaries, including regional and other geographic categories.

**Balancing Politics and Advocacy**

There is also a need to balance electoral participation, action at the state level, and local, national, and even international arenas. These are extremely powerful avenues for change. However, elections aren’t the only avenue for change and states are not the only levels at which change takes place. Ultimately, resolving the U.S. healthcare crisis requires a national frame, and changing relationships requires many different approaches, beginning at the local level. Dealing with climate change or a globalized economy requires an international perspective, yet no organization can do all of this and most organizations struggle to excel at one small piece.

Recommendations include promoting an ecological approach to movement-building and creating an ecosystem in which organizations throughout the system are connected to each other and valued, and creating needed programs to engage the base in political analysis, research, and communications skills.
Bridging a Potential Class Divide
The growing sophistication of political analysis and academic research, as well as communications theory, has led to a growing body of consultants who may be more advantaged when it comes to funding and less representative of the communities most deeply affected by health and environmental crises. While these consultants are important to achieving movement goals, there is the potential of creating a class divide within the movement. Programs like SALTA at the Center for Community Action and Environmental Justice offer models for developing skills and leadership at the base. Likewise, consultants who work with community organizations may need training to hone their relationships with the base.

Recommendations include creating a guide to best practices, and assistance for duplicating what works; providing scholarships for students of color and adults to acquire research and communications skills; initiating a community consultants track/training to encourage experts to serve as bridges between community organizations and the institutions where they practice their craft (lobbying the legislature, dealing with the media, etc.).

Transitions in Leadership
Organizations need assistance with leadership and generational transitions. The aging of the baby boomer generation is creating stress, even in established and effective organizations. Both veterans and new leaders, and the organizations they steer, need additional support and nurturing. One recommendation is to provide transition grants for organizations, including coaching for leaders (both arriving and departing) and strategic planning for organizations.

Case Study: Asian Pacific Environmental Network, San Francisco, California
APEN seeks to empower low-income Asian Pacific Islander (API) communities to achieve environmental and social justice. They believe the environment includes everything around us – where we live, work and play – and they strive to build grassroots organizations that will improve the health, well-being, and political strength of API communities.

In 1991, there was a historic convening of the national environmental justice movement, the People of Color Environmental Leadership Summit in Washington, DC. At this convening, a group of fewer than 30 APIs among 600 activists of color realized that a vehicle was needed to represent the specific issues of concern to API communities. APEN’s formation in 1993 reflected this growth of the national environmental justice movement and the recognition that API voices needed to be at the table.
APEN currently works on three levels: direct organizing in local communities, building a network of API organizations, and working in multiracial alliances to affect regional and national social change. Direct organizing is at the center of APEN’s vision of environmental and social justice. Two local San Francisco Bay Area projects are the 5-year old Laotian Organizing Project (LOP) in Richmond, which also houses the Asian Youth Advocates program for young women, and the recently launched Power in Asians Organizing (PAO) that works with a pan-Asian immigrant community in Oakland.

Case Study: Center for Community Action and Environmental Justice, Riverside, California
The goal of the Center for Community Action and Environmental Justice (CCAEJ) is to build a strong movement for change that recognizes the connections between environmental and worker exploitation and oppression on the basis of race, gender, sexual orientation and class. The Center works with community groups in developing and sustaining democratically-based, participatory organizations that promote involvement of a diverse segment of the community in ways that build power.

CCAEJ facilitates and provides assistance with information and publications; direct, “hands-on” assistance with groups; outreach, referral and network development; and training and leadership development. They create partnerships with organizations that are working on issues related to environmental justice, social justice, and economic development to broaden agendas and effectively disseminate resources. They actively seek opportunities to bring together groups of people working on a variety of social, economic and environmental justice issues, exploring the interconnections among issues and seeking common ground for cooperative actions.

In addition to working locally, CCAEJ works on global issues. Their work seeks to link struggles for justice in the United States with struggles for justice in the Global South.

Case Study: Desert Alliance for Community Empowerment, Coachella, California
Desert Alliance for Community Empowerment (DACE) was formed in 1999 and implements the mission of the Desert Alliance Empowerment Zone, initially one of ten federally-designated Rural Empowerment Zones in the nation. It is the only one designated in the thirteen western states of the United States and encompasses nearly 4,200 square miles located within eastern Riverside County, California. DACE’s mission is to provide residents and their
communities with the means to achieve a quality lifestyle that is self-sufficient and sustainable.

DACE supports and finds solutions for the needs of its zonal communities and partnering organizations. Through their strategic planning and community involvement process, DACE has identified six strategic areas from which all their projects and programs stem: capacity building, community development, economic development, education, health and human services, and housing (which is provided through their sister organization RANCHO Housing Alliance, Inc.)

Of particular interest is DACE’s Health and Human Services Program, where they are committed to improving patient-physician relationships; improving the healthcare delivery system; resolving language problems; and understanding cultural and folk illnesses, patient beliefs, literacy, and transience. Farm workers and migrant farm workers make up the largest percentage of the residents of the Eastern Coachella Valley and DACE helps address their needs and initiate improvements.

Their vision is a region with vibrant and sustainable communities where all residents have the opportunity to achieve an enhanced quality of life and self-sufficiency through innovative and collaborative community-based public and private partnerships.
Institutionalizing Change: The Community Health Center Movement

By Leslie Hunter-Gadsden

The Bottom Line

• The community health center (CHC) movement started in many different communities with many different entry points yet these diverse movements came to think of themselves as part of one movement in addition to holding other “identities”

• The movement bridged many issues and placed them in the context of a broad definition of health.

• The work has matured and become highly institutionalized compared to its early years but it still maintains strong community leadership and leadership development. Much of its leadership comes from its grassroots patient constituent base.

• CHCs created their own intermediary structures by growing centers into “hybrid” groups that both provided services and supported networks and by developing a strong member based structure. This collaborative governance extends from the site level to the national networks.

• CHC boards, members and patient base offer an important base for future work on quality healthcare.

The Need for a Community-Oriented Healthcare Movement

In the United States, costs for healthcare have continued to rise while politicians and policy makers on both sides of the issue have argued about the best ways to make healthcare available to all Americans, regardless of their ability to pay. According to an August 2007 study published by the National Association of Community Health Centers, the Robert Graham Center of the American Academy of Family Physicians, and Capital Link, Americans spent $2 trillion for healthcare in 2005 (16% of the national economy), yet our healthcare system remains dysfunctional.

The study “found that 56 million Americans – many of them with insurance – don’t have ready access to primary care. Other research shows that half of
Americans aren’t getting the care they need and the numbers are even worse for minorities and the poor. Something needs to change in how we spend our healthcare dollars. As a nation, we are desperate for investment in better care.” Whether they have health insurance or not, many Americans continue to search for a healthcare home where they feel comfortable – culturally, economically, and with an emphasis on quality.

As healthcare costs have risen, more and more employers have reduced the amount of healthcare they provide for their employees, if they provide it at all. Combine that with the fact that Americans do not become eligible for Medicare until after age 65, and it is understandable that more than a third of Americans under age 65 went without health insurance of any type in 2006. Using data from the August 2007 U.S. Census Bureau, non-profit organization Families USA found that 47 million Americans were without health insurance for all of 2006. Nearly half of those Americans without health insurance are people of color.

The staggering number of people without health coverage in this country has catapulted healthcare to a major domestic issue in the 2008 presidential campaign. It is for this reason that alternative tactics, such as community-based healthcare have a prominent place on the public agenda. The recent controversy over President Bush’s veto of Congressional legislation to increase spending on the State Children’s Health Insurance Program (SCHIP) from about $5 billion to $12 billion annually is just another sign of a nationwide demand for access to quality, affordable healthcare.

The Birth of Community Health Centers
A successful model for improved healthcare that has received bipartisan support is the community health center. According to a study conducted by the National Association of Community Health Centers, Inc., Community Health Centers: A Smart Investment in Healthcare and Communities, “Over 40 years ago, Community Health Centers began delivering healthcare to the medically underserved. 1,100 Community Health Centers now serve more than 16 million people in 6,000 plus sites located throughout all 50 states and U.S. territories. Community Health Centers never turn anyone away for care – regardless of insurance status or ability to pay. They are local, non-profit, community-owned and federally-supported.”

To truly understand how community healthcare has developed since the mid 1960s, one must look at the work of Dr. H. Jack Geiger, Arthur C. Logan Professor Emeritus of Community Medicine at the City University of New York Medical School and founder of the first two community healthcare centers to receive federal funding. Dr. Geiger launched his model for community healthcare in rural Mound Bayou, Mississippi, and an urban public housing project in Columbia Point, Boston. Both models combined community-oriented primary healthcare, civil rights, community empowerment and economic development
initiatives, and public health reform. These two centers were a focal point of the nationwide “War on Poverty” from the middle 1960s through the early 1970s; they also represented models that led to the development of the 1,100 community healthcare centers that exist today.

The centers were funded by the Office of Economic Opportunity, which also funded a variety of social service programs developed to better equip minority and underserved segments of the American population to achieve “the American dream.” Many of those programs have come and gone or been retooled significantly, but community-based healthcare remains.

Dr. Geiger, also a founding member and past president of Physicians for Human Rights, was in Mississippi in 1964 as field coordinator for the Medical Committee for Human Rights’ program to protect and provide medical care for civil rights workers. Reflects Geiger, “Those first community health centers were an offshoot of the Civil Rights Movement. That’s what got me to Mississippi in the first place.”

What Geiger observed when he went to the Mississippi Delta was that for the majority of share-cropping blacks, living conditions were often without basic needs in plumbing, lacking clean-piped water for showers, toilets, or baths. Malnutrition was high as were birth morbidity rates. “People were not just without access to healthcare, they were living in housing not suitable for humans, in rural areas. They were drinking polluted water, often rain water collected in tubs that had originally held pesticides, for example. There was no indoor plumbing. They were growing cotton instead of food that they could feed their families with.”

Similarly, Geiger says that in Columbia Point public housing in Boston, although it was an urban area, “you had families who could not afford the 4 hours from work it took to get across town to get to better healthcare or even a babysitter if they needed healthcare as the head of the family.” Reflecting on the beginning of community centered healthcare movement, Geiger notes, “The context of the movement to provide primary healthcare to defined populations was political from the very beginning.”

The centers were funded by the Office of Economic Opportunity, which also funded a variety of social service programs… Many of those programs have come and gone or been retooled significantly, but community-based healthcare remains.
Political Aspects of the Movement
The political aspects of this movement led toward unconventional tactics and the identification of the need for policy advocacy on local, state and federal levels. In Mississippi, Geiger and his colleagues wrote prescriptions for food to be filled at local black-owned grocery stores and paid for them out of the health center’s pharmacy budget. This was unconventional, but it was the clearest way to treat the disease of malnutrition, according to Geiger.

Whether in 1965 or today in 2007, Geiger notes that filling a prescription for a disease without investigating the environment that has led to the disease is meaningless. Says Geiger, “It’s not either/or; just giving primary healthcare without affecting the root causes is having a revolving door. Particularly in Mississippi, we went after root causes. Today that is called the social determinants of health.”

Not only did the community health center in Mound Bayou, Mississippi improve primary healthcare, it also spurred the creation of jobs and a revamping of the economic system. Families joined forces, began growing vegetables in food cooperatives, and some community members pursued additional education or health-related jobs after volunteering in the community health center.

In an article published in the October/December 2005 issue of the *Journal of Ambulatory Care Management* from the Department of Community Health and Social Medicine, City University of New York Medical School, Geiger wrote that the grant in 1965 for the two community healthcare centers “reflected a conclusion that the existing system of charity care, emergency departments, fragmented outpatient departments, and separate public health clinics and programs, north and south alike, had failed adequately to serve the primary care needs of the nation’s poor and sick populations – especially communities of color – and that a new kind of institution, located in such communities and directly responsive to their needs, was required.” Fast forward forty years, and we see that the need for community-based healthcare still exists. The model from 1965 is still relevant, even if there have been changes in healthcare financing, organizations and epidemics, such as HIV/AIDS.

Successful Leadership and Resource Models
One thing that has not changed over the past 40 years is the fact that physicians should work with trained community organizers when it comes to developing community-based healthcare. Outreach to members of the community was the lifeblood for the early community-based centers and the idea was institutionalized by the requirement that each center have at least 51 percent of its board members be from the community it served. That way, members of the community would not feel that an outside body was deciding what services they needed and they would have a voice.
From the mid-1960s through the mid-1970s, information about the community health centers spread, often by word-of-mouth. Initially, many centers were staffed primarily by volunteers and as the structure for obtaining federal support took shape, paid staff positions evolved.

The creation of community healthcare centers not only served medical needs, but fostered leadership roles among the citizens in those communities. Martin Waukazoo, chief executive officer of the Bay Area’s Native American Health Center, had his first contact with the center as a patient. “I started as a patient (suffering from alcohol addiction) in 1980. In 1982 I became assistant director and later that year became executive director in San Francisco. When I started, I worked in the same treatment center where I had been treated.”

And Sherry Hirota, chief executive officer of Asian Health Services in Oakland, California, first encountered her organization in 1976 as an uninsured patient. She was impressed by the treatment she received and later joined the staff when a position became available. She notes, “I came to the organization with a history of community organizing myself.”

Just as race and class shaped the scope of culturally sensitive patient care, so did gender. Lyon-Martin Women’s Health Services, for example, was started in 1979, initially as a research project being funded by University of California, San Francisco. The project was a study looking at STDs in women, comparing the lesbian and bisexual population with straight women. According to Leslie Ewing, associate executive director of marketing and development at Lyon-Martin, “One of the major findings was that lesbian and bisexual women did not go to the doctor until the symptoms of the STDs were far worse than among straight women.” This finding led a group of medical providers and health activists to create a clinic that could respond to the gap in sensitive health services available to lesbians.

Finally, because community health centers reflected the ethnicity of the populations they served, major media began to contact them when there were news issues affecting those communities. Most community health centers worked to create positive media. The Native American Health Center, for example, established their own outlet, Strong Medicine, a community newspaper-style publication.

**Sustainable Funding and Policy Advocacy**

Another reason for the growth in the number of community health centers nationwide is that they are widely respected across the political spectrum. These centers are urban, rural, affiliated with public housing, school-based, and a range of other types that are members of the National Association of Community Health Centers. Under the law, each community health center gets base funding from the federal government, Medicaid, Medicare, and
private institutions, as long as no one is ever turned away - even if they cannot pay for health services. Even in America’s ever changing political landscape, funding for community health centers is relatively secure.

“Today the nationwide network of community, migrant, and homeless health centers stands on the threshold of new growth and development,” says Thomas J. Van Coverden, president and chief executive officer of the National Association of Community Health Centers (NACHC). “Both the President and Congress have called upon this nation to double the capacity of health centers and build a stronger primary care infrastructure for America’s communities.”

In the 40-plus years since the first two community health centers received federal funding, more than 1,000 additional centers have joined the ranks of NACHC. These health centers “are the family doctor to 15 million people and a critical part of the nation’s health delivery system,” and while no two health care centers are exactly alike, they all share a common purpose – to serve the needs of the community where those needs exist. These centers are about community empowerment, aided by a federal grant program that provides seed money which in turn allows these community health centers to provide affordable healthcare. Patients pay what they can and the health centers bill Medicare, Medicaid, and private insurance for those patients with coverage.

However, funding hasn’t been secure for all community health centers. In the early 1970s, the Asian and Pacific Island (API) community did not receive a lot of federal funding even though the API population had almost doubled. The tide of federal funding began to shift through advocacy efforts and coalition-building with other groups.

These efforts included mobilization around Proposition 13, which brought about a crisis in public funding and resulted in the formation of a national coalition anchored by Asian Health Service to protect taxpayers’ rights to services; the passage of the 1979 Federal Urban Health Initiative, which allowed funds to go specifically to primary care clinics targeting Asian patients; and the filing of an administrative complaint in 1981 in the Office of Civil Rights, issued by Asian Health Services and other agencies against Highland Hospital for discriminating against non-English speaking persons. For many organizations, key tactics included becoming politically active, developing partnerships with other organizations, and diversifying their funding sources.

On a policy level, groups like Asian Health Services and Native American Health Center have collected their own data about the populations they serve. Martin Waukazoo, chief executive officer of the Native American Health Center, said, “The county doesn’t often keep track of our statistics.” And at Asian Health Services, Hirota says, “We always do research from the perspective of where our challenge is.” Their data was shared with public health officials, legislators, and policy makers and led to the health concerns of APIs being included in the
Disadvantaged Minority Health Act of 1990, which in turn brought to light the health access problems of the API population and the need for programs and funding.

**Tensions Between Public Health and Community Health Centers**

There has sometimes been tension between public health entities and community health centers. According to the National Association of Community Health Centers (NACHC), “Everyday centers are meeting escalating health needs and bringing doctors and needed health facilities into medically underserved communities to address costly and devastating health problems, such as HIV/AIDS, diabetes, asthma, and substance addiction…The health system and American taxpayers could save up to $8 billion per year if non-urgent emergency room visits were redirected to health centers.”

The growth of the NACHC is a striking example of how local healthcare centers have matured. Every state has an umbrella organization to look at legislative trends and lobbying as well as identifying local district leaders and congressional representatives to advance programs and services. Having a clear message which in turn leads toward the ability to influence debate is key for leaders of community-based health centers, according to Sherry Hirota. “You need to see the full picture. Ron Dellums helped us to see the difference between federal expenditures versus local expenditures. It’s like looking at what it costs to fund a B1 Bomber versus the cost to fund community healthcare.”

**California as a Leader in the Community Health Center Movement**

While community health centers have evolved nationally, the state of California has the largest number of federally-funded centers. According to data compiled by the National Association of Community Health Centers (NACHC), Robert Graham Center, and Capital Link in 2005, California had 97 federally-funded health centers at 716 sites across the state. The data further showed the number of sites represented a total economic impact of over $2 billion with over 22,000 jobs being created due to the existence of those health centers. The state with the second largest number of health centers and total economic impact was New York, with 47 community health centers and an economic impact of $1.1 billion.

The seven states with highest number of health centers are California, New York, Florida, Illinois, Massachusetts, Texas, and Washington. According to the study’s data: Predominantly rural states also see a substantial economic benefit driven by health centers. In 13 states and Puerto Rico, at least 75 percent of grantees are located in rural areas and together they generate a
combined impact of $1.8 billion. Furthermore, health centers located in rural areas are often among the largest employers in their communities.

One of the keys to looking at the economic impact of community health centers on states is to see that preventative care at a health center cuts down on emergency room and inpatient hospital stays. According to data on California collected by the NACHC, “Medicaid patients (when excluding maternity services) using health centers were 33 percent less expensive overall, and had 52 percent fewer inpatient hospital costs per year.”

California, with both a diverse base of immigrant citizens and native-born minorities, is a state where the community healthcare movement began in the 1970s, and over the past 30 years has moved from storefront clinics to well-organized, multi-site healthcare providers. This transition has required advocacy, increased funding, development of community leadership, and the identification of emerging needs and practices.

Many California-based community health centers have moved from grassroots approaches to helping communities sustain basic health services to organizations that have matured in how they deliver those services to their patients. They have moved from being almost completely run by volunteers to adding paid staff positions on the administrative and medical sides. They have learned how to understand tax structures and generate state and federal funding for their organizations. They have learned how to pinpoint their needs and plan strategies to get those needs met. They are continuing to gather data from their communities and put it to use. They all have websites which not only serve to spread information about their services but also provide links to identifying new funding sources. Most importantly, they are continuing to communicate with the communities they serve to identify emerging needs for additional programs.

Case Study: Establishing Healthcare Models in 1960s Mississippi
In 1965, Dr. H. Jack Geiger wrote a proposal to establish a new type of healthcare model that addressed the links between poverty, race, and poor health in the U.S. Within six months, Dr. Geiger’s proposal was funded by the Office of Economic Opportunity (OEP), a new federal agency developed at the height of the Civil Rights Movement to wage war on poverty. Within a year, new community health centers were established in Boston’s Columbia Point housing project and the Mississippi Delta.

The Tufts-Delta Health Center in Mound Bayou, Mississippi, was the result of health services being intertwined into the OEP’s Community Action Program. Dr. Geiger modeled Tufts-Delta after Pholela Health Center, a community-oriented primary care center in South Africa that he observed on-site early in his career and studies. It represented an experimental idea that a health program
could not only provide curative and preventative medicine, but also be
designed as an instrument of community development and social change.

Tufts-Delta was designed to serve a majority African-American population
of 14,000 in an impoverished 500 square mile area of northern Bolivar
County in the Mississippi Delta. According to Dr. Geiger, Tufts-Delta’s
community empowerment program led to significant long-term changes
for African-Americans in Bolivar County. Ten local health associations were
formed to identify local needs and plan satellite centers and they each had a
representative on the North Bolivar County Health Council. The Council was
chartered as a non-profit community development corporation and set about
to change many of the social wrongs in the Delta. Council members informed
local banks that the health center’s million dollar annual funding would be
deposited into the bank that used fair mortgage loan practices, opened a
branch in the black community, and hired residents as tellers rather than only
for custodial jobs.

This convergence of healthcare justice and social change work created
opportunities for local health associations to get mortgages for satellite
centers, which were rented to Tufts-Delta during the day and used as
community centers at night. Health center staff members were also able
to obtain mortgages to build new homes. And since there was no public
transportation, the Council established a bus transportation system linking the
satellite centers to the main health center.

Other community improvements included the creation of North Bolivar
County Farm Co-op, where 1,000 families pooled their labor and shared food
grown in a 600-acre vegetable farm; the development of a pre-Head Start early
childhood enrichment program and nutritional and recreational program for
elderly and isolated rural residents; and the hiring of a part-time lawyer to
supervise state and federal agencies’ provision of equitable aid in housing
development, recreational facilities, water systems, and other aspects of
physical infrastructure.

“By 1970, the Council and Tufts-Delta had ties to 7 universities, a medical
school, and numerous foundations and agencies,” says Dr. Geiger. “In the
summer of 1970 alone, the programs were host to black and white student
interns from 8 medical schools, 2 nursing schools, 3 schools of social work,
2 public health schools, and 3 environmental health programs.” The project
was successful because it created fundamental systemic changes in practices
that traditionally kept members of economically disadvantaged, minority
communities unaware of sources of support from government agencies,
philanthropic foundations, universities, and professional schools.
Case Study: La Clínica de La Raza, Oakland, California
La Clínica de La Raza was founded in 1971, initially as a storefront free clinic by a group of volunteers that included doctors, community members and students from the University of California at Berkeley. At the time it was the only place in Oakland’s Fruitvale district where patients could receive healthcare sensitive to their culture and language. La Clínica has grown from that storefront clinic to 23 locations, including five school-based clinics, in Alameda, Contra Costa, and Solano counties. It is the largest community health center in the San Francisco Bay Area, serving 44,000 patients with a mission to improve the quality of life of the diverse communities they serve by providing culturally appropriate, high quality and accessible health care for all.

Before La Clínica was established, low-income residents in the East Bay had few options available to them for affordable healthcare. As a result, many were forced to go to emergency rooms for problems that could have been avoided with adequate primary care. Since 1971, La Clínica has played an important role in the East Bay by offering low-cost quality health care services for multilingual and multicultural populations. Services include: pediatrics, family medicine, women’s health care, mental health services, dental and vision care, and health education. They offer these services regardless of peoples’ ability to pay.

To better serve their diverse communities, La Clínica hires health professionals fluent in Spanish, English, Chinese, Hindi, Arabic, and Amharic. They also recruit doctors, nurses, health educators, and other providers who come from the same cultures as their patients. Their pediatrics department has been recognized twice with Appreciation Awards for Excellence in Pediatrics by residents from Children’s Hospital in Oakland. In 2006, La Clínica’s chief executive Jane Garcia was awarded a Certificate of Special Congressional Recognition signed by Congresswoman Nancy Pelosi for her “Outstanding and Invaluable Service to the Community.”

They believe healthy communities produce and nurture healthy individuals and healthy individuals are able to bring about and maintain healthy communities. Their health education programs include having people actively participate in and take responsibility for their own education, while promoting the idea that the community is capable of creating positive social change. La Clínica is governed by an 18 member board of directors, with 10 of those members being consumers of their medical services.

Case Study: The Origins of the LGBT Health Center Movement in California
Without question, HIV/AIDS brought the national healthcare needs of gay men to light. Many assume the Lesbian, Gay, Bisexual, and Transgender (LGBT) health center movement sprung from the Gay Rights Movement, but it was in fact an outgrowth of the women’s rights movement. In the 1970s, especially in San
From Concern to Action: A Look at Consumer Engagement to Advance Quality Health Care

Francisco, the idea that people with a variety of sexual lifestyles deserved to have culturally-sensitive healthcare began to take hold.

Joel Ginsberg, executive director of the Gay and Lesbian Medical Association, says, “As I understand it, the LGBT health center movement grew up out of the woman’s movement, especially as it related to lesbian cancer care. Then HIV moved to the forefront.” He also stressed the importance of LGBT community-based healthcare having an infrastructure “where [healthcare providers] have the skills they need for cultural competence to make sure LGBT patients are getting good care.”

Another organization at the forefront of this movement is Lyon-Martin Women Health Services, which began as a research project in 1979. “I don’t think UCSF thought they were funding a lesbian health center,” says Leslie Ewing, associate executive director of marketing and development at Lyon-Martin. “It started out as a study that was looking at STDs in women in the lesbian and bisexual population versus STDs found in straight women. The study found that many lesbians and bisexuals weren’t comfortable going for medical care where they thought they would be judged about their sexual preferences, so they weren’t going to doctors regularly to get pap smears or breast cancer screenings.”

Since its inception, Lyon-Martin has expanded its services to other groups of women who are not lesbians, but lack affordable access to culturally sensitive healthcare. As Lyon-Martin became more known in San Francisco, Ewing says, “Women outside the LGBT community started coming to us because they realized they could get treated without a lot of hassle or questions about their lifestyle. Also, Lyon-Martin does not take private insurance, so we see only low income patients. In 29 years, we’ve never turned a patient away who couldn’t pay.”

Ewing adds that Lyon-Martin has benefited from some multi-constituency alliances. “We have partnered with the Susan G. Komen Foundation with breast cancer screening and we also have nursing students from UCSF who work here in a rotating cycle for coursework credit on a volunteer basis.” The organization has also partnered with San Francisco General Hospital and the San Francisco chapter of the American Cancer Society on a variety of outreach projects. “The city government in San Francisco looks at numbers. It’s cheaper for a patient to come to a bare-bones clinic like ours than spend that money for the patient to use the emergency room as their primary healthcare.”
Case Study: Multi-Constituency Alliances in California

Many community health centers exist in neighborhoods with several distinct racial and ethnic populations. Collaboration and alliances with centers that serve different populations make all of the health centers stronger in the long run and increase the impact the centers can collectively make on policy and advocacy issues.

Asian Health Services (AHS) targets the Asian Pacific Islander (API) population in Oakland, San Francisco, and Alameda County, but they also collaborate with centers serving other ethnic groups in the area. “While battling the model minority myth, we gained insights into the relationships of race and developing coalitions with African-American and Latino organizations and other underserved populations,” said Tessie Guillermo during a statewide hearing in 1990. “We realized that Blacks and Latinos did not have adequate resources to deal with their disparities in health and we had to lead with that agenda.”

That hearing led to API concerns and the concerns of other minority groups being included in California’s Disadvantaged Minority Health Act of 1990 and made room for more collaboration and coalition-building among other minority-based health centers. For example, AHS collaborated with the Latino Coalition for a Healthy California in 1994 to advocate for cultural and linguistic requirements for all MediCal-managed care contracts. This was a landmark provision – it meant patients would have 24-hour interpreter services, bilingual materials, and bilingual staff for two-thirds of the languages spoken throughout the state of California.

In 1996, the California Health Department’s Task Force on Multi-Cultural Competence established statewide standards for linguistically and culturally accessible health services, an outcome of coalition work. More recently, in 2003, a forum was held which unified the Black, Latino, and Asian Congressional Caucuses and communities of color to ensure a national response to health disparities for those populations.

Another example of successful multi-constituency alliances is the partnership between the Native American Health Center and the East Bay Asian Local Development Corporation. Together, they completed the Seven Directions project, which will combine a state-of-the-art medical and dental clinic with an outdoor ceremonial space and 36 units of affordable housing. The project began its first phase of construction in June 2007.
Disability Rights: Putting Access on the Public Agenda

By Njere Alghanee

The Bottom Line

- The disability rights movement has developed an interesting model for collaborative decisionmaking across diverse partners called operational unity.

- The movement has made significant gains in ensuring that those most affected lead the work, a concept they call “self advocacy.”

- The public sector plays important intermediary roles as convener, funder and even mediator and many agencies have developed effective ways of collaborating with advocates.

- Academicians have played a critical role in helping to document the movement although increasingly, thanks to adaptive technologies, more and more leaders in the disability community are writing their own stories.

- The movement has developed strong “hybrid” organizations that organize and address immediate needs. Service agencies, especially those led by people with disabilities have developed a great deal of competency and comfort in both arenas.

The disability rights movement is the largest advocacy movement in the United States. This movement is largely comprised of thousands of organizations working directly and indirectly on disability rights as civil rights or human rights issues. People with disabilities constitute our nation’s largest minority group and perhaps its most diverse: all genders, sexual orientations, ages, religions, socioeconomic levels, and all ethnicities and cultures are among those living with disabilities.

What unites this diverse group is a shared experience of societal misunderstanding, prejudice, and discrimination. Historically, people with disabilities have been defined as objects of shame, fear, pity and ridicule. This is the only group anyone can join at any time – at birth, in the split second of an accident, through illness, or during the aging process.
Discontent, frustration and exclusion helped catalyze one of the nation’s most vital and militant organic and grassroots organizing efforts. Society’s stereotype as “helpless” rendered the disabled population mostly invisible—until they organized, mobilized, and popularized a movement led almost exclusively by those most affected. Disabled individuals forged their own front line leadership to demand inclusion in making public policy, increasing public access, and thus societal change. The struggle for public access as a right regardless of ability is still a challenge -- especially for communities under tremendous pressure to acquire even adequate capacity for basic living.

The goals of the disability rights movement are to bring about the empowerment of people living with disabilities through inclusion, independent living and advocacy; to achieve equality for people with disabilities through access to education, employment, and cultural development; and to preserve the legacy of peoples with disabilities who make contributions to society, i.e., inventors, scholars, heroes, archivists. A central principle is that people with disabilities must lead the work and that leadership must include every segment of the disability community.

The participants in the disability rights movement frame the work around three key sectors:

- self advocates – people with disabilities (born or acquired) leading institutions or efforts;
- institutional advocacy – nonprofits, service providers, advisors, professionals and scholars; and
- public sector advocacy – government agencies, health institutions, and foundations.

Each segment has its own way of strategizing, capacity building, and mobilizing for change. Although each segment is accountable for its strategy, disabled advocates often take on the work of holding institutional and governmental sectors accountable as part of their work.

Although direct service provision is important, a central tenet of the disability rights movement is that people with disabilities are human beings with inalienable rights and that these rights can only be secured through collective political actions. The emphasis on organizing and policy advocacy combined with a mandate to address immediate needs creates an important hybrid approach that engages program “clients” as partners in their own change agenda.
The merging of the disability rights movement with the independent living movement established the foundation for this hybrid framework – a three-pronged approach comprised of work to address inclusion, independent living, and to build capacity for advocacy led by disabled. The communities must have the support and resources to speak for themselves. Issues of inclusion include education, employment and cultural development. The demand for independent living addresses attendant assistance, transportation, housing and other supports that enable those with disabilities to fully realize their potential as responsible, functional human beings. Advancing work in these areas requires advocates to hold government agencies, health institutions and foundations accountable to their policy and programmatic agendas.

The Historical Struggle for Public Access
Advocates have organized locally, nationally and globally championing their own frontline leadership in demanding inclusion in public policy making and widening public access. The struggle for public access is perhaps the movement’s most well known. Decades of social prejudice kept children with disabilities out of public schools and sanctioned discrimination against adults with disabilities in employment, housing, and public accommodations. This exclusion was exacerbated for people of color, women, ethnic minorities, and sexual minorities. Although groups and individuals since the nineteenth century have advocated for an end to this oppression, large-scale activism did not begin until the late 1960s, encouraged by the examples of the Civil Rights Movement and the Women’s Rights Movement.

The focus began with access to public and private buildings and general accommodation for people with mobility challenges. This included advocating for the inclusion of wheelchair ramps, automatic doors, wide doors and corridors, and the elimination of unnecessary steps where ramps and elevators were not available.

Although there were earlier experiments with the concept of independent living, it wasn’t until 1972 that the first Center for Independent Living was founded by disability activists in Berkeley, California, led by Ed Roberts. These centers were run by people with disabilities and were created to offer peer support and role modeling for independent living. Depending on the depth of public services in the community, centers assisted with housing referral and adaptation, personal assistance referral, and legal aid needs. Typically, centers worked with local and regional governments to improve infrastructure, raise awareness about disability issues and lobby for legislation that promoted equal opportunities and prohibited discrimination.
At the same time, a series of landmark court decisions came about as a result of sustained self-advocacy including protests, demonstrations, and sit-ins like the Rolling Quads at Cowbell at UC Berkeley. Legislation such as the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act of 1975 secured for disabled Americans unprecedented access to their civil rights, and thus to the society around them.

The independent living movement helped establish the tenet that people living with disabilities must be instrumental in designing and promoting solutions for the problems they face; they must do the work of organizing themselves for political power.

Another crucial turning point was the nationwide sit-in conceived by Frank Bowe and organized by the American Coalition of Citizens with Disabilities (ACCD) in 1977. ACCD was a national, consumer-led disability rights organization commonly referred to as “the handicapped lobby.” It was created, governed, and administered by individuals with disabilities, which was very unusual at the time, and rose to prominence when it mounted a successful 10-city sit-in to force the federal government to issue long-overdue rules to carry out Section 504 of the Vocational Rehabilitation Act of 1973, the world’s first disability civil rights provisions.

ACCD also helped to secure federal funding for what is now a national network of 600 independent living centers and helped pave the way for accessible public transit in the U.S. ACCD closed its doors in 1983. Prior to the 1990 enactment of the Americans with Disabilities Act, the Rehabilitation Act was the most important piece of disability rights legislation in the U.S.

The independent living movement was and continues to be driven by people with disabilities who work for self-determination, self-respect, and equal opportunities. The right to have an independent life as an adult, sometimes using paid assistant care instead of being institutionalized, is a major goal. This challenged the prevailing views on rehabilitation and special education at the time, shifting the focus away from medical “experts” to people with disabilities as the best experts on their needs. The independent living movement helped establish the tenet that people living with disabilities must be instrumental in designing and promoting solutions to the problems they face; they must do the work of organizing themselves for political power.
Limited Victories
These victories, as significant as they are, have not ended discrimination, exclusion, or prejudice. Instead, recent years have brought several high court decisions that have limited the scope and effectiveness of disability rights laws, while millions of disabled continue to suffer.

The landmark passage of the Americans with Disabilities Act of 1990, which prohibits discrimination based on disability especially in the context of employment and public services, in addition to the existence of hundreds of independent living centers across the United States demonstrate that great achievements have been made. However, accountability and success in the disability rights arena is measured by the reduction of the unemployment rate; increased educational opportunities; increased the sense of pride and dignity through integration into the community; holding meaningful and valuable jobs; full participation in governance at all levels; and full inclusion into society.

Today, Americans with disabilities largely remain locked into poverty, consigned to nursing homes and frozen out of society. However, it is impossible to deny that the disability rights and independent living movements have transformed American society. Any history of American social and political life of the late 20th century must include reference to the contributions of disability rights and independent living activists.

While physical access remains an ongoing need, advocates for the rights of people with developmental disabilities are also focusing their efforts on gaining acceptance in the workforce and other areas from which they have been historically excluded. Compared to the gains of the physical disability rights community, people organizing for the rights of those with developmental disabilities have faced even more difficult challenges. Public awareness of the rights movement for this population remains limited while stereotyping this community as dependent and non-contributing is still commonplace.

A Look at the Movement's Infrastructure
Communications. Access to computer technology and the internet has significantly improved communications. Adaptive technology has increased access and capacity for virtually every disability community. The differently abled in speech and cognition are increasingly able to participate in discussion, planning and other forms of strategic work. Technology is also increasing the capacity of groups to document their own work.

Much of the communications efforts are driven by publications targeting the activist community. However, a number of media savvy advocates submit articles and opinion pieces as often as weekly to various major newspapers.
including The New York Times and the Boston Globe. National advocacy groups sponsor regular editorial board meetings with major outlets and local groups have access to training and support for local media efforts.

Oral history collections in libraries have been created to preserve the stories of victories of disability rights activists and authors at places like UC Berkeley’s Bancroft Library and the Auburn Avenue Research Library in Atlanta.

There has also been an increase in the number of television and radio shows produced by disabled activists and advocates, through public access television and community radio. Advocates have access to outlets like Radio Free Georgia, Harambee Radio, WLIB Radio, People TV, and Pacifica Radio.

**Funding and Resources.** Funding continues to challenge work in the disability rights arena, especially for self-advocates who are not linked to non-profits, advocacy groups, or public sector advocacy agencies. As a result, the best funded organizations tend to be direct service oriented and led by traditionally able bodied people while advocacy groups led by people living with disabilities tend to be under funded. Advocates often create their own independent funding sources, which can include pan-handling for daily living needs, developing church ministries and speaking bureaus, and crafts.

Another barrier in acquiring funding is the competition and tension between those born with disabilities and those who acquire disabilities during the course of their life. However, there are affinity groups that work together for funding support such as disAbility Links, which houses ADAPT; the State Developmental Disability Councils/Partnerships Funds; County Libraries’ Oral History projects and other nonprofit alliances.

**Coalition Building, Networks and Reflective Space.** Coalition-building is the key to achieving a base of individual advocates and public sector advocates. The progress of coalition-building in the disability rights movement has endured over four decades. There are hundreds of organizations, agencies, and institutions that are directly and indirectly addressing civil rights, social justice and human rights issues that bridge the disability movement. However, the disability/access movement has developed some tools to create a kind of operational unity that is utilized to garner support for an overall policy agenda. Although this approach has yet has to be effectively extended to the funding arena, it has been useful in developing a shared agenda for action.

The operational unity approach creates a venue for affinity groups to agree upon strategies, issues and implementation. Typical issues include mobilization plans around demanding legislative compliance or demands for the creation of legislation, the selection of leadership and the creation of agency services. Public sector advocates also act as intermediaries when tensions arise within the disability rights arena by providing space, funding, and other types of support.
for conferences, summits, workshops, and forums. These create networking, mobilizing, and leadership training opportunities.

Collective Future Plans. Through the operational unity process, groups have come together to chart long term objectives that have had the benefit of input from a diverse spectrum of advocates. These objectives include:

- Exercise power through civic participation: establish cross-disability coalitions, including parent support groups and children’s supports groups. Increase voter participation to ten million by 2015; monitor implementation of old and new policies; establish an association of disabled elected officials.

- Achieve economics success: transform public and private disability benefits and health insurance to jobs with a livable wage; leverage more partnerships; create mentorship and career exploration programs for youth.

- Transform society by influencing attitudes and improving access: enhance communications capacity; work with policymakers; expand public awareness campaigns; develop disability rights curricula.

- Build a disability pride and cultural identity: hold pride parades, run campaigns; spread history through websites, libraries, and oral histories collections; shape cultural awareness programs.

- Develop diverse disability leadership: staff development; identify affinity groups.

- Improve Fiscal strength: grow reserve funds and endowments; best corporate practices; increase membership dues.

- Establish centralization: headquarters; clearinghouse; strengthen relationships with stakeholders.
HIV/AIDS: From The Margins To Mainstream Attention

By Shani Jamila

The Bottom Line

- Decentralized and localized nature of actions provided opportunities for leadership development and capacity building among grassroots activists. These activists were nurtured into savvy organizers that could effectively navigate the policy arena.

- Strong relationships with researchers and writers helped to develop a body of work that supported activism and policy demands.

- The movement leveraged strategic communications and effectively linked its communications work to policy advocacy and grassroots engagement.

- Through a combination of confrontation, collaboration, professional development and strategic planning, HIV/AIDS advocacy underwent dramatic and relatively rapid changes in leadership. These changes were made possible in large part by an early commitment to democratic values, values that continue to guide much of the work today.

Since the HIV/AIDS virus was originally detected twenty six years ago, the movement to combat it has evolved into a struggle of national and even global proportions. How the struggle moved from a small group of activists working on an “obscure” disease to an international agenda setting movement is about more than the impact of the disease. As issues like malnutrition and malaria still struggle for limelight despite being more prevalent, HIV/AIDS advocacy offers important lessons in movement building and (in the transition of leadership to ensure it continues to represent those most affected) lessons in movement resiliency.

In 1981, the Centers for Disease Control and Prevention (CDC) first became aware of the “gay cancer,” an illness that was named GRID (Gay-Related Immune Deficiency) and was soon renamed AIDS (Acquired Immunodeficiency Syndrome). In 1984, the Human Immunodeficiency Virus (HIV) was established to be the cause of the disease. Whatever the terminology, a dedicated group of activists, primarily led by gay men, knew something was terribly wrong. Friends and loved ones were dying and because many of the victims were gay, they believed that public agencies were not acting quickly enough to address what was becoming an epidemic.

1 Aisha Satterwhite contributed to this profile.
ACTing UP Against HIV/AIDS

While some of the more established gay rights groups were at the negotiating table with federal agencies, groups like the Lesbian Avengers, People With AIDS Coalition (PWA), Gay Men’s Health Crisis (GMHC) and the AIDS Coalition to Unleash Power (ACT UP) took the battle to the streets and even to the ballgame. Many of the individuals who started these groups were living with the virus and living in communities where people were infected and dying at rapid rates.1 “People have no idea what it was like,” said ACTUP pioneer Larry Kramer in a recent interview on Democracy Now! “Everybody walked down the street, and you would hear about five more guys who died. It just went on and on and on.”

Building on earlier foundations of the feminist health movement and civil rights and Black power struggles, these groups engaged in creative, in-your-face tactics designed to draw media attention and controversy. The SILENCE=DEATH Project conceptualized by Avram Finkelstein, Brian Howard, Oliver Johnston, Charles Kreloff, Chris Lione, and Jorge Soccaras is among the best known. The group of gay men, many of whom worked in art and graphic design, developed the posters before joining forces with ACTUP in 1986. The posters called on those dealing with the epidemic to engage in federal policy advocacy anyway they could. They, like many in New York City’s advocacy scene, were drawn to ACTUP after their controversial concentration camp float at the Gay Pride March in 1987 – an action that called on those affected to meet the following week and develop a more radical response to the AIDS crisis.

“ACT UP was about people doing stuff for themselves. We weren’t being philanthropists. We weren’t a vanguard. We were trying to save our own lives and the lives of people we knew.”

Maxine Wolfe, another of the early pioneers in HIV/AIDS advocacy recalls, “First, ACT UP was about organizing the unorganized. It wasn’t a lefty coalition where there’s one person from this group and one person from that group and one person from the other group and you claim you have a coalition but you really have three people. It was about mobilizing a community that had not been organized to do this kind of direct action in at least twelve or fourteen years. Secondly, ACT UP was about people doing stuff for themselves. We weren’t being philanthropists. We weren’t a vanguard. We were trying to save our own lives and the lives of people we knew. We were very materially affected.”
These advocates, frustrated with the “milder” tactics of more mainstream groups like the Gay and Lesbian Alliance Against Defamation (GLAAD) and the National Lesbian and Gay Task Force, were ready for more confrontational action. The Lavender Hill Mob, started by Marty Robinson (a former GLAAD staffer and early member of the Gay Activists Alliance), had already begun doing “zaps” – disruptive actions at meetings to force policymakers and other, more reform oriented groups to address the “Mob’s” alternative agenda.

More than 300 people, including the Lavender Hill Mob members, attended that first post Gay Pride ACTUP meeting, which resulted in direct action and civil disobedience events throughout the next several years. Says Maxine Wolfe, “ACT UP has always been called a gay white male group. But the group of people who started ACT UP initially included women and people of color. There have always been lesbians and gay men of color and straight women. About the only group not really represented in ACT UP were straight men, and there have been a couple of those too.”

The ACT UP Women’s Committee played a pivotal role in organizing the 1988 national campaign known as the Nine Days of Action. They also led a watershed effort to target the largely heterosexual male attendees and television audience of baseball games at New York City’s Shea Stadium. The group created press by buying strategically-located blocks of seating during a home game held on Women and AIDS Day. Mid-game they unfurled slogans on banners with white letters on black backgrounds, designed to be easily read at night and distributed flyers underscoring the importance of condom use in preventing the spread of the disease. The action helped make visible the impact of HIV/AIDS on women and influenced the public conversation on policy and funding to address AIDS and women’s health. The Shea Stadium action was one of many ACT UP’s many bold strategic communication initiatives. The impact of these tactics still resonates today.

ACTUP’s success was fueled by an experienced leadership and organizing base and a number of savvy, professional communicators (in journalism, visual and graphic design) that helped tell their stories to the world. Building on previous gay and lesbian rights advocacy networks, feminist health movement infrastructure and direct organizing of those affected, ACTUP, the Lavender Hill Mob and other direct action groups were able to build a movement that compelled public attention and public policy change. Key features of the work include:

- Comprehensive communication strategy that linked compelling individual stories, strong visuals and clear structurally focused policy demands
- Animation of a grassroots base of those affected to engage in activism
and solidarity work at various levels of engagement – anyone who wanted to do something could find work to do within their capacity

- Skillful use of the available technology to plan and implement the work including fax and phone trees, early web tools and “street” media
- Strong relationships with researchers and writers to develop a body of work that supported activism and policy demands
- Decentralized and localized nature of actions provided opportunities for leadership development and capacity building among grassroots activists who were nurtured into savvy organizers who could navigate the policy arena

Given the country’s deeply held attitudes of heterosexism and homophobia, the early association of HIV/AIDS with gay men could have resulted in a complete marginalization of the issue. These advocates not only forced attention and resources toward addressing the epidemic, they recreated the public conversation in ways that helped people see their connectedness to the epidemic regardless of their sexual orientation. Projects like the NAMES Project AIDS Memorial Quilt, started in 1987 by long time activist Cleve Jones, helped others see that, literally, we share a common thread. The quilt, now more than 44,000 panels, is just one example of the movement’s lasting legacy of creative communications and engaged base.

The Changing Face of HIV/AIDS
Data from 1998 show that 11.7 million people have died since the start of the epidemic and over 30 million people are infected with HIV with rates of infection stabilizing in some regions of the world with access to new treatments. In the U.S., African-Americans represent 49 percent of AIDS deaths, with Black mortality rates nearly ten times that of whites and three times that of Hispanics. By 1999 the number of women living with the virus in Sub-Saharan Africa surpassed that of men and UNAIDS noted a record high of 2.6 million deaths from the disease worldwide.

Today, more than one million Americans are currently living with HIV, with racial and ethnic minorities representing the majority of new AIDS cases (72 percent). African Americans represent approximately 54% of newly identified cases and 66 percent of new diagnoses among women. The disease has become the primary cause of death for Black women between 25-34 years of age. Further, the CDC “estimate[s] nearly half of all Black gay and bisexual men in some of America’s urban centers are already infected.”

Poz,
“In 2006, AIDS in America is a black disease. No matter how you look at it, black people bear the brunt of the AIDS epidemic in America. You can’t stop AIDS in America without stopping AIDS in black America.”

— Phil Wilson, Executive Director of Black AIDS Institute

A magazine dedicated to chronicling the HIV/AIDS crisis, reports that nationally, about 2 percent of African Americans are HIV positive, a rate on par with parts of Africa. And there are more Black children with AIDS than all other racial and ethnic groups combined. 7

Although HIV/AIDS’ impact on the African American community is clear, Poz reports that in spite of the scope of the problem, national black organizations like the NAACP and Rainbow/PUSH did not speak out about HIV until 2003.8

As a result, most of the organized resistance to the disease emerging from African American communities was shaped by community-based groups working from a paradigm that acknowledges the intersecting forces of oppression and their impact on health status. These organizations include Atlanta-based SisterLove founded in 1989, Philadelphia’s Blacks Educating Blacks About Sexual Health, (founded in 1985)9, Washington DC based groups like The National Minority AIDS Council founded in 198710, Us Helping US (1985)11, The Women’s Collective (1993);12 and the Los Angeles based African American Advocacy, Support Services and Survival Institute13 and Black AIDS Institute founded in 1993 and 1999 respectively.14

These organizations were founded as a direct response to the demographic change among those contracting and living with HIV/AIDS. As rates spiraled upwards, new agencies were formed to institute programming that addressed these communities in more culturally sensitive ways. Unfortunately, organizational programming was not always able to align with the situation on the ground. As longtime advocate Gloria Crowell points out, many groups were shifting programmatic priorities to align with funding priorities. “You can’t do work without any money… policy drives programmatic work.”

Much of the work funders wanted to see was treatment based according to Dr. Mindy Fullilove, author of Root Shock and Columbia University professor: “We’re always trying to figure out what to study next, which is balanced by
what you can get money to study... because we are looking at how society kills poor and working people of color, there’s not a lot of support for what we have to do.”

The pressures that accompany the struggle for funding, resources, and infrastructure are not relegated solely to academia. Sue Simon, Project Director of the Sexual Health and Rights Project (SHARP) at the Open Society Institute, says, “Resource allocation [has affected] how difficult it’s been to form coalitions. The word ‘political’ is an apt one when talking about AIDS funding. It’s always been driven by discrimination. It’s looked at in a moral or judgmental way of separating who are the innocent victims and who are the guilty people who have brought this to themselves.”

It was out of this context of shifting funding and political landscapes that the next generation of HIV/AIDS advocacy was born. With new players and constituencies at the table, new infrastructures for collaboration had to be developed. Groups that previously led a militant struggle for inclusion found themselves the target of intense dialogues with “newcomer” groups on the same issues of marginalization they were fighting less than a decade earlier.

In 1985, a series of meetings were held about the disproportionate impact of HIV/AIDS in communities of color. The following year, a group of leaders came together to discuss the formation of a national organization that would address their needs. Many leaders broke away from the group after a heated discussion that took place during the American Public Health Association, where the first AIDS panel was held and the organization was dramatically introduced. The all white panel prompted Craig Harris, an African-American gay man living with AIDS, to rush the stage shouting “I will be heard!” Harris took the microphone from then San Francisco Health Commissioner Dr. Merv Silverman and announced the formation of the National Minority AIDS Council (NMAC) as a venue for addressing HIV/AIDS in communities of color.”

After initial struggles with direction and financial troubles, NMAC emerged as a technical assistance and capacity-building intermediary for “minority” HIV/AIDS groups. Many of the organizations they worked with were having problems with fundraising and financial management, so NMAC began holding trainings to help build organizational development practices of the field. Through growing networks like NMAC, there were organized spaces in which groups could negotiate thorny political issues like funding and power sharing as well as work with funders and policymakers to prioritize funding according to need. Predominantly white LGBT groups had organizations to which they could turn for assistance around diversity and inclusion. Organizational development frameworks that stressed intersecting
oppressions of race, class, gender and even physical ability were increasingly institutionalized into organizational convenings, policy and practice.

Perhaps one of the earliest tests of these new coalitions was the fight to keep Ryan White funding intact. For many Americans, Ryan White more than any other high profile case brought home the reality that anyone ever likely to use the healthcare system, which was just about anyone, was at risk for contracting the disease.

White, a 13-year-old hemophiliac when he was diagnosed with AIDS in 1985, made headlines when his HIV status became the basis for banning him from attending his Indiana school. His struggle was widely covered by the media and served to educate the general public about the disease and the attendant discrimination faced by those living with HIV. His death in 1990 became the catalyst for the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act – one of the first major appropriations funding treatment for vulnerable communities affected by the disease, especially impoverished people and those who were wrestling with health insurance coverage. The funding created an influx of new organizations, many of which were not involved in the tumultuous politics of the early days of HIV/AIDS advocacy.

These new, emerging policy advocacy formations were less militant than their predecessors. Many of the groups were primarily focused on direct service with little experience in advocacy and strategic communications. However, groups were able to mobilize lobby days and other forms of policy advocacy to ensure the Act’s survival. Since the establishment of the program, which delivers HIV/AIDS care to more than a half million individuals annually and funded over 2,500 organizations in 200417, it has been reauthorized in 1996, 2000, and 2006. The last reauthorization in 2006 marks the first time the Minority AIDS Initiative was codified in law.18

Work continues to progress in the area of infrastructure building. Earlier this year, the Black Women’s HIV/AIDS Network, in concert with the National Black Gay Men’s Advocacy Coalition and the National Minority AIDS Council, held a conference to address funding tensions head on. And NMAC kicked off the National Minority HIV/AIDS Policy Partnership in February with members from national organizations across several sectors and communities to help increase policy advocacy capacity on these issues.

Case Study

Black Coalition on AIDS: Moving from Direct Service to Policy Advocacy

In 1986, a diverse intergenerational group of Black men and women in San Francisco joined together to address a void they felt existed in HIV/AIDS
services in their community. The original intent of the community-based, volunteer-staffed coalition was to work on treatment and policy for Black people affected by the crisis. With the Bayview/Hunters Point Foundation as their fiscal sponsor, BCA got a grant in 1987 to implement a needle exchange prevention program known as the 3 Street Project. Over time, their programming expanded to include transgender services, HIV/AIDS testing, and the establishment of a successful volunteer network called Rafiki Services that helped raise consciousness about the disease.

This was particularly important to BCA, as many Black politicians were reluctant to engage an issue that was at the time associated with homosexuality or drug abuse. In 1992, when 24 of 26 members of the Congressional Black Caucus had refused to come to an AIDS workshop that had been organized for them because of the controversy surrounding the disease, then BCA director Reggie Williams was quoted in The New York Times saying, “It felt like a slap in the face.”

BCA began to retrofit to better focus on policy advocacy at the federal and state level by building relationships with staff and members and increasing briefings and publications to place them more firmly in the public debate. Today, BCA holds an annual briefing for the Congressional Black Caucus and is a frequent participant in policy roundtables.

Case Study

The Fight for Access to Treatment: HIV/AIDS Advocacy Goes Global

One example of successful on-the-ground efforts driven with minimal, decentralized resources is coalition work in the late 1990s and early 2000s around HIV/AIDS treatment and access to medications. In 1999, thirty-nine pharmaceutical companies got together and launched a lawsuit against the South African government for patent violations. The South African government decided that it was going to produce and distribute generic HIV/AIDS drugs to treat the extremely high and growing numbers of people living with the disease in their country because they could not afford to pay the high prices these companies were charging. The pharmaceutical companies involved the World Trade Organization, an international organization founded in 1995 to supervise and liberalize international trade, in what was largely believed by advocates to be an attempt to intimidate South Africa and them (and as a result, other countries considering following its lead) into paying higher industry prices.

U.S. advocates working on national and global HIV/AIDS education, outreach, and treatment issues began to mobilize around a common frame:
pharmaceutical companies, by suing South Africa, were placing corporate
greed over people’s lives. The frame resonated strongly within the U.S. among
advocates and activists working on increasing access to affordable HIV/AIDS
treatments to people of color and people without adequate health coverage.
“Profits over people,” “greed over lives,” “health as a human right,” and “global
apartheid” soon became slogans used in organizing communities in New York
City, Washington, D.C., Seattle, and Boston, where groups like ACT UP, African
Services Committee, Student Global AIDS Campaign, Africa Action, Physicians
for Social Responsibility, Doctors Without Borders/Medicines Sans Frontieres
(MSF), and UNAIDS mobilized a massive grassroots base. The coalition used
media campaigns, legal interventions as well as direct action protests at the local
headquarters of targeted companies. These groups were also working in tandem
with partner organizations in South Africa, Brazil, and other countries as efforts
were coordinated around the world.

Together, these grassroots organizations created a public relations nightmare
for the pharmaceutical companies. Many international petitions were launched
including one by MSF that amassed 300,000 signatures from more than 130
countries calling on the companies to drop the suit.

In 2001, after three years of intense global grassroots pressure, the pharmaceutical
companies dropped the lawsuit. They yielded to a powerful combination of
public pressure, solid legal strategy and (South African) government resolve. The
first United Nations General Assembly Special Session on HIV/AIDS was held
in New York City a few months after this victory, pulling together activists and
advocates from around the globe. The mood was celebratory, but the sense of
urgency among activists was still quite high as they were eager to continue the
fight for free and low price HIV/AIDS drugs and to influence policies around
treatment and access worldwide.

The New York Times and The Washington Post were regularly pushing front page
articles about activism and grassroots pressure. CNN and other television and
radio stations were regularly running features as well. And advocate frames of
“health as a human right” and “global apartheid” related to HIV/AIDS were
on the agenda of the World Conference Against Racism later that year. In the
U.S., organizers on the ground felt the movement was heading in a very positive
direction as the work was gaining momentum at home and abroad. Then the
events of September 11 forced these issues off the nation’s agenda virtually
overnight.

Although this movement has yet to regain the level of public visibility it once
had, the largest take-away is perhaps the type of coalition foundation it built
around the issue of health as a basic human right and how that frame could be
used to mobilize others and affect policy change. Groups working on issues
ranging from healthcare advocacy to environmental justice, from immigrant
rights to gender disparities in research, from LGBT issues to reparations for slavery, from student mobilization to global debt cancellation – all managed to find common ground. Many of these groups are still working together today.

Case Study

Sista II Sista: Creating Reflective Space for Organizational Structures for the Future

Sista II Sista, a Brooklyn-based organization comprised of young women of color, provides a potent example of how emerging groups in the sector are integrating values of inclusion and collectivism into their organizational structure. The multi issue organization launched a comprehensive internal evaluation of how power functioned within their organization. The goal: to create an organization that truly reflected its principles of equity and inclusion.

“It was a painful process to [create] a collective that would function on a consensus base, trying to create something where everyone’s voice was equally important,” reflects member Loira Limbal. “We had come from other spaces where our voices weren’t valued, because we were young, women, young women of color altogether [and we didn’t want to] keep reproducing it.”

It was for many a new project without much of a blueprint – how to build on the lessons of early advocates from the feminist health collective movement and other grassroots efforts to develop new, representative forms in communities with little history of agency, institution building or collective work. A number of intermediaries were developed to support these new structures including the Interaction Institute for Social Change, LISTEN, and Movement Strategy Center.

“Groups wanted a new paradigm for how they operated, how they collaborated with one another,” recalls former LISTEN Executive Director Ditra Edwards. “They were embracing an integrated framework and wanted to be engaged in a learning community that could support that kind of approach to the work.”

Currently Sista II Sista’s decisionmaking powers are shared by three bodies, a youth leadership group that does outreach and programs, the collective that takes on the bulk of the administrative duties of the organization, and an advisory board that is responsible for helping with the finances and programming.
Base Building Matters: The Fight for Public Hospitals

By Alec Dubro

The Bottom Line

• This is a relatively nascent movement with little dedicated support, staffing or networks. These conditions significantly affect outcomes.

• Work in this area proves the rule that funding, staffing, networks and research and analytical resources truly matter. In those cases where all of the components of the change model were present, there were good outcomes.

• Primarily, policy advocacy efforts are exclusively focused on the defense of the hospital under attack. There has not been much in the way of broader policy development to address underlying issues such as financing, patient share or indigent care.

• There are important political lessons on the importance of simultaneously building power and leadership among those most affected while building support and solidarity beyond the patient base.

• Organized labor in the health sector played a significant role in virtually every campaign and articulated stake in the issue beyond job loss. Unions, patients and in some cases, even local businesses, have demonstrated an interest in local health quality issues. Further examination should be conducted in order to assess support for specific initiatives.

The Current Crisis
When Hurricane Katrina hit New Orleans in 2005, it forced the evacuation of the city’s major public hospital. Charity Hospital, founded in 1736, was “the oldest continually operating hospital in the U.S. and the safety net for the poorest patients in one of the poorest cities in America.”

In March, 2006 Charity’s doctors, calling themselves Doctors Without Hospitals, staged a demonstration of “doctors, residents, medical students, nurses, hospital employees, patients, community members, and political activists”
to demand that Charity re-open and continue to serve New Orleans. Nevertheless, the state of Louisiana, and the hospital’s operator, Louisiana State University, decided to permanently close Charity and replace it with a new hospital.

According to The New York Times, “The state plans to replace it with a $1.2 billion complex that officials believe will attract insured patients as well as the poor, will also care for veterans and will serve as an economic catalyst for the city.” But there are no firm plans for the new hospital. In the meantime, the city is desperately short of hospital beds and the poor and sick have to travel to suburban hospitals or to inadequate clinics.

This story, minus the hurricane, has been repeated in American communities from Los Angeles to Washington DC. Public hospitals in the United States are under unrelenting political and financial pressure to either privatize or close. The immediate causes are growing competition, tighter management of care and diminished government funding. Citizen groups have fought hospital privatization and closures, sometimes successfully, often attracting the support of politicians, media and, sometimes businesses.

Public opinion is often unsupportive of public hospitals; most of the information that is widely available tends to focus on lapses of care, corruption, and favoritism. In reality, public hospitals are as good as private hospitals. In June 2007, the National Association of Public Hospitals issued a report that said “compared with all reporting hospitals nationally, NAPH members... are performing above the median score of all reporting hospitals nationally.”

And as Sam Vaknin wrote in The Sickly State of Public Hospitals, “there is no data to support the contention that public hospitals provide inferior care at a higher cost – and, indisputably, they possess unique experience in caring for low income populations (both medically and socially). So, in the absence of facts, the arguments really boil down to philosophy. Is health care a fundamental human right – or is it a commodity to be subjected to the invisible hand of the marketplace?”

**The Role of Public Hospitals as Safety Nets**

In the United States, unlike other industrialized countries, private and non-profit hospitals were the rule. However, from the time of the Civil War through most of the 20th century, most large and middle-sized cities had at least one public hospital to care for those who could not afford any other forms of acute treatment. Near the end of the 20th century, one by one, public hospitals began consolidating, converting to profit or non-profit hospitals, or started shutting their doors.
According to one public health study, “Between 1980-1993, nearly 374 acute care public hospitals were privatized, usually through an acquisition by either a non-profit or for-profit organization.” And, the number of public hospitals continues to decline. According to a 2005 study by the State University of New York’s (SUNY) Downstate Medical Center, public hospitals in major cities went from 83 to 70 between 1996 and 2002. At the same time, suburban public hospitals in suburban areas dropped from 134 to 98. Both for-profit and non-profits also declined, but not nearly as steeply.

Despite a diminished role in American health care, public hospitals remain indispensable for the country’s low-income citizens – particularly that segment of the public which has no health care insurance. The National Association of Public Hospitals and Health Systems, which represents over a hundred of the major public hospitals and health systems, states its purpose clearly: “Members of the National Association of Public Hospitals and Health Systems continue to fulfill their safety net mission to provide care to all, regardless of their patients’ ability to pay.”

Moreover, according to the SUNY report:

“Public hospitals appear to care for more seriously ill patients. Public hospitals continued to have a longer average length of stay overall and for Medicaid patients in both cities and suburbs, compared to for-profit and non-profit hospitals, which suggests that they are caring for relatively sicker, and thus more costly patients.”

In 2004, National Association of Public Hospitals (NAPH) members provided over $60 billion in total inpatient and outpatient services, but in a very lopsided fashion. NAPH members represent only 2 percent of U.S. acute care hospitals, but deliver 25 percent of the uncompensated (uninsured) hospital care in the country. That lack of compensation falls heavily on the public hospitals. “In 2004, 21 percent of public hospital costs were uncompensated, compared to 5.6 percent of costs for hospitals nationally,” said the NAPH.

**Institutions Under Fire**

Despite their essential community role, public hospitals are not rewarded. Financing remains precarious for most public hospitals, even in the wealthiest of states and municipalities. The result, according to the NAPH, is that:

“Although the entire hospital industry experienced workforce shortages, NAPH members reported an average vacancy rate for nursing staff and pharmacists significantly higher than hospitals nationally. NAPH members experienced steadily rising costs for training and supplies, adding to their financial burdens.”
Specifically, that burden meant that in 2004, the average margin for NAPH members was 1.2 percent, below that necessary minimum of 2 percent and well below the average hospital margin of 5.2 percent. In short, public hospitals are just hanging on, and they don’t have enough allies at the moment to keep them viable. That’s what makes citizen movements all the more critical.

**The Fight To Save Public Hospitals**

Despite the vast scope of public hospital closures, there are no U.S. national grassroots organizations dedicated to preserving these hospitals. In fact, there does not seem to be any national organizations with dedicated anti-closure campaigns. Fernando Losada, an official with the California Nurses Association, who helped fight privatization and closure at Chicago’s Cook County Hospital system, said, “If there are any national campaigns, I’m not aware of them.”

According a spokeswoman for the National Association of Public Hospitals (NAPH), there is only one national group advocating for public hospitals and they’re it. “We partner with other groups on specific issues,” she said, “but no one else is dedicated only to public hospitals.” NAPH functions as a trade association: lobbying, monitoring, public relations – mostly at the federal level. But they cannot galvanize communities or organize phone banks.

That means local anti-closure and anti-privatization groups confront huge problems. For one thing, they are usually facing much of the community’s power structure: elected officials, bureaucrats, the mainstream media, business groups and of course, the health care industry. All of those opponents can call on state and national resources to bolster the campaign for hospital closure or privatization.

Despite the vast scope of public hospital closures, there are no U.S. national grassroots organizations dedicated to preserving these hospitals. In fact, there does not seem to be any national organizations with dedicated anti-closure campaigns.

On the other hand, community activists have to fashion a meaningful coalition out of disparate and often mutually wary local groups: progressive community organizations, churches, progressive health care groups, unions and sympathetic media. And they must somehow find the resources to fight well-financed opposition.
In some areas of the country, union-organized healthcare workers have taken the lead in fighting hospital closures. The most notable are in the Chicago area and in New York State where the New York State Public Employee Federation (PEF) has taken the lead in opposing closures and cutbacks. PEF has been joined by a half dozen other unions. However, in other areas, such as Los Angeles, unions have not been as visible.

However, the biggest problem many public hospital supporters face is the indifference of the larger community. Except for public hospital users – by definition poor, relatively disenfranchised and often racially segregated – other members of the community are often distant from the problem. Many middle-class city residents would not use a public hospital if their life depended on it, and for most, they don’t have to make that choice.

DC General Hospital provides a clear example of how these challenges can play out. In 2000, Washington, DC Mayor Anthony Williams announced his intention to close DC General Hospital, the only public acute-care hospital in the District. Like most public hospitals, DC General served largely low-income, uninsured and underinsured people of color. Pro-hospital activists faced an uphill battle. According to DC Green Party founder Jenefer Ellingston, “The mayor put together a task force to decide on the fate of DC General, but everyone knew that it was a foregone conclusion – they would close it.”

The Green Party formed the Public Health Alliance to fight the closure, but they had another opponent unique to DC’s governing structure: in the wake of former Mayor Marion Barry’s administration, the District of Columbia was being governed by the DC Financial Control Board under a Republican-controlled Congress. The Board was supportive of closing the hospital. Within a year, “Mayor Anthony Williams, cooperating with the DC Financial Control Board, dismantled DC General and privatized its services.

Although Williams had promised that DC General would be replaced by 50 to 60 neighborhood clinics, few materialized. And with the closure of DC General’s emergency room, other local hospitals quickly found their emergency rooms overwhelmed with cases that were once handled by DC General. In short, closure led to a public health care meltdown in the District.”

The Green Party fought on. Says Ellingston, “We lobbied, testified, marched, and even chained ourselves to the hospital gates.” In one last effort, in 2003, at the urging of an ad hoc group, Health Care Now, the Green Party launched a ballot initiative that would have reopened the still-standing DC General. When they failed to get the signatures of even those city council members who had supported DC General, they took the initiative to the streets. They were invited by a well-known African-American church and political leader, Reverend Willie Wilson to Union Temple Baptist Church and were promised the support of 41 local churches. But the support never translated into ballot signatures. The Green
Party carried the bulk of the signature gathering but still fell short of the necessary 20,000 signatures.

Various attempts to reopen or repurpose DC General have come and gone over the years but the area it served still has no viable hospital while the rest of the city has ten. The Green Party and the ad hoc alliances, although they had the sympathy of many DC residents and some of the media, never created enough power to change the plans of former Mayor Williams and the business community. Moreover, Washington’s vibrant labor movement never became involved in the struggle, although many union members did. There is a strong probability that the Green Party, which is predominantly white, never had a chance of attracting sufficient African-American support. But there is also the strong likelihood that even those who depended on DC General came to believe that it was outmoded, corrupt and substandard – hardly worth fighting for.

It didn’t have to be that way. When Chicago faced the privatization of Cook County Hospital, the county was opposed by well-financed and media-savvy unions, as well as by progressive doctors and other medical organizations. According to Fernando Losada, collective bargaining director for the National Nurses Organizing Committee, his union joined with others in Chicago to form the Emergency Network to Save Cook County. It was critically important, he said, that the coalition drew on experienced organizations like AFSCME, DC 31 and Illinois Citizen Action. “We put together sustained, militant, street-heat demonstrations,” he said. In all, some 70 groups participated, asking for a radical restructuring of the hospital. “It was being controlled by the highly-political Cook County supervisors,” he said, “and we wanted it run by an independent board of trustees.” Although the administration of Cook County Hospital remains uncertain, it remains open and working. To date, Cook County still operates as a public hospital.

**Challenges on the Ground**

Campaigns to save public hospitals faced several infrastructure challenges. In the examples studied, only the Campaign to Transform King/Drew had a communications person working principally on this issue. In the other cases, communications was driven by a union public relations department, volunteers, or officers of multi-issue organizations. And although public hospital closures tend to generate media attention, the views of public hospital proponents have usually gotten second-class treatment at best.
In terms of campaigns connecting, there is no national organization dedicated to supporting public hospitals other than the National Association of Public Hospitals. If the remaining public hospitals are to be saved, groups around the country need to be linked. The first step could be an information clearinghouse, so local efforts could begin with a legacy of previous experience.

Another challenge is around policy advocacy and organizing. All of the anti-closure groups presented cogent public policy positions. The real problem, however, was that pro-closure groups had far more legislative muscle. Older African-American legislators, for example, generally support public hospitals but represent a minority in any state legislature. This does not explain why African-American-dominated city administrations like Washington, DC did not support DC General, which may be a matter for further investigation. Moreover, in the groups studied, only in the unusual case of the Community Hospital of Long Beach did hospital administrators ally themselves strongly with the community.

With regard to research, the Campaign to Transform King/Drew was the only healthcare organization with staff working largely on the public hospital campaign. In Chicago, SEIU’s Hospital Accountability Project put out several well received reports and carried the bulk of the research effort supporting Cook County Hospital. In DC, research was carried out in a more decentralized fashion with coalition members pitching in where they could. The group secured an early report by the Urban Institute but mostly relied on volunteers to pull together data and policy briefings.

**Funding and the Road Ahead**

Unless supporters of public hospitals are exceptionally adept and financially self-sustaining, which was the case in Long Beach, they need funding and infrastructure. The fights to save public hospitals are generally protracted and benefit from experienced activists and staff. The ad hoc nature of fights, like that in Washington, D.C., was invariably insufficient. Where a campaign was able to call on union resources, as it did in Chicago, or could use an experienced organizer capable of fundraising, as was the case in Los Angeles, then hospital supporters can mount a credible defense. It doesn’t guarantee the survival of the hospital, but without money and staff, the hospital is almost certainly doomed to closure.

There are practices that have emerged, even in losing campaigns, which might have succeeded with more resources and more attention. Linking with doctors and healthcare unions, for instance, seems to be essential. Creating knowledgeable staffers is also critical. Perhaps the most important lesson is that sustained, institutionally based support – staffing, research, communications and broad base building – has made a difference.
Case Study: King/Drew Hospital, Los Angeles, California

Los Angeles’ Martin Luther King Jr.-Harbor Hospital, also known as King/Drew, was built following the Watts riots in 1965. As The Los Angeles Times said, “It is a hospital that holds deep symbolic significance to African Americans in Los Angeles, and evokes a strong protective sentiment…”

Despite that sentiment, in August, 2007, after four years of official investigation, the federal government withdrew half the hospital’s $400 million budget, citing that King “was unable to meet minimum standards for patient care.”

But the closure of King/Drew, unlike that of Washington’s DC General, was not slipped by an indifferent public. The opposition to cutbacks, then closure was well-organized and widespread. King/Drew was simply unable to counter the charges that they were criminally inept, corrupt and hopeless.

Most of King/Drew’s patients, who came from the Watts/Willowbrook area of Los Angeles, were going to be left without a safety net for health care,” said Janice Hahn, a Los Angeles city councilwoman whose district includes Watts. “There will be no trauma care, no emergency care and a lack of the basic services this community needs and deserves.”

And according to a reporter at the UCLA Bruin:

“King/Drew is a textbook example of the staggering numbers. The hospital provides sustained care for more than 10,000 patients, and it treats nearly 170,000 outpatients. It is only one of two hospitals with emergency rooms in South Los Angeles, and one of only four hospitals to serve a population of more than 1 million. By comparison, in West Los Angeles, there are seven hospitals for a population of 620,000.”

According to supporters of King/Drew, the hospital administration and Los Angeles County actively opposed efforts to keep the hospital open. One nurse told radio station KPFK:

“We hear about how incompetent the staff of the hospital is. Let us look at some of the reasons this might be so…In 1993 there was a wholesale removal of middle management (associate directors of nurses, nurse managers, etc.) This was done with incentives of golden handshakes and threats of demotions for nurses who didn’t take the money.”

A coalition to save King/Drew began in 2004 which evolved into the Campaign to Transform King/Drew, now housed at the Coalition for Health & Justice in the racially-mixed Crenshaw district of Los Angeles. According
to director Nancy Watson, there are more than 60 organizations and 500 individuals active in the organization. The campaign made a concerted effort to broaden the base beyond its African-American core by approaching Latino organizations.

They had a public presence as early as possible, maintaining a website at www.transformkingdrew.com, and holding regular community meetings. From the beginning, said Watson, the goal was “to put together a multiethnic group and to do real research.” The campaign applied for funding and today has Watson plus two full-time staff. One, she said, “works on keeping the coalition together and the other on research.” With a real staff, an office and funding, the campaign was able to build relationships and even engage in strategic planning.

In 2005, the group surveyed doctors and health care administrators at 40 organizations in Los Angeles County about the pending loss of King/Drew. Seventy-five percent that the closure would impact the entire local health care system and a similar number thought the hospital should remain open and continue to exist as a training facility. Moreover, the coalition decided to take a “fix it, don’t just save it” approach with the media and took the message to The Los Angeles Times and to local television stations. They held press conferences. They appeared at the hospital advisory board and at meetings of the county board of supervisors.

Some of the campaign’s work was complemented by a second organization, Save King/Drew Coalition, formed by U.S. Representative Maxine Waters (D-CA). Waters was the most outspoken and persistent of African-American politicians on the subject, and used the coalition to push (albeit unsuccessfully) for federal legislative relief for King/Drew.

Although the hospital was eventually closed, the creation of a well-subscribed, funded and permanent organization remains a part of the capacity and infrastructure for low-income communities to engage in health policy advocacy in the future.

**Case Study: Grady Memorial Hospital, Atlanta, Georgia**

Rita Valenti has been a nurse at Grady Memorial Hospital in Atlanta for eight years and has been deeply involved in the fight to keep Grady open. “What we’re dealing with is happening all over the country,” said Valenti. “They’re closing regional and state-funded hospitals. Most public hospitals are in some form of financial crisis.”

Valenti is an eight-year veteran at Grady, the largest public hospital in the South other than Miami’s Jackson Memorial Hospital. Five thousand people work at Grady, the regional hospital for Atlanta’s metropolitan area and beyond,
serving an increasing number of uninsured and underinsured patients. The increasing number of small and medium businesses who provide either no health insurance or high-deductible, high co-pay plans means that public facilities like Grady are under increasing strain.

This is a critical issue for the region. According to one story:

“Grady is more than just a large hospital nestled in downtown Atlanta. It is an entire health system from which the entire state benefits. It has an annual operating budget of approximately $700 million, more than the entire budget of the City of Atlanta, and manages over 900,000 patient visits each year.”19

Grady receives almost two-thirds of its funding from Medicare and Medicaid with more coming from county governments, grants and in-kind services. Even so, it runs in the red. According to Valenti, Emory University and Morehouse College which staff much of Grady, are owed $50 million in reimbursements. As of early September, 2007, Grady had only funds to operate for a few months.

Despite Grady’s essential role in local health care, the Atlanta Chamber of Commerce, The Atlanta Constitution, and numerous state politicians are working to end Grady’s status as a public hospital. In July 2007, Georgia’s statewide Greater Grady Task Force recommended that Grady be given to a private, non-profit corporation. And for the past seven years, the Grady Coalition has been fighting to save the hospital, winning some important victories.

The Grady Coalition, an umbrella coalition made up of civil rights groups, AFSCME, Jobs with Justice and other progressive organizations, beat back a plan to impose high co-pays at Grady. Another smaller group, the New Grady Coalition, has also joined the fight. Neither organization maintains a website or a dedicated office.

Despite its smaller size, the New Grady Coalition filled an auditorium at the Hospital in early September 2007 for a public discussion. The majority of supporting organizations came from African-American groups and churches, whose members and parishioners rely on the hospital. Although, Grady’s future as a public facility is an open question, the active participation of neighborhood and faith leadership could lead to success if more resources are invested in these efforts.
Case Study: Community Hospital of Long Beach, Long Beach, California

In 2000, the U.S. Census Bureau pronounced Long Beach, California the most ethnically diverse city in the country. Its diversity includes White, African-American, Latino, Asian and Pacific immigrant groups, as well as a large senior citizen population. These communities had been relying on Community Hospital for acute and other hospital care since 1924. But in 2000, the operators of Community Hospital announced they were shutting the doors. This provoked a citizen uprising called Save Our Neighborhood Hospital.

The fight to save Community Hospital of Long Beach differs significantly from the other illustrations cited. Community Hospital was not strictly a public hospital and the community campaign did not spring from progressive community groups, but rather from a group of concerned physicians and hospital donors.

The Save Our Neighborhood Hospital campaign arose in 2000, when Catholic Healthcare West (CHW), Community Hospital’s owner and operator since 1998, decided to shut hospital doors and leave town. Long Beach realtor Betty Keller was chair of the hospital board when she got word of CHW’s plans to close Community Hospital. “I then warned a member of the city council,” she said, “that CHW was negotiating to sell the land to, among other possible buyers, Home Depot. We found out that when CHW bought the hospital in 1998, they had already decided to merge it with another of their properties. When that plan failed, they just wanted to dump it for cash.”

One evening Keller called an organizing meeting at her home of the senior hospital staff and a few local hospital supporters. “A local businessman gave us a $5000 check on the spot and we began organizing.” They quickly found that CHW’s purchase of Community Hospital contained a restriction: it could not be sold and had to be maintained as a non-profit hospital or turned over to the city. CHW nevertheless closed the hospital and the newly-christened Save Our Neighborhood Hospital turned into a fundraising campaign.

The public face of the campaign became hospital physician Robert Pugach and the campaign was joined by local politicians, The Long Beach Press-Telegram and the business community. “One supporter,” said Keller, “quietly gave us $250,000; others followed. Our research then found that if a non-profit hospital becomes for-profit, the previously saved tax money must revert to the community. That way, we got $2 million.” In June 2001, the emergency room doors at Community Hospital opened for the first time in nine months.
“I don’t think too many people ever thought we would get to this point,” said Dr. Robert Pugach, a founder of Save Our Neighborhood Hospital and Community Hospital’s president and CEO when it opened. “Just the ability to survive as a stand-alone hospital in today’s environment is absolutely astounding.”

Save Our Neighborhood Hospital was extraordinarily successful. According to Community Hospital community relations director Kathy Berry, “As far as we know, this is only the second acute-care hospital in the United States that was closed and re-opened as an acute-care facility. Some were closed and re-opened as specialty hospitals, but most were razed or converted. One, we know, re-opened as a bed and breakfast.”

Community Hospital, with a base broader than its predominantly poor patients and their allies, was able to survive and thrive despite the prospect of closure and sale. This victory appears to prove the rule that resources, leadership development and a supportive base can make a real difference. The strong partnership between administrators, medical personnel and community stakeholders helped establish the issue on the public agenda and avoid divisions that typically sabotage other anti closure efforts.
Promising Community Organizing Practice in Health Policy Advocacy

As the previous movement profiles show, there is a rich legacy of committed, effective movement building for health justice. As the next five case studies show, that tradition is alive and well in base building organizations as well. Three of the groups work locally building power in a geographic area. Two support base building efforts statewide. All five are committed to building power at the grassroots level but each group has developed different approaches to their organizing, specifically their organizing to advance health policy. However, all offer practices worth replicating.

Tenant and Workers United: Place Based Resident Organizing for Quality Care

Tenants & Workers United (TWU) is a democratically-controlled, grassroots organization working to build power in low-income communities in Northern Virginia. With a diverse base of Latinos/as, African Americans, tenants, immigrants, workers and young people, TWU conducts a broad range of campaigns and organizing initiatives to build regional power and a broad, political-economic justice movement “centered in the leadership of working-class women and communities of color.”

TWU took up health care issues as a part of their agenda to advance justice and improve quality of life where they organize. Given the demographics, health care is a top priority. An estimated 150,000 or more African Americans and Latino, African, and Asian immigrants work in sub-living wage jobs, with few employment benefits and limited access to healthcare. The multinational immigrant population is particularly at risk, with 50 to 80 percent of low-wage immigrant workers uninsured. Access to subsidized care for those ineligible for Medicaid is limited, and in a metropolitan area with a large international community, linguistic and cultural barriers to health care remain high.

First developed in 1996, their Comunidad Saludable/Healthy Community Campaign is led by an organizing committee of over 100 low-income, uninsured immigrant community members. Comunidad organizes members directly affected by care issues, collects stories and uses participatory research to document issues and craft policy initiatives. The organizing committee conducts neighborhood canvasses, organizes patients in waiting rooms and outside local clinics and hospitals, and engages in media and policy briefings – including community accountability sessions with policymakers and administrators.
Members are also trained as promotoras, community-based health workers that conduct outreach, share information and leverage their service work for organizing their “client” base. The work has provided big payoffs. TWU has helped to expand and improve access to healthcare benefiting thousands of mostly uninsured Latino and other immigrant residents in Northern Virginia. Since 2002, the campaign has organized and successfully advocated for the implementation of a 35% medical discount for uninsured patients at the region’s largest healthcare provider and staff have helped eliminate $850,000 in inappropriate medical debts at regional hospital facilities. These campaigns help set new standards for emerging community healthcare organizing initiatives nationwide. Comunidad has focused on improving cultural competency at local care facilities through patient monitoring, training and institutional policy change. TWU’s program staff also serves as interpreters, advocates, and informal case managers for hundreds of uninsured residents with limited English proficiency.

A key feature of this model is the centrality of organizing – every aspect of the work including health education and direct services (i.e., TWU’s community health fairs and monthly health promotion clinics) are structured in ways that move participants into deeper levels of political engagement. Participants help document problems, chart policy approaches and engage in direct action and advocacy for structural change. Trainings and support for cultural competency at the practitioner and institutional level also features action components. This work is supported by research and strategic communications to keep these issues on the public agenda. A recent case in point is TWU’s release of Waiting for Health Care: Alexandria City Health Clinics Lag Behind in Timely Access for the Uninsured. The report details resident stories and data that illustrate problems with the local clinic system. The report and the people behind the data are actively pitched to the press to provide a supportive communications context for their organizing and policy agenda.

**Community Coalition: Bringing Health Organizing Close to Home**

The Community Coalition (CoCo) was founded in 1990 by a diverse group of activists, service providers and people in recovery with funding from the federal Center for Substance Abuse Prevention. From the beginning, CoCo looked to grassroots advocacy and policy change as primary tools to address alcohol and other drug problems in South Central Los Angeles.

“We wanted to address the drug epidemic in South L.A. Our beginning thought was that it was rooted in the economic and social divestment in the area,” says former staffer Sylvia Castillo. “We thought that the reason that individuals were using drugs was to medicate the pain of racism and unemployment. So, built on that, what do you do to respond? One of the ways we felt we needed to respond -- and respond immediately -- was to
organize individuals to see the power that they had. We felt there was a need to involve people in leadership development to take positions, to have a say in what was happening not only at the neighborhood level but at the city level, at the level of policymaking.”

More often than not, South Central is portrayed as a set of mean streets full of violence and abject poverty with little opportunity for those who reside there. In reality, the 40-square mile area where CoCo works is one of the most ethnically diverse communities in the United States. About a third of residents live in poverty and the median income in the area is only slightly more than half of the median income for Los Angeles as a whole. Despite areas of high crime, many areas have older, stable neighborhoods with residents who have lived in the area for decades.

The area, like many inner city communities, has gone through many changes. Half a century ago, immigrants from Texas, Louisiana, Arkansas and other parts of the South settled in the area for the many manufacturing jobs nearby. Then, there were plenty of jobs and residents enjoyed a level of prosperity impossible “back home.” They bought homes and rental property, built churches and social clubs and opened small businesses that catered to the growing community of southern immigrants. As the community became increasingly African American, banks and other businesses stopped investing to the same degree. Some manufacturing firms relocated while others fell prey to the larger macroeconomic shifts that afflicted the manufacturing sector nationwide. As businesses left or folded, unemployment and poverty spiraled upward.

CoCo has built an impressive resident base in South Los Angeles in order to build power with an emphasis on influencing local policy. Work is mostly geared around five projects: (1) the Land Use Committee, which utilizes city land use ordinances and policies as a strategy to prevent, reduce, and eliminate sources of crime; (2) the Prevention Network Providers, a multidisciplinary alliance of social service providers working to build a strong social safety net; (3) South Central Youth Empowered through Action, which develops the next generation of activists capable of leading their peers and impacting public policy in their schools and community; (4) Parents In Action, which organizes caregivers and parents to advocate for their children and work together to improve the conditions in their schools; and 5) Kinship In Action, a program to improve family care in Los Angeles for children who have lost their parents to incarceration.

CoCo has extensive mechanisms for leadership development and political education of its members. Members move into deeper levels of analysis and leadership as part of a program that includes annual study intensives and regular training and retreats. Given CoCo’s extensive organizing capacity,
networks and systems, the organization is particularly well poised to take up their own “TWU style” organizing on quality care issues. CoCo, TWU and CPA are also already connected via informal organizer networks.

**PICO California: Statewide Network Supporting Local Organizing and Coordination**

PICO California works to bring its local, neighborhood based affiliates to the statewide policy arena. As an organizing network primarily working through its 350 congregations and 450,000 “families,” PICO’s base is diverse and politically divergent. Their grassroots leadership is multiethnic, multicultural and representative of the communities in which they organize. Scott Reed, PICO’s national director of organizing has characterized its membership as “basically conservative” and representative of the political mainstream. With such a broad and diverse base grounded in a faith context, PICO focuses on “bread and butter” reform issues with direct impact on its members – and within a framework of active faith. Issues include health care, education, housing, fair wages and immigration.

PICO’s healthcare work has primarily focused on issues of access with special attention to access to coverage and increased funding for local clinic services and efforts to save the Supplemental Child Health Insurance Program (S-CHIP) as part of a national PICO initiative. They have developed an eight pronged health policy agenda around which they have member support and organizing resources to support basic policy engagement at the community level. (See www.picocalifornia.org/Files/healthcare_plan.pdf) Base building efforts extend well beyond their membership including other community based groups, faith networks, policy organizations and some labor formations.

PICO California has fought for and won a number of campaigns dedicated to improving and expanding health insurance programs, clinic services, and health outreach efforts. Efforts include supporting initiatives that would provide health care for everyone in the state, especially children and families. According to PICO California, member leaders are actively organizing in 73 cities in Northern and Southern California and in over half of the State Assembly and Senate districts with working relationships at every level of government and on both sides of the aisle.

**Chinese Progressive Association: Worker Organizing and Health Policy Advocacy**

Chinese Progressive Association (CPA) is a grassroots organization founded in 1972 organizing mostly low income Chinese Americans in the San Francisco area. Their primary geographic focus is San Francisco’s historic Chinatown where, despite widespread gentrification and displacement, a large community of low income Chinese reside, many of whom live in single
residential occupancy (SRO) hotels. CPA has worked on living wage campaigns, tobacco control, tenant rights and a range of health and safety issues.

CPA’s projects include: (1) The Workers’ Organizing Center, which trains tenants on macroeconomics, organizing, advocacy, and the importance of broad-based social change; (2) The Housing Justice Campaign, which integrated smoke-free campaigns into work on environmental health, rent control, affordability, and other health safety issues; (3) The Common Roots Youth Organizer Program, a collaboration with San Francisco’s PODER, to build alliances between Latino and Chinese communities, and (4) The Chinese Power Against Tobacco project, which has mobilized immigrant youth around tobacco control and targeted marketing.

CPA initiated its Workers’ Organizing Center after years of building with residents, many of whom worked in low wage jobs with little protection. Restaurant workers are a particularly significant segment in Chinatown where small, non-chain eateries are major part of the retail base. Restaurant workers are at particular risk for health issues where long hours, occupational hazards and frequent lack of health coverage are barriers to quality care. According to The Center on Policy Initiatives, restaurants have the lowest coverage of workers in the state. The vast majority of restaurant workers are immigrants who speak English as a second language and CPA’s base of workers certainly proves this rule.

The Worker Organizing Center conducts introductory and intermediate leadership training sessions that combine political education, organizing training and analysis of the sectors where they work (usually garment or restaurant industries). Participants get hands-on training in CPA campaigns. Community members are engaged in organizing efforts such as outreach activities, community education, leafleting, one-on-one recruitment efforts, and protests. CPA trains community members to conduct outreach and education in all program areas and how to speak out at public hearings and press events.

**Women’s Economic Agenda Project: Broadening the Base for Health Care Rights**

When members of the Women’s Economic Agenda Project (WEAP) started organizing around health and human rights issues, they began with their considerable base of low and no income women in Northern California’s East Bay. The group has a long history of organizing women and progressive ally

“We are all in the same boat. The system hurts health workers. It hurts patients and it hurts low income communities even more.” — SEIU 790 Education Director Karega Hart
organizations around “bread and butter” issues such as welfare rights, access to childcare and living wage using a human rights framework. As part of the Poor People’s Economic Human Rights Campaign, an international movement to advance economic human rights (www.economichumanrights.org), WEAP was already grounded in a global context.

“The human rights framework just made sense to us,” says WEAP Executive Director Ethel Long-Scott. “It is a higher standard. It is not about what the market will bear. It does not end with whether it is profitable. It simply says, ‘here are standards for how every human being should be treated.’ We were clear this should be the law.”

Health issues have long been a challenge for WEAP members. These issues spanned beyond health coverage to access to care, linguistic access, environmental health and more. Reflects Long-Scott, “There was no way to fight for a just economic agenda without addressing health as a human right. Health was connected to work, to wages, to education, to safety, to family quality of life, to credit, to benefits. The connections are endless. Moving a health as human rights agenda requires a ‘big tent’ so to speak.”

WEAP organized discussion groups with its members to better understand how health issues were affecting their communities as well as to identify strategic goals for advancing a health justice agenda. It was important to build a broad coalition of those affected by these issues, so WEAP reached out to organized labor and health care advocates to help build support for a more comprehensive framing of adequate health care as a human right.

This led to a partnership with Service Employees International Union (SEIU) 790, the California Nurses Association (CNA) and the San Jose Communication Workers of America (CWA). With their networks, WEAP was able to expand its reach to more than 130,000 workers in California alone. For the unions, the need was clear. The health care system was broken for workers, and for patients, and it would take a broad based movement to fix it.

The first phase consisted of building a common framework among its base and coalition members. “It was important to get everyone on the same page,” says Long-Scott. “We studied the various proposals, studies and approaches that made the poverty-health connection. We looked at the proposals for systems change and felt it was important not to settle for minor reform. We had to build unity around the understanding that healthcare must be part of the broader struggle to eliminate poverty.”

The group conducted a series of two-hour trainings that allowed participants to share their experiences interacting with the healthcare system. The sessions
took place at worksites, union meetings, church groups, house meetings – anywhere WEAP could go to engage coalition constituents on the issue.

Building on the work of the trainings, WEAP worked with coalition partners to organize a Truth Commission/Congressional Hearing on health issues. The hearing was co-chaired by congresswoman Barbara Lee (D-Oakland) who, along with a number of Bay Area luminaries, listened to a series of painful personal grassroots testimonies on how the lack of healthcare in the area was ruining people’s lives.

“These hearings are a way of telling our stories so that those in power can hear them. Making the invisible visible,” says CNA’s Nancy Lewis. “It’s about forging solutions.”

The hearings were used as newshooks, to engage the media in ways that allowed the coalition to control the frame. “When we developed our own event, we could be proactive. We could start where we wanted the discussion to go,” says Long-Scott. “We did not have to react.”

The half day hearings drew a diverse group of more than 200 including several key policymakers at the local state and federal levels. WEAP continues to build on the success of these efforts through continued trainings, member surveys, articles and interviews that amplify the health as human rights frame.

The alliances built with unions remain strong as WEAP works to take their efforts statewide. Says Long-Scott, “We are constantly saying that we are fighting for a system with ‘everybody in, nobody out.’ We know that part of this is a communications task but the bulk of the work we must do comes down to organizing.”
A Look at California Capacity for Advocacy on Quality, Culturally Competent Health Care

### Capacities of Organizations Likely to Engage

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<tr>
<th>Intermediaries serving health advocacy groups. Groups like Health Policy Coach, Prevention Institute, Berkeley Media Studies Group, Hablemos Junto</th>
<th>Policy Advocacy</th>
<th>Leadership and Base Building</th>
<th>Research and Analytical</th>
<th>Strategic Communications and Technology</th>
<th>Connective/Reflective Space</th>
</tr>
</thead>
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<tr>
<td>High level of policy advocacy support available, especially at the state level around specific health issues. There are fewer intermediaries supporting local policy development on health care as few of these groups have identified local policy approaches in this area. Hablemos Junto has developed best practices and recommendations regarding language access.</td>
<td>Although there are intermediaries supporting base building for groups taking on health issues, dedicated capacity building to support health organizing is limited.</td>
<td>There are several entities producing high-quality research to support state level advocacy on health care and related issues including groups like Latino Health Access and California Pan Asian Health Network that develop policy resources to support advocacy in communities of color.</td>
<td>The state has an advanced strategic communications research and search to support state level advocacy on health care and related issues.</td>
<td>Although California has an extensive health intermediary sector, it is currently not dedicated to funding in the area, there are not that many gatherings that bring together grantee formations for intermediary planning and coordination.</td>
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<tr>
<th>Intermediaries serving core constituent groups. Groups like Children Now, National Network of Immigrant and Refugee Rights, California Alliance of Retired Americans, Center for Third World Organizing (CTWO), Black Women’s Health Project, Lambda Medical Association, Latino Issues Forum, Vision &amp; Compromise</th>
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<tr>
<td>This diverse sector has a great deal of capacity. Many of these institutions have extensive grassroots networks and members they support. Groups like CTWO, SCOPE-LA and the National Network have regular retreats and planning spaces to convene networks and build capacity. As a network of promotoras, Vision is a great example of an intermediary that is both health-focused and serving key constituencies. Partnered with content specific intermediaries in ways that support mutual learning and exchange, these groups have the capacity to bring key constituencies into the work and support field development.</td>
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### Base building groups with immigrant and/or “newcomer” base

| Groups like Central California Coalition for Immigrant Rights, Alianza de Federaciones y Organizaciones Mexicanas, Asian Immigrant Women Advocates, Chinese Progressive Assn. (CPA), Women’s Economic Agenda Project | Capacity is emergent and growing. Women’s Economic Agenda Project (WEAP) has played a critical leadership role in forging a coalition that brings together their largely low-wage base of women, researchers and policy wonks, organizational labor and other advocates on access to care issues. The group has developed briefings and white papers. | Vital models of organizing are in play. groups are also building impressive bases that are ideal in helping to form core support for quality care initiatives. | CPA and AWPA are among the groups that have developed strong ties with local researchers as well as developed member leaders to conduct their own research. | Although many of these groups do not have dedicated strategic communications staff, they have experience dealing with media and have been able to frame their issues when they get access. | Thanks to the support of groups like the National Network, SCOPE-LA and American Friends Service Committee, these groups do get some access to collaborative planning and network support. However, it appears that much of this space is organized around specific campaigns and not always geared toward field building at large. |

| Resident organizing/neighborhood groups working on related issues. Groups like Community Coalition, local PICO and ACORN affiliates | Community Coalition (CoCo) is an example of how a member group can build incredible capacity across every component of work. It is poised to operate as a hybrid group that both engages in base building and supports replication and better practice. PICO and ACORN has also developed capacity across many of the components but their current structure does not allow for the deeper levels of leadership development and capacity building of CoCo’s single emphasis on South LA. | | | | |

| Base building groups representing key constituents as workers. This includes organized labor like SEIU, California Nurses Association and worker center formations like Chinese Progressive Association’s restaurant worker center. | SEIU has established initiatives like Community Strength with a specific emphasis on health access and advancing health disparities. Of course, trade unions have extensive capacity if they make the commitment to mobilizing resources. California Nurses Association is involved in a partnership with WEAP in advancing access issues and local worker centers are working on occupational health and safety issues. All great potential partnerships. |

| Health related, issue specific coalitions and advocacy groups. Groups include Sickle Cell Foundation, California Breast Cancer Organization, AIDS/HIV advocacy groups | Although many of these groups are not engaged in base building, they do have great content capacity and relationships in the policy arena. Some of these networks have communications staff and fundraising capacity that would certainly be an asset in a well organized coalition setting. It would take work to move these groups to the level of development of a shared agenda on quality care. However, the rewards for effective coordination would be substantial for everyone concerned. | | | | |
Implications for Consumer Engagement on Quality Healthcare

1. Base Building is Critical to Success and Good Base Building Takes Time
   If there is one take home lesson from the research in this scan, it is that base matters. As important as money is – and it is vitally important to successful work – nothing trumps the power of broad based support. When advocacy efforts move beyond traditional coalitions and content experts to engage the people most affected, things change.

   Of course, funding plays an important part in base and infrastructure development. In fact, in each effort we examined, funding and resource development were critical to expanding the existing base and building new ones. Base building is part infrastructure (organizers, training, tracking systems, etc.) and part engagement strategies (employing messaging honed by outreach and listening). Efforts that bridge racial justice and health organizing, broadly define “health,” and build networks and alliances across race and discipline are the most successful. In short, organizing efforts that clearly articulate an issue in ways that communicate what’s at stake in concrete, local terms have attracted strong support. However, base building is not a short term strategy. It requires years of investment to truly grow and sustain public support over time.

2. Intermediaries Make A Difference
   “The distinctive common characteristic of the new intermediaries is that they consciously integrate the intermediary roles of policy development and regional networking with the infrastructure tasks of grassroots organizing, leadership development, and community empowerment. To put it another way, their strategies continuously link their goals for policy formation, coalition building, and constituency organizing. We identify such organizations as hybrid intermediaries…there is also growing recognition that social issues and program areas no longer fit easily into segmented, vertical categories – housing, health, education, the environment, economic development, violence prevention, etc.”

   — A New Look At Intermediaries, The New World Foundation, New York, November 2000

Groups need care, support and connective tissue. Even vibrant movements like work in environmental justice found it difficult to maintain national momentum after its intermediary core was defunded. Although there are many strong, health focused intermediaries in the state to support policy development and strategic communications, intermediaries supporting organizing are primarily multi issue, multi sector, hybrid intermediaries.
California has the good fortune to be home to a number of hybrid intermediaries with a strong record in field development. Groups like Movement Strategy Center, Center for Third World Organizing and SCOPE-LA define the new intermediary framework and have established relationships with the core constituencies necessary for movement building to advance quality care. Immigrant rights groups, youth organizing, multi issue community-based organizations and worker centers are often part of intermediary networks where groups connect, plan and learn from one another. Given California’s extensive networks, any plan moving forward should incorporate these intermediary structures.

3. **Leadership development and organizational health matter to a movement’s survival.**
Organizations are a movement’s foundation. When they don’t work, there is no work being done. Therefore, attention to leadership development, organizational development and the healthy functioning of institutions and coalitions are instrumental to sustaining work over time.

4. **Learning communities are critical in moving the work forward**
In nearly every case, the best work was inspired by learning opportunities – especially opportunities that allow advocates to get out of the United States and explore alternative visions of what’s “possible.” Given the limited public policy debate on health care in the U.S., exposure to more dynamic approaches to quality care will foster greater innovation and learning.

5. **California is uniquely positioned to build a diverse consumer base for quality care**
With its extensive intermediary and organizing networks and diverse patient base, California is poised to set the bar for organizing to advance quality care. The state has more than a million residents needing translation in order to effectively use health services. Most health care consumers in public facilities are people of color. And many local health departments already have some support for promotoras or other more organizing oriented approaches for engaging residents in health advocacy.

Other assets include:

- Many base building groups working at the neighborhood level or organizing key constituencies across geography have some aspect of health work already on their agenda.

- Organized labor and other worker formations are engaged in aspects of this work and under the right conditions, could play a pivotal role in base building and policy advocacy.
• There are several “mature” health movements that could play a vital role in efforts to advance quality care. For example, the environmental justice movement offers a powerful framework to engage policy-making and political institutions around issues of equity and accountability. With the right kind of organizing infrastructure, community health centers – especially their client boards – could revive their advocacy tradition and bring new voices into the quality care debate.

• The disability community has hundreds of trained organizers and activists with experience in policy advocacy. Issues of healthcare access for the disabled are certainly consistent with a comprehensive quality care agenda. Engagement of this constituency would require clear handles that allow members to see a strong connection between the quality care agenda and their own.

• Engaging HIV/AIDS advocates may require more support in order to expand the sector’s base building and organizing capacity, but the growing populations of color living with HIV/AIDS will need advocacy venues in order to ensure access to quality care – especially those living away from urban medical centers.

Although there is a great deal of ready infrastructure to support the work, this infrastructure must be expanded and better coordinated in order to effectively take this work to scale. There must be a multi sector approach to building a cohesive yet decentralized field that enables a diverse set of stakeholders to work together but also chart their particular community’s agenda for quality care. The chart below suggests a change model for how these sectors and constituencies might interact.
Emerging Change Model to Advance Culturally Competent, Quality Care A Comprehensive Approach to Funding and Capacity Building*

View 1: The way activities work together

Circles are outcomes to achieve
Outer “arrows” are methods to help get there, they work across all “circles”

- **Better Practice**
- **Convenings**
- **Environmental Change**
- **Legal Advocacy** to shift the context of what’s possible re: code, applied legal principles and consequences for non compliance
- **Network Building/Information Systems** to connect communities, constituencies, the movement to information and each other
- **Policy Change**
- **Strategic communications**
- **Base Building and Advocacy** in target communities to shift priorities, win change and build political and institutional will for more change
- **Awarding innovation**, models, tools development with ‘prizes’ and other forms of recognition
- **Trainings and Capacity Bldg**
- **Convenings** Gatherings that help set policy agenda and recruit decisionmakers, bring advocates together for movement building and agenda setting, cross fertilization, media attention, network development, etc. **Good Research** that builds credibility for promising practice, good policy **Supporting change agents** with better information, promising practice, good policy info, skills, etc. **News, papers, study releases, polling, case studies, profiling leaders, etc. for agenda setting, framing, building political will, supporting replication**

*This model prioritizes movement building for policy and environmental change, not interventions designed to influence individual behavior change (i.e., social marketing to patients)
View 2: How key constituencies can be engaged in comprehensive change (see details below)

Main strategies:
- Set the public agenda and build public awareness by convening key actors and developing effective communications strategies.
- Policy development through support for replication, awards for innovative policies and practice (legislative and institutional)
- Leadership and network development through capacity building, retreats, “seeded” collaborations, fellowships, etc.
- Supportive research through more effective partnerships between affected communities and researchers
- Infrastructure development for expanded base building and organizing capacity
- Advocacy to change policy, build political will
<table>
<thead>
<tr>
<th>SECTORS</th>
<th>Set Public Agenda/ Build Public Awareness</th>
<th>Policy Development/ Innovation</th>
<th>Cultivating New More Effective Leaders/Network Development</th>
<th>CBPR Partnerships and Research</th>
<th>Expand Base Building/Organizing Infrastructure and Capacity</th>
<th>Advocacy for Specific Policy/ Environmental Changes</th>
</tr>
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<tbody>
<tr>
<td>1. Intermediaries serving key constituencies</td>
<td>X</td>
<td>X with emphasis on groups in their networks</td>
<td>X support groups in engaging as appropriate</td>
<td>X Leverage existing training capacity and modules</td>
<td>X</td>
<td>X local policy advocacy and come together to provide strong, influential constituent foundation for state and local policy</td>
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<tr>
<td>2. Place Based Multi Issue, Multi Constituent Groups</td>
<td>X Start with clear local campaigns within the mission of groups, develop unified messaging and coordination</td>
<td>X Groups should be supported in developing relevant policies and sharing with emerging network</td>
<td>X Working with experienced intermediaries to help strengthen networks among groups and others in the field. Given historic tensions in the sector, this will require investment and work to nurture into statewide network</td>
<td>X Groups should lead these collaborations and participate in identifying research agenda to support institutional change</td>
<td>X Expand and train organizing core, support exchanges, ensure consistent capacity for data management and tracking of members, etc.</td>
<td>X help shape policy content with advocates in a mutual relationship (all are “experts”)</td>
</tr>
<tr>
<td>3. Health Advocacy Groups and Intermediaries</td>
<td>X Working collaboratively set frame, help develop and support strategic communications tools and frameworks, host key convenings leveraging networks</td>
<td>X (especially health dept. level and public health practice)</td>
<td>X (field development)</td>
<td>X In the case of advocacy groups with member base (i.e., Breast Cancer networks), support to retrofit to better engage base in this work would be worthwhile</td>
<td>X</td>
<td>X Help shape and support initiatives</td>
</tr>
<tr>
<td>4. Worker and Labor Orgs</td>
<td>X Leverage communications and networks to support statewide campaigns, host convenings and briefings, etc.</td>
<td>X Examine how might occupational and labor issues fit into quality and competency frame</td>
<td>X Retreats and leadership development support that engage members in concrete work on the issue and bring them in contact with other organizers for field building and strengthening practice</td>
<td>X as appropriate</td>
<td>X</td>
<td>X Help shape and support initiatives</td>
</tr>
<tr>
<td>5. Media Makers and Journalists</td>
<td>X support good coverage and documentation of inspiring “stories” from base work</td>
<td>X Cultivate and support journalists to do investigative, structurally focused stories on health care</td>
<td></td>
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<tr>
<td>6. Researchers and Legal Advocates</td>
<td>X Develop “credible” info for policy conversation and conduct convening for field agenda setting</td>
<td>X model policies – esp. for local “handles”</td>
<td>X fellowships, retreats and other gatherings that help build relationships with organizers and create shared agendas, goals, etc.</td>
<td>X</td>
<td>X Inform policy development, disseminate to key actors. As appropriate, litigation, legal advocacy and policy drafting</td>
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</tr>
<tr>
<td>7. Issue and Constituent Based Member Groups</td>
<td>X Leverage networks to help move issue to sector agenda</td>
<td>X Support groups to develop policies/share with network</td>
<td>X Same as place based groups: connecting with others, identify common work</td>
<td>X Help lead collaborations and tailor work to specific areas of common ground</td>
<td>Expand and train organizing core, support exchanges, ensure effective data mgmt/tracking , etc.</td>
<td>X Based on common ground issues, develop specific state initiatives</td>
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Recommendations

Augment the capacity of willing groups currently involved in effective base building — even those not currently working on health care -- to work on quality care issues. One of the important lessons from the tobacco control movement is that it was more cost effective to engage multi issue organizing groups to undertake tobacco control policy than it was to “encourage” tobacco control groups to engage in base building. Health policy advocacy groups should play to their strengths – convening, research, policy development and communications and work in partnership with experienced organizing groups to develop a strong advocate base.

Set the ground work for principled, multi sector and single sector partnerships early in the work. Collaboration can be challenging, especially if there are no formal venues and ground rules for how issues are resolved. The best collaboratives have formal network support in the way of organizational development experts, facilitators and regular convenings in order to build the relationships and shared language necessary for effective work together. It will be important to convene partners in a variety of combinations including “affinity” groups or networks comprised of groups working in the same sector, similar communities and/or demographics as well as cross sector/community formations.

Base building groups should be an integral part of research and policy planning. A common pitfall in multi sector work is the exclusion of base building groups from the policy development and research segments of the initiative. Base building groups are accountable to members and need input in order to ensure that emerging work is consistent with organizational values and agreements. In addition, they have useful insight and experience to offer the process. Their participation should be formally incorporated into any planning.

Expand resources for advocates in languages other than English. Our assessments turned up few health organizing resources in other languages. Given California’s large base of limited English speakers, materials, resources and trainings will need to expand to better serve the state.

Support learning, experimentation and risk taking. There are no clear cut models for patient engagement at scale – especially in the U.S. Therefore, advocates must build on what they do know and be willing to “discover” how to take the work to more unfamiliar places. “Exchange” visits to places (especially outside of the United States) can help advocates get “unstuck,” inspire innovation and even prevent burnout.

Provide organizational development and management support to key groups that need it. It is extremely sad when great work is undermined by
organizational infrastructure challenges. Even the best groups face these problems and need help navigating them effectively. Growing a field requires investing in the people and institutions carrying out the work. Support for organizational development up front can prevent problems down the line.
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5  http://www.talewins.com/healthbuilders/hospitals.htm


9  Interview with Fernando Losada, director of collective bargaining for the National Nurses Organizing Committee, 2007.


12 Telephone interview with Fernando Losada, director of collective bargain, National Nurses Organizing Committee (a national affiliate of the California Nurses Association).


17 Telephone interview with Campaign to Transform King Drew Director Nancy Watson, September 16, 2007.


19 Interview with Community Hospital of Long Beach board member Betty Keller, 2007.

(Endnotes for HIV/AIDS: From the Margins to Mainstream Attention)

1 Goodman, Amy. From a March 29, 2007 interview on Democracy Now! Interview of Larry Kramer http://www.democracynow.org/article.pl?id=07/03/29/1352252

2 Goodman, ibid.


4 Somella, ibid.

5 Somella, ibid.

6 Black AIDS Institute: First Published: 6/28/2006


8 Scott, ibid.

9 “The nation’s first African-American AIDS organization [founded in 1985], BEBASHI offers services in prevention, testing and treatment as well as a range of innovative programs including a women’s initiative, prison-discharge planning and a diabetes intervention.” http://www.bebashi.org/index1.html

10 “NMAC was founded in 1987 to develop leadership within communities of color to address challenges of HIV/AIDS. http://www.nmac.org/about_nmac/

11 Us Helping US, an organization located in Washington DC, was the first to establish a hotline the specifically targeted men who were not open about their homosexuality. For more information about the organization's evolution, see www.washblade.com/2005/12-9/locallife/cover/ushelping.cfm

12 The Women’s Collective is a nonprofit 501(C)3 organization dedicated to meeting the needs of women with HIV/AIDS. Founded in 1993, the organizations mission begins with the premise that women with HIV/AIDS must be involved in every aspect of health care service delivery and their empowerment through peer support must be encouraged. http://womenscollective.org

13 AmASSI is an award winning organization that, since 1993, has provided healing to over 10,000 primarily African American and Latino men, women, and children in the South Central Los Angeles. http://www.amassi.com/templates/about_us.htm


15 For an explanation of how disparate resource allocation impacts treatment of the illness along regional lines, which in concert with the level of care necessitated by the progression of the illness can cause a great deal of variation in the cost of inpatient care and medications, see “HIV/AIDS Care Costs and Categorical Capitation Rates” http://www.medscape.com/viewarticle/450515_2


17 http://en.wikipedia.org/wiki/Ryan_White


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From Concern to Action: A Look at Consumer Engagement to Advance Quality Health Care

(Endnotes Base Building Matters: The Fight for Public Hospitals)

1 Vanessa Dixon, a DC based organizer playing a leadership role in the DC General struggle contributed the case study on the fight to save DC General Hospital.


5 Research Brief, June 2007, National Association of Public Hospitals and Health Systems, http://www.naph.org/Template.cfm?Section=Home&amp;Template=/ContentManagement/ContentDisplay.cfm&amp;ContentID=8508

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18 Telephone interview with Campaign to Transform King Drew Director Nancy Watson, September 16, 2007.


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(Endnotes Promising Community Organizing Practice in Health Policy Advocacy)

1. Presentation at Organizers Forum Dialogue #9, April 21, 2005
Contributing Authors

**Njere Alghanee**
Njere Alghanee is with Disabled In Action, a nonprofit Atlanta based organization dedicated to equity and inclusion for people living with disabilities with an emphasis on communities of color.

**Alec Dubro**
Alec Dubro is a Washington-based veteran writer, researcher and editor. He is former national president of the National Writers Union.

**Kim Fellner**
Kim Fellner is Washington-based organizer and writer whose work history spans work in organized labor, women’s rights and environmental justice. She has written numerous articles and studies on community organizer and is the former Executive Director of the National Organizers Alliance.

**Leslie Hunter-Gadsden**
A graduate of Northwestern University’s Medill School of Journalism, Ms. Hunter-Gadsden has over 20 years experience as a reporter, writer and editor. In addition she has also worked as an educator specializing in reading comprehension and writing with students in elementary and middle school. Ms. Hunter-Gadsden is currently a freelance writer and educational consultant.

**Shani Jamila**
Shani Jamila is the host and producer of Blackademics, a Washington-DC based program on the Pacifica Radio network that features provocative discussions on news and contemporary affairs as they impact the hip hop generation. Shani is a proud Spelman graduate and former Fulbright fellow who has a Masters degree in Africana Cultural Studies from the University of California, Los Angeles. Her work has received international recognition in publications such as the Trinidad Guardian newspaper, the London-based literary magazine Sable, and ESSENCE where she was honored as “One of the 35 Most Remarkable Women in the World.”