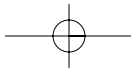
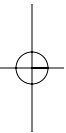
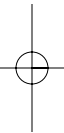
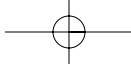




Real Clout





Real Clout

A how-to manual for
community-based activists
trying to expand healthcare access
by changing public policy.

Judith C. Meredith
Catherine M. Dunham

The Access Project is a national initiative of The Robert Wood Johnson Foundation, in partnership with Brandeis University's Heller Graduate School and the Collaborative for Community Health Development. It began its efforts in early 1998. The mission of The Access Project is to improve the health of our nation by assisting local communities in developing and sustaining efforts that improve healthcare access and promote universal coverage with a focus on people who are without insurance.

If you have any additional questions, or would like to learn more about our work, please contact us.

The Access Project
30 Winter Street, Suite 930
Boston, MA 02108
Phone: 617-654-9911
Fax: 617-654-9922
E-mail: info@accessproject.org
Web site: www.accessproject.org

Catherine M. Dunham, Ed.D.
National Program Director
Mark Rukavina, MBA
Deputy Director for Programs and Policy
Gwen Pritchard, MPA
Deputy Director for Communications and Administration

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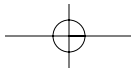
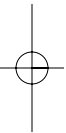
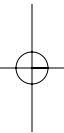
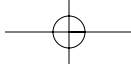
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Preface

There is a void in the shaping of public policy in this country. It is the voice of real people, grounded in the reality of their communities, their health, and their values.

E. J. Dionne, in his book *Why Americans Hate Politics*, wrote that people have been distanced from public life because of empty and negative partisan battles between majority parties that don't address real problems. The increasing complexity of laws and regulation, the role of money in determining public policy, and the generally uninspiring performance of our elected leaders have widened the gulf.

Now, in a time of prosperity, many Americans can afford to dismiss or disregard government as a necessary but minor player in their lives. This is obviously not true for the more than 60 million people who rely on public programs like Medicare, Medicaid, and Social Security. It is also not true for the nearly 44 million people who have no health insurance and who don't hold much hope for the public process.

This guide is intended to assist you in your entry into the politics of health policy. If you are like a lot of Americans, policy and politics are probably not your first choice for recreational activities. However, the exercise of your civic responsibility is one of the most important activities you will undertake.

We have failed for the past 50 years to comprehensively solve the problem of unequal access to health care in this country. The defeat of the Clinton health bill was not only the latest failure, but it also coincided with a period of particularly regressive budget balancing. It reinforced distrust of government just at a time when economic conditions normally would have yielded some relief for those in need of help.

We have collectively assigned the responsibility for restraining the cost and assuring the quality of care to the market in the hope that capitalism will solve the problems the government has not mustered the fortitude to confront—we have a large, dysfunctional health system that overserves many who are insured and underserves those who are uninsured or otherwise disadvantaged by geography, culture, or language.

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The returns on the market are coming in: Pervasive anxiety affects many managed care customers; people are disgusted by the profit-driven system of many healthcare providers; and a growing number of people are uninsured due to fundamental changes in the U.S. job market and rising healthcare costs.

The need for informed public policy to sort out this mess has never been higher. The pressure for reform will increase as baby boomers age and the economy returns to normal cycles.

Devolution has pushed more than federal authority out of Washington. It has also dignified a philosophy of government that assumes that most decisions can be better made closer to the taxpayer. State lawmakers have honored this trend by tossing control and responsibility for the healthcare access issue down the policy chain to counties, local governments, and nonprofit charities. But many communities do not have the resources to either control or solve the issues they have been assigned. The problems are bigger than they are. State and federal governments set insurance rules. The overwhelming majority of financing rules are made far from the communities affected by them. Markets, HMOs, state legislators and regulators, and the Congress make these decisions.

So, where does this leave the issue of limited access to health care? In the laps of consumers, providers, and other civic leaders who care—people such as those who manage the multitude of free clinics and other volunteer efforts that have grown over the past 10 years in response to the growing need for care, or activists who think it is unbecoming for an enlightened, wealthy democratic society to deny people health care. It is neither right nor fair to have quality of health care determined by the accidents of employment or income.

This is some of the thinking that went into the preparation of this guide. We think that *real* people should have a real impact on reforming the health system, starting with the expansion of access to care for those who need it. We believe that involvement in the public policy process is good for community leaders and good for the public process. Consumer and community participation on this issue is particularly critical. To paraphrase the late Tip O'Neill, Speaker of the U.S. House of Representatives, all

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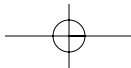
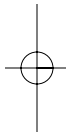
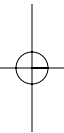
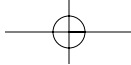
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health care is local. No more important policies exist than the ones that affect your health. The system must be responsive to local differences. The solution to the distribution of healthcare resources must honor that variability or the problem of access will not be solved.

This guide does not solve the health system dilemma. We believe that the discussion should be restarted with the active participation of those people most invested and involved in the issue—people working on the issue at the local level, exercising their political clout.

Real clout. For this to occur, we need to help community health activists reconnect with the public policy process at the county and state levels. Many gifted providers and savvy consumers do not remember their civics lessons: how laws are created, who writes regulations, what role the courts play, who spends public money, how priorities are decided. It is also important for those of you working within a nonprofit, tax-exempt organization to be diligent about understanding and following the letter and spirit of the federal tax laws governing your ability to participate in the lawmaking process. There are clear restrictions on the use of private foundation funds for this activity. See the Appendix A, for further guidance.

We are here to help. We hope this guide is informative and that it motivates you to take your appropriate role in the health policy process.



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Acknowledgements

Acknowledgments

Thank you to all of our colleagues who stepped away from current campaigns to contribute their time, advice, and stories to *Real Clout*. Your support and encouragement was essential to this project.

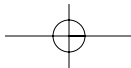
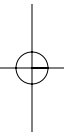
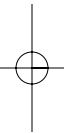
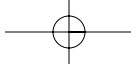
Thanks also to The Boston Foundation, which provided Judy Meredith with a grant in 1991 to write a public policy training curriculum for staff, boards, and volunteers of nonprofit agencies and United Ways. This work was the inspiration for this book.

We are extraordinarily grateful:

... To Gwen Pritchard, Deputy Director of The Access Project, who managed to corral two overscheduled authors into a reasonable production schedule and perform as a gentle but firm final editor at the same time.

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Introduction

Introduction

Real Clout is a how-to manual for community health activists who must figure out how their state or county governments *really* work when it comes to health care.

You might be a person who works with sick or injured people or a person who works to prevent people from getting sick or injured. Perhaps you are:

- a provider in a nonprofit health center trying not to get lost in the new Medicaid managed care maze
- an outraged neighbor worried about an unsanitary landfill
- a church leader upset about the closing of a free clinic
- a business owner trying to find affordable health insurance for your employees
- an outreach worker from a community multiservice center for at-risk teens
- a teacher in a Head Start program starting an immunization program for immigrant children
- a union activist organizing low-wage workers without health insurance
- a community organizer mobilizing neighbors to demand better community benefits from a local teaching hospital
- an ordinary person who has become a leader in a community-wide health crusade

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Some of you may have tried to increase access to medical care by:

- developing free clinics for people who can't afford health care
- working to get better health coverage for those caught in the web of managed care
- helping medical providers better serve all ethnic and cultural populations in your community
- removing barriers to healthcare access, such as lack of public transportation, lack of child care, or unstable and inflexible jobs

Or, you may have:

- mounted campaigns to remove lead paint and asbestos from low-income housing
- developed public awareness campaigns about seat belts, bicycle helmets, tobacco control, or substance abuse
- spearheaded drives to put hunger and nutrition programs in public schools, establish food banks, or organize shelters for victims of domestic violence
- worked with local businesses to develop job-training programs for welfare recipients or family-friendly employment policies
- worked with organized labor to promote living wages and safe working conditions for newcomers in your community

Approaching State or County Officials

After all this good work in your community at the local level, you find yourself needing to approach state or county officials for one or two reasons.

- Your community has a problem that cannot be fixed at the local level. For example, in your town a new environmental hazard is uncovered, a substance abuse epidemic develops, or there is a growing number of uninsured working families who do not have health care. You've turned over every charitable stone. You've stretched every local institution to the limit. What do you do?

The solution requires your state or county to change the way it funds or manages a specific program, or it requires them to create and fund a new program. You may have to convince state or county officials to interpret existing laws differently. Or you may have to convince them to pass new laws.

- You have to figure out how to keep your community health programs strong as your state or county officials develop policies to manage devolution (a new federal policy that has drastically changed federal funding streams). The federal government no longer sets strict eligibility guidelines or practices strict enforcement. State and county officials now have more power than ever before over how federally funded health programs are administered and managed.

The solution requires that you identify the state and county officials who are making the funding decisions that affect your community and your agency, and figure out how to influence them.

This book is designed to help you solve exactly these types of problems.

Taking the First Steps

As a community health activist, you probably know more about your state, county, and local government than most citizens do. Those of you who have successfully mounted public health prevention and outreach campaigns are especially well informed. Still, the notion of driving farther, going to another, bigger public building, and talking to a bunch of important politicians and bureaucrats fills you with anxiety and dread. There are so many questions.

- What do you have to do to convince state or county officials to interpret existing regulations differently?
- What do you have to do to convince a state or county official to work with you to design, create, and fund a new program?
- How do you change a law? What do you have to do and when?

*What are nice people like us
doing in a place like this?*

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- How are budgets created? How can you get your project included in the funding process?
- Can organizations on a shoestring budget accomplish this kind of change?
- Can nonprofits really do this stuff?
- Where do you get honest answers?
- Do you have to hire a high-priced lobbyist?
- Where do you start?

First, you have to have a good answer to the question asked in the cartoon. Read the Appendix to reassure yourself that it's okay for nonprofit organizations to get involved in this stuff—it's how our Founding Fathers envisioned our system would work. If your lawyer is nervous, tell him or her to consult the listed resources from the Council on Foundations and the Independent Sector. If he or she is still nervous, find another lawyer who's up to the task.

Second, ask yourself these questions to make sure the solution to your problem lies in state or county government:

- Have you exhausted all possible remedies on the local level?
- Are other programs and organizations like yours struggling with the same issue?
- Are you sure your problem can't be traced to an incompetent public employee in your region or maybe even inexperienced staff in your own agency?

If you've done all the research and thinking you need to do, then it's time to get started. Or, as George Wiley said when he organized the National Welfare Rights Organization in the early 1970s, "All we have to do is make a winning plan and make it happen."

Let's start by demystifying the public policy arena you are about to enter.

The IRS has drawn up clear rules and restrictions that govern a nonprofit's ability to participate in the legislative process that leads to the creation of new laws. These rules vary depending on whether the nonprofit is a 501(c)(4) or a 501(c)(3). There are no IRS restrictions on a nonprofit's ability to participate in other policymaking processes, such as meeting or talking with administrators or participating in the development of policies, programs, or regulations.

1. Influencing the public policy process isn't rocket science. You already know how to do it.

The public policy world is a human place. It is inhabited and managed by ambitious, energetic, imperfect human beings (elected officials) who are selected by other busy, distracted, imperfect human beings (us, the voters) every few years to make the rules that govern our lives.

Interpreting and implementing the laws is another group of busy, unappreciated, imperfect human beings (unelected public officials) who create regulations and manage the day-to-day business of running government.

These people all are very much like the ambitious, energetic, unappreciated human beings you encountered in your local healthcare access campaigns aimed at changing the private policies of community institutions. From these experiences, you may already know how to:

- convince the business community to sponsor an antidrug campaign
- persuade a hospital board to initiate a free family-planning clinic
- organize your neighbors to demand evening and weekend hours at the health center

The organizational and strategic skills you used during your community health campaigns to change private policies are the same ones you will use to change the public policies of your county or state governments.

Public policymakers often think they're more important than private policymakers because they establish the rights and standards for an entire group of citizens. Consequently, they are affected by the same human decision-making dynamics that parents and tribal chiefs encounter. Opinion counts as equal to fact and public opinion is a fact.

This may seem like sloppy thinking, but public policymakers say lack of time and resources prevents them from scientifically testing every new idea or hypothesis. So they rely heavily on public opinion to help them make decisions.

Sloppy or not, this human side of policymaking acts to support representational democracy by making it difficult for elected officials to support a policy against the wishes of a critical mass of voters, however misinformed they may be. Consequently, we all expect our elected policymakers to respect our opinions and treat them like facts, or lose our confidence and possibly our votes.

2. The public policymaking process is pretty simple.

There are basically two ways to make public policy: creating or amending policies or interpreting and implementing policies.

Policymaking in the Administrative Branch

Every state, county, city, and town elects a chief executive who appoints competent (hopefully) administrators to manage public departments and agencies that do everything from repairing roads to running preschool programs.

Every single hour of every single day, these appointed officials make public policy by deciding on an action in response to their bosses' orders, their interpretation of current laws, and the latest demands of citizen groups. In this regard, appointed officials are similar to hospital administrators who initiate a new service based on policy set by the hospital board or providers.

Generally speaking, chief executives and their appointed administrators are the ones you want to go to in order to change the way a health program is funded or administered. (Chapter 3 goes into great detail about how these policymakers make decisions and take action.)

Policymaking in the Legislative Branch

Every state, county, city, and town legislative body organizes itself into a leadership structure, develops rules governing debate and voting procedures, and sets up a meeting schedule. Eventually everybody in the state legislature, county commission, city council, or town meeting gets together in a large room where the members propose changes in the law, argue back and forth, vote, and go on to the next proposal. At some point they finish and go home.

The grand architecture, the arcane rules, the public hearings, the eloquent speeches, and the elaborate debating procedures hide an imperfect institution in which human nature meets ideal policy and creates law, probably not unlike other “imperfect institutions” that you’ve encountered.

Generally, the legislature must approve new programs or major changes to existing programs that require spending taxpayer dollars. (Chapter 4 goes into elaborate detail about policymaking procedures in the legislative branch of government.)

3. It’s not business as usual in the public policy arena anymore, for anybody!

The public policy world is undergoing profound dislocation and disturbances associated with profound change because of:

- new political and procedural ground rules
- new communication tools and methods of information gathering
- new policymaking opportunities at the state and county level caused by devolution

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New Ground Rules

Term limits, increased public scrutiny, and constant media exposure of traditional fundraising practices have forced the early retirement of powerful public officials. Newly elected reformers have pushed through modifications that make the policymaking process more open and more democratic than ever by limiting both the power of leaders and the influence of special interest groups.

Today, most political observers agree that campaign finance reforms, increased regulation of lobbyists, rules reform, and term limits have opened up the policymaking process. The downside is that the process is messier and more inefficient than ever.

Still, every state capital, county seat, and city and town hall sits under a cloud of public mistrust as the press continues its scrutiny of powerful incumbents and special interest groups. Surviving public officials must scour the public policy landscape for *hero opportunities*—compelling, sympathetic issues they can champion and fix—to bring concrete improvements into their constituents' lives.

hero opportunity (*n*) a compelling problem or crisis that provides policymakers with public occasions to propose and champion a solution that brings a measurable difference in the lives of a critical mass of constituents, as in “desperate for hero opportunities.”

New Communication and Information

Gathering Tools

The worldwide information revolution has opened up the front doors and even some back rooms where policymakers make important public policy decisions. Online government tracking services—some free on the Internet, others fee-based—provide daily calendars and journals, the text of proposed bills, and amendments, committee schedules, and recorded votes.

*Nam et ipsa scientia
potestas est.*
Knowledge is power.

—Francis Bacon, 1561–1626

Cable television coverage of hearings, sessions, and committee meetings has made it easy for citizens, reporters, or lobbyists to observe and monitor public officials. Today, low-budget organizations use e-mail, broadcast faxes, and auditorium conference calls to organize and mobilize powerful grassroots networks capable of influencing health policy.

New Policymaking Opportunities

A devil in the name of devolution has changed the direction and flow of the flawed-but-dependable federal funding streams. In 1995, the new Republican majority in Congress rewrote national policies on poverty, crime, and health care, giving states new powers and responsibilities. They called this process devolution, and used it to transfer much of the power and authority over federal dollars to the states.

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Many community health activists view devolution as evil because it eroded federal standards that guaranteed health care to needy people. Many state, county, and local officials, however, have embraced devolution as a way to throw out cumbersome, inflexible regulations that hobbled their use of federal funds.

Community health activists must now figure out how to place themselves at a new negotiating table in order to protect services for their clients. They must build or repair relationships with state bureaucrats and civil servants whom they had heretofore ignored or bypassed when dealing with their favorite member of Congress. (We suspect there is a movie in the making here, perhaps called *The Revenge of the Nerds IV*.)

Community health activists can learn how to take advantage of these new, closer-to-home opportunities to influence policy.

Enter the Healthcare Policy Entrepreneurs

A policy entrepreneur is defined nicely by John Kingdon in his premier text, *Agendas, Alternatives, and Public Policies*. Kingdon defines a policy entrepreneur as any player in the public policy arena—elected or appointed, staff person, community activist, professional lobbyist, or crusading reporter—who has the intelligence and wit to spot a window of opportunity through which she or he can push a solution to a public problem.

Policy entrepreneurs are people willing to invest their resources in pushing their pet proposals or problems, are responsible for prompting important people to pay attention, for coupling solutions to problems, and for coupling problems and solutions to politics. While government agendas are set in the problem or political streams, the chances of items rising on a decision agenda—are enhanced if all three streams are coupled together. Significant movement is much more likely if problems, policy proposals, and politics are all coupled into a package.

—John Kingdon, *Agendas, Alternatives, and Public Policies*. 2nd edition.
New York: Harper Collins College Publishers, 1995.

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The healthcare movement has produced its share of policy entrepreneurs. This book attempts to identify, describe, and categorize capacity-building, organizing, and persuasion techniques that activists can use to promote good, new public policy that improves the health of thousands of uninsured or underserved people.

Here are a few stories that illustrate the point.

Referenda and Legislative Campaigns to Use Tobacco Taxes to Fund Public Health Programs

In 1989, a coalition of public health activists in California won a grassroots voter referendum campaign that increased tobacco taxes and directed that the money raised be used for public health programs, including comprehensive tobacco control efforts and health care for children and families.

Similar campaigns won voter referenda or initiative campaigns in Massachusetts (1992), Arizona (1995), and Oregon (1995).

In Massachusetts in 1996, health access advocates, including key legislative leaders, joined provider trade associations, tobacco control advocates, business leaders, and the health insurance industry to win a second tobacco tax campaign. The money raised from this second tax is used to deter young people from smoking and to fund health care for children, seniors, and the disabled. The coalition won in the state legislature because a powerful, consumer-led, grassroots lobbying effort was able to overcome a veto from a no-new-taxes governor.

A Legislative Campaign to Reform Managed Care

In 1996, parents of children with cerebral palsy in Texas organized to fight insurance plans that denied their children coverage for physical therapy. They formed an organization they called the Texas Advocates for Special Needs Children (TASK), and they worked with a coalition of managed care reform advocates that included powerful consumer advocacy organizations, provider trade associations, and public health groups.

TASK members helped organize a consumer-led public hearing on managed care that led to the creation of a Texas Senate Interim Committee on Managed Care and Consumer Protection. When the 1997 Texas legislature began to develop a managed care reform bill, TASK worked with key legislators to draft an amendment forbidding managed care companies from denying medically necessary therapy. Their amendment, the first of its kind in the nation, was included in the final managed care reform bill.

Administrative Reform of Medicaid

When Tennessee launched its Medicaid managed care program, TennCare, in 1994, eligibility for the program was severely limited. The Tennessee Health Care Campaign immediately launched a campaign to convince the administration to enroll working uninsured families, who were ineligible under the plan as it stood at the time.

First, a coalition of powerful community leaders from the Business Roundtable and the Tennessee Justice Coalition launched a statewide public awareness campaign targeted at the business community. Meanwhile, another statewide coalition of consumer groups, religious groups, primary care providers, nurses, and the AARP conducted research to back up a specific proposal for open enrollment.

They persuaded the Tennessee legislature to begin public hearings on the open enrollment issue. Legislative leaders, the business community, and health access advocates testified in support of expanding TennCare to cover uninsured working families. In 1996, the governor agreed to take the first step toward open enrollment by expanding eligibility to the children of working families.

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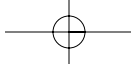
What do these three stories have in common?

1. The community health activists created hero opportunities for state and county officials. They did this by explaining access problems in the form of a compelling story with an easy-to-fix policy solution.
2. They put together strategic campaigns to convince everyone affected by the problem—no matter how remotely—to help achieve the solution.
3. They figured out how to preserve public policy initiatives and put their solutions on the public agenda for discussion and action.
4. They recruited shrewd policymakers to join them in partnership with savvy consumer groups and well-financed provider organizations.

Through these partnerships, community health activists organized members willing to communicate with public officials through a network of ordinary citizens.

Through these kinds of partnerships, community health activists all across the country accomplished two important goals:

1. They won. The partnership campaigns mounted campaigns that delivered tangible improvements in the lives of ordinary citizens.
2. They empowered themselves and other local activists. The grassroots base of coalition members, many of whom had become articulate constituents of key elected officials, acquired their own political power. Through united action, they connected to the public policymaking process and continued the struggle to win universal health care.



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In this book, we hope to make the public policy process human, understandable, accessible, rewarding, and sometimes even fun.

From our own experiences and those of colleagues and friends in all 50 states, we will share with you successes and lessons we have learned.

From our hearts, we bring our personal and political commitment to social and economic justice, and we hope that through our work as public policy practitioners we can move, each day, one step closer to realizing that goal.

