

Health Care Reform and Social Movements in the United States

Beatrix Hoffman, PhD

Because of the importance of grassroots social movements, or “change from below,” in the history of US reform, the relationship between social movements and demands for universal health care is a critical one.

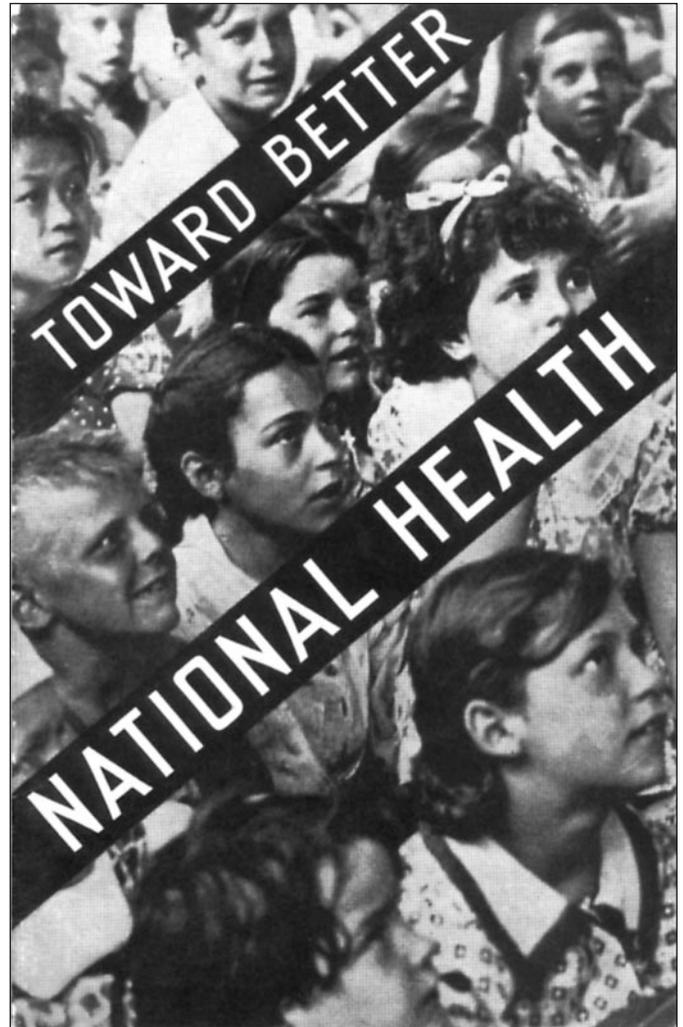
National health reform campaigns in the 20th century were initiated and run by elites more concerned with defending against attacks from interest groups than with popular mobilization, and grassroots reformers in the labor, civil rights, feminist, and AIDS activist movements have concentrated more on immediate and incremental changes than on transforming the health care system itself.

However, grassroots health care demands have also contained the seeds of a wider critique of the American health care system, leading some movements to adopt calls for universal coverage.

THE UNITED STATES IN THE

20th century witnessed the flowering of social movements demanding access to the American Dream. Women, workers, African Americans, seniors, and welfare recipients, to name just a few, organized to change a society that made them second-class citizens. Although each movement had its leaders, each relied on grassroots participation, or “change from below”: they were made up of ordinary people demanding reform, often on their own behalf.¹

Yet no movement of comparable size or intensity has arisen in the United States to demand universal health care. Labor unions, senior citizens, socialists, and other groups have certainly participated in campaigns to redesign the health care system, but the campaigns themselves have most often been initiated and run by elite organizations and individuals with little connection to a popular base of support. Public opinion has generally run in favor of health care reform, but popular approval has not been matched by the rise of a large-scale, activist popular movement for change.² Because of the importance of grassroots movements to reform in the United States, it is important to ask why there has never been



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such a movement for universal health care, and whether and how one may emerge now and in the future.

This article brings together some recent historical depictions of struggles for universal health care in the 20th century, with an emphasis on the role of popular mobilization—or lack thereof—in these struggles. It offers a new understanding of social movements and health care reform. Many grassroots movements, including the civil rights and women’s movements and those on behalf of people with particular diseases like AIDS, have de-

manded changes in the health care system. But their health care demands were for specific changes on behalf of their particular group, such as racial desegregation of hospitals, access to abortion, and the release of experimental AIDS drugs. These grassroots demands have not coalesced into a movement for universal health care. In fact, some scholars and reformers have seen such small-scale improvements in health care delivery as impediments to, or distractions from, more comprehensive reform.

But grassroots health care demands have also contained the

seeds of a wider critique of the American health care system. Activists who worked for immediate and particular changes found that their experiences with health care led them to a new and urgent understanding of the need for major reform, and some eventually incorporated demands for universal access as part of their social movement agendas. By combining the history of national reform campaigns with that of grassroots activism for changes in the health care system, we can better see how these 2 types of movements have been kept apart, and also how they might come together.

TWENTIETH-CENTURY CAMPAIGNS FOR HEALTH CARE REFORM

Early in the 20th century, industrial America faced the “problem of sickness”: when working people missed work owing to ill health, they also lost their wages. This loss of income, even more than the cost of medical care, made sickness a major cause of poverty. In 1915, progressive reformers proposed a system of compulsory health insurance to protect workers against both wage loss and medical costs during sickness. The American Association for Labor Legislation’s (AALL) proposal, modeled on existing programs in Germany and England, was debated throughout the country and introduced as legislation in several states.

This early campaign for compulsory health insurance set a precedent for a continuing distance and lack of cooperation between reform leaders and popular movements. The AALL was a group of academic reformers who drafted their proposal without input from the working people it would cover. Samuel Gom-

pers, president of the American Federation of Labor (AFL), thought workers should win their own benefits through union organizing rather than government action; he denounced the AALL for neglecting labor’s opinion and directed his membership to oppose the plan as elite paternalism. The health reformers chose a strategy of research and lobbying rather than political organizing; expertise, not popular pressure, would be their tool of persuasion. AALL leaders felt that the most important constituency for their bill was the medical profession, and they spent much of their energy persuading doctors to support the legislation—a cause that turned out to be futile in the face of practitioners’ fears that compulsory insurance would erode their incomes and independence.³

When reformers did look to the popular movements of the Progressive Era, they found substantial support for health insurance. The Socialist Party had endorsed a compulsory system as early as 1904, and in 1912 Theodore Roosevelt’s insurgent Progressive Party included a health insurance plank in its campaign platform. In New York and California, local labor leaders defied the AFL’s directive and threw their support behind the AALL’s plan, arguing that health insurance would protect both workers’ health and their wages. Women trade unionists and suffragists were intensely interested in the proposal because it included maternity benefits for women workers. In New York in 1919, women reformers adopted the AALL plan as part of a slate of bills to protect working women, and when suffragists joined with the New York State Federation of Labor in a mass

march and rally on the state capitol, their demands included compulsory health insurance.

A somewhat bewildered AALL gratefully accepted this popular support, which led to their campaign’s first and only victory: a majority vote in the New York Senate. But when the powerful speaker of the house (antisocialist campaigner Thaddeus Sweet) killed the bill in committee, the first campaign for health insurance was over. Cooperation between elite reformers and popular movements had been too little and come too late to overcome a united opposition of physicians, businesses, insurance companies, and conservative legislators intent on branding health insurance “Bolshevism.”⁴

The emphasis of health reform shifted during the 1920s as medical care became both more effective and more expensive; soon, medical costs and access to care replaced wage support as reformers’ primary concern. But the character of reform leadership changed little, and health reformers continued to share the elite status of their predecessors. The most prominent reform group of the 1920s, the Committee on the Costs of Medical Care (CCMC), which was financed by large foundations and made up of physicians, academic economists, and representatives of private interest groups, again relied on research rather than popular mobilization. The CCMC’s modest proposals for group medicine and voluntary insurance were denounced by the American Medical Association (AMA) as “socialized medicine,” but the battle was fought in the pages of newspapers and academic journals, with no attempt to enlist ordinary people as advocates for the reformers’ recommendations.⁵

The Great Depression was a time of extraordinary popular upheaval, as farmers, workers, the unemployed, veterans, elderly Americans, socialists, and communists organized and marched in the streets and on Washington calling for relief and justice.⁶ The demands of these New Deal-era social movements centered on economic security for workers and the aged; at the height of the depression, the ravages of unemployment and national economic collapse commanded more immediate attention than did the cost of medical care. For example, the Lundeen bill, an alternative to the Social Security Act drafted by Minnesota’s radical Farmer–Labor Party, outlined a program of social insurance for all workers, including wage replacement for those “unable to work because of sickness,” but it made no mention of medical care or health insurance.⁷ With unemployment crowding out health care as a social movement priority, health reformers needed to make a concerted effort to persuade social activists to join their crusade.

But New Deal health reformers remained out of touch with the grassroots. In the 1930s, some CCMC leaders became political insiders as they joined the committees charged by President Franklin D. Roosevelt with creating proposals for health care to add to the Social Security Act (the Committee on Economic Security and the Technical Committee on Medical Care). These New Deal committees worked mostly in secret, isolated from public input and debate. Their members were constantly on alert for attacks from the medical profession and business, and this caution led to less-than-sweeping proposals for health reform; both committees recommended federal subsi-

dies to states rather than a national system. But even these reforms raised the ire of physicians, and Roosevelt so feared attacks by the AMA that he dropped health coverage from his New Deal agenda.⁸ Because New Deal insiders did little to win grassroots participation and support, their cautious and technical proposals for health care restructuring failed to capture the imaginations of ordinary Americans. And without pressure from a strong social movement on behalf of medical insurance, Roosevelt bowed to the AMA rather than to health reformers.

In the 1940s, new potential for grassroots mobilization arose when organized labor became a major backer of national health insurance. As the cost of medical care began eating up more of the average worker's budget, both the AFL and the Congress of Industrial Organizations (CIO) took leadership roles in the struggle for health reform. In 1943, labor unions joined the reformer-experts of the Committee for the Nation's Health and liberal administration officials in drafting the Wagner–Murray–Dingell bill (named for its congressional sponsors), the major health insurance legislation of the Truman era. This bill proposed a national medical insurance program financed through social security payroll taxes, and it enjoyed the strong support of Harry S. Truman.

During the struggle over Wagner–Murray–Dingell, the opportunity to mobilize a broad-based movement was once again lost. Labor leaders and policy intellectuals believed they could make change from within the system and so did not need the organized activity of union members to back up their efforts. The “failure of union leaders to enlist

union members in the battle,” historian Alan Derickson argues, was “a crucial flaw in the campaign for health security.” Both AFL and CIO leaders, aiming for a place in the postwar power structure, “discouraged rank-and-file initiatives” and “never considered grassroots mass mobilization.” The lack of rank-and-file participation greatly weakened the cause of union-led health reform as it became associated with “union bosses” rather than ordinary workers. The other major reform backer, the Committee for the Nation's Health, a successor to the CCMC with many of the same members, also decided not to solicit grassroots participation on behalf of the Wagner–Murray–Dingell bill, arguing that it lacked the funds to organize local branches.⁹

Reformers needed all the help they could get to fight an unprecedented onslaught by the AMA. After Truman's electoral victory in 1948, the doctors' organization spent over \$1 million on an anti-health reform public relations blitz that included advertising, television and radio spots, telegram and letter-writing campaigns, and the lobbying of legislators by their own personal physicians. Unlike reformers, AMA members successfully reached out to the grassroots with “doctor-to-patient” letters denouncing the Wagner–Murray–Dingell bill.¹⁰ And in the midst of the Cold War, health reformers' insider status made them vulnerable to opponents who saw a Soviet-inspired conspiracy for “socialized medicine” at the very heart of the federal government. Prospects for the passage of the health bill vanished when most of its congressional supporters were unseated in 1950 with the help of the AMA's campaign.¹¹

By then, organized labor's attention had turned elsewhere. Unions were increasingly winning health benefits for their members through collective bargaining agreements with employers, so the need for national reform seemed less urgent. The failure of national health legislation further encouraged labor to

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pursue private solutions, while these solutions themselves, by meeting the needs of at least some of America's workers, made it more difficult to argue for systemic change. Organized labor would continue to be a major supporter of universal health care proposals, particularly through Walter Reuther's Committee for National Health Insurance in the 1970s. But, “because most of the working-class constituency for social insurance had been accommodated [through private coverage], the potential for building a mass movement . . . dwindled.”¹²

Possibilities for grassroots mobilization resurfaced in the 1960s during the debate over Medicare. Health reformers had been working on a plan for medical coverage of the elderly for a decade when the idea was adopted by John F. Kennedy and his successor, Lyndon Johnson. The outpouring of civil rights activity in the early 1960s spurred politicians to support Medicare as part of Johnson's War on Poverty, and major civil rights groups all endorsed the legislation.¹³ Organized labor was again a strong supporter of

health reform, not just to ensure care for the uninsurable but also “to eliminate the increasingly costly problem of negotiating health benefits for [union] retirees.” The AFL-CIO created the National Council of Senior Citizens, made up of retired union members, to publicly campaign for Medicare. The organization soon expanded to include other retiree groups. The council launched petition drives and letter-writing campaigns and, writes sociologist Jill Quadagno, “endeavored to create the sense of a grassroots political movement.” Retirees disseminated “millions” of pieces of literature in an attempt to thwart AMA propaganda, and 14,000 seniors marched down the boardwalk at the 1964 Democratic Convention in Atlantic City.¹⁴ Americans were highly sympathetic toward the elderly as a group, which made it harder for the AMA and other opponents “to engage in open warfare” against health reform, and in July 1965 Medicare became part of the Social Security Act.¹⁵

The organization of senior citizens on behalf of Medicare signaled the rise of a significant new reform constituency. Although initiated by trade unions, the pro-Medicare retiree groups succeeded in mobilizing ordinary senior citizens who sought health reform based on their own experiences in a system that denied them insurance coverage. Even after Medicare’s passage, which may have quieted some discontent among the elderly, seniors continued to be major supporters of reform. In the 1970s the National Council of Senior Citizens and other seniors’ groups joined the labor-led Committee for National Health Insurance (CNHI) and worked hard for the passage of a plan

co-sponsored by Senator Edward Kennedy.

The CNHI reached out to an impressive number of civil rights and antipoverty groups, but still relied on professional staff, conferences, and Washington-based lobbying, not on grassroots activism. Comprehensive reform was again weakened by interest-group squabbles; the CNHI bill competed with 13 other health insurance proposals, including ones sponsored by the AMA and commercial insurance companies, and reform lost momentum when the massive health care inflation of the 1970s led to an emphasis on cost control rather than on expanding coverage.¹⁶ But as the number of uninsured began to rise in the 1980s, public discontent intensified. In 1992, when Bill Clinton rode into the White House on a wave of popular support for major changes in the health care system, the potential for mass mobilization around universal coverage had never seemed greater.

But again, the opportunity was squandered. The Clinton administration relied on the same elite-based decisionmaking that had isolated previous reform efforts from grassroots influence. Activists complained that the secretive Clinton Health Care Task Force, made up of policy experts and led by Hillary Clinton and the president’s close friend Ira Magaziner, “completely controlled” the drafting of the Health Security bill and only later turned to citizen groups asking for support “for a plan that they’ve already written.”¹⁶

And the plan itself dismayed potential supporters. Clinton, fearful of business and insurance company opposition, proposed a dauntingly complex system of “health alliances” that would pre-

serve both employer-based coverage and the commercial insurance industry. Advocates for universal health coverage argued that this model would increase the power of private insurers and take away patients’ choice of doctors. One physician-activist dubbed the plan the “Health Insurance Industry Protection Act of 1993,” and another agreed that managed competition “won’t control costs and the entire health care system will be owned by a handful of insurance giants.”¹⁷ And the nearly 1,400-page proposal was far too complicated and confusing to inspire a popular movement on its behalf; activists concluded that “few could, or should, rally to this banner.”¹⁸

While the mainstream AFL-CIO approved the Clinton plan for meeting its goal of worker coverage through an employer mandate, many grassroots organizations supported more comprehensive, universal reform modeled on the Canadian “single-payer” system, in which tax-funded government payments to providers would replace employer health benefits and the private insurance industry. The Gray Panthers, the Consumers’ Union, mental and public health groups, and progressive labor unions decided to back an alternative single-payer bill in Congress, and the group Citizens’ Action organized supporters to send 1 million postcards favoring a single-payer system to the White House.¹⁹ But the single-payer coalition was divided and weakened by its groups’ varying commitments to grassroots organizing. Some labor unions wanted to run a vigorous campaign including mass mailings and a cross-country bus caravan, but 2 powerful unions, the United Auto-

mobile Workers and the American Federation of State, County and Municipal Employees, balked: they did not want to be seen as attacking the new Clinton administration, which depended on labor support. Like other labor leaders before them, union officials “reportedly told other health care activists that they would only work from ‘inside’ the Clinton team to influence the course of health reform.”²⁰ Without a mass base of support, the Clinton Health Security bill fell before its powerful and well-financed opposition.

This brief overview of some 20th-century reform efforts reveals that 2 major explanations for their defeat—the power of private interest groups to block reform and reformers’ failure to inspire grassroots activism—are inextricably connected. The relentless opposition of medical, business, and insurance interests pushed reformers to design health care proposals around placating their opponents more than winning popular support. In turn, ordinary people had trouble rallying around complex proposals that emphasized administrative design and federalist fragmentation rather than a universal right to basic health care.

None of these major reform attempts was initiated or fought primarily at the grassroots level. The problem in 1994 was not much different from that in 1949 or 1918: reformers put their faith in expertise and professional lobbying rather than popular activism. Writing on the defeat of 1940s health legislation, Alan Derickson argues that “[b]y relying on . . . progressive lobbying groups” such as the liberal Physicians Forum, reformers “unwittingly contributed to the perception that the goal of uni-

versal health care, an element of the general welfare, was merely an object of interest group maneuvering.” Another scholar points out that during the Clinton health campaign, the reform environment was “dominated by advocacy groups,” professionally run organizations mostly based in Washington, that were “accustomed to insider lobbying rather than popular political mobilization.”²¹ Important as they are in the US political system, coalitions of professionalized reform groups are not the same thing as people’s movements.

GRASSROOTS MOVEMENTS AND HEALTH CARE REFORM

There has been a gap between health care reformers and their potential constituencies, a gap that has created a significant obstacle to popular mobilization on behalf of universal health care. But a large part of the story still needs to be told. If we stop using only the well-known campaigns for national health coverage as a yardstick, grassroots activism and social movements for health care reform become much more apparent.

By grassroots health care activism, I mean movements that include, and are sometimes led by, patients or potential health care consumers, themselves. As opposed to elite health reform, which has relied on research and expertise, health care activism is rooted in people’s experiences with the health care system. Examples from the 20th century include workers’ attempts to establish medical cooperatives and clinics, civil rights activists’ demands for greater racial equality in health care, feminist challenges to gender bias in medi-



cine, and the activism of particular groups of patients, including people with AIDS, breast cancer, and disabilities.

These types of activism have ostensibly focused on a single issue (such as abortion or desegregation) or on demanding benefits for one particular group (such as AIDS patients or the disabled). The reforms they advocated, and in many cases won, made important changes in the health care system but, arguably, did not alter the nature of the system itself. These movements, then, might be described as part of the tradition of pluralism or incrementalism in American health politics, which has generally been seen as an impediment to large-scale reform.²² But the dichotomy between particular and universal reform is sometimes a false one. Through their experiences in the medical system and also their experiences with activism, members of social movements for health reform repeatedly concluded that their de-

mands could be fully realized only with universal access to health care. A recurring theme of health care activist movements has been the broadening of their single-issue and particular demands to include fundamental change in the US health care system.

This theme can be traced as far back as 1913, when the International Ladies’ Garment Workers’ Union (ILGWU) established a Union Health Center in New York City to treat urban clothing workers, who had a high incidence of tuberculosis and other health problems. The Union Health Center was different from physician- and employer-initiated clinics in that it was created and staffed by those who would be using the health care themselves. As the union members who ran the center cared for workers’ immediate health problems, they came to see the need for more universal provision.

Former garment worker Pauline Newman, who headed the

Members of Disabled in Action lead a march through downtown Philadelphia sponsored by Health Care for All/Philadelphia, on April 22, 1992, demanding that the candidates for US president endorse a universal and comprehensive single-payer health insurance plan. Photograph by Julie Davids. Courtesy of the Institute of Social Medicine and Community Health.

Union Health Center for 5 decades, argued that union-run health care threw into sharp relief the vastly greater needs of the unorganized. “[T]he great mass of workers are not in any position to look after their own sickness and their own problems,” said Newman in 1917. “That is why [the ILGWU] is in favor of health insurance and social insurance. We can take care of ourselves, but who are we? A mere hundred and fifty thousand.” Newman and the ILGWU were the most active union supporters of Progressive Era compulsory insurance proposals, and Newman continued to advocate universal health care for the rest of her long life. Similarly, the Western Miners’ Federation, which established a worker-run hospital system early in the century, passed strong endorsements of compulsory health insurance in the 1910s.²³ Unlike in the post-1945 era, these private benefits schemes did not draw unions’ energies away from advocating broader reforms; rather, they inspired a comprehensive critique of a health care system that left so many workers without access to medical care or sick pay.

Civil rights activism has often been at odds with elite-led campaigns for health reform. Progressive Era and New Deal reformers deliberately left the mostly Black agricultural and domestic workforce out of their schemes, and the Committee on the Costs of Medical Care excluded Black households from its studies.²⁴ For much of the 20th century, racial discrimination deprived African Americans of basic health care and forced them to concentrate on building their own institutions, like fraternal societies, life insurance companies, and com-

munity public health movements.²⁵ And civil rights activists rightly distrusted reform proposals that either explicitly maintained segregation or ensured inequality by other means, such as giving states control over health provision. The National Association for the Advancement of Colored People (NAACP), for example, supported the Wagner–Murray–Dingell bill only reluctantly because the proposal lacked “‘safeguards’ to ensure ‘equitable distribution of funds in the states where Negroes and whites [were] forced to use separate hospitals, clinics and other health services.’” Decades later, civil rights organizations feared that some aspects of Clinton’s Health Security bill, including the emphasis on employer-sponsored coverage and the inclusion of private insurance companies with their long history of racial “redlining,” might hurt African Americans.²⁶

Still, the goal of universal health care has been an integral part of civil rights agendas. For many civil rights activists, the fight against segregation was inseparable from demands for national health care. Physician and NAACP leader Dr Montague Cobb in 1947 called for the National Medical Association, the organization of Black doctors, to attack racial discrimination in medical care, and also demanded a “vigorous and forthright confirmation” of national health insurance. The NAACP, the National Medical Association, and the Urban League have been longtime, if critical, supporters of proposals for universal medical coverage.²⁷

Civil rights activists have recognized that desegregation in and of itself is insufficient to bring about racial equality in health care. Activist physicians

formed the Medical Committee on Human Rights in 1964 to give medical aid to civil rights workers in the South, but they quickly became involved in fighting “inadequacies in health care” in the North as well.²⁸ After winning the hard-fought battle for hospital integration in the mid-

medical profession than for its advocacy of universal access. Yet feminists early on drew connections between the nature of the health care system and its treatment of women. In 1971, the first edition of the feminist classic *Our Bodies, Ourselves* argued that profit-driven medicine had

“*The activism of people with AIDS and HIV fighting for their very lives led to unprecedented changes in the health care system.*”

1960s, civil rights activists confronted the daunting problems still faced by low-income African Americans in getting medical care. Hospital limitations on care for the poor, and the refusal of many hospitals and physicians to accept Medicaid, demonstrated the link between economic and racial barriers to access. Civil rights groups initiated a series of class-action suits demanding that federally financed hospitals accept more poor patients and continue to serve inner-city neighborhoods rather than fleeing to the suburbs.²⁹ As Black communities were ravaged by epidemics of hypertension, diabetes, and infant mortality, national civil rights organizations helped local activists set up neighborhood health clinics and demonstration projects. Like union clinics earlier in the century, the local health care projects of the 1960s and 1970s worked not only to address immediate needs but also to spread the idea of universal access—the idea that, as one Urban League clinic poster stated, “Good health is a right, not a privilege.”³⁰

The women’s health movement of the 1960s and 1970s is better known for its powerful critique of the sexism of the

led to an epidemic of unnecessary hysterectomies while women without access to primary care died of preventable cervical and uterine cancers. The authors declared, “We believe that health care is a human right and that a society should provide free health care for itself. Health care cannot be adequate as long as it is conceived of as insurance. . . . Health care for everyone is possible only outside of the profit system.”³¹

Feminists’ demands for safe and legal abortion have been portrayed as emphasizing individual rights, especially since the Supreme Court based its *Roe v Wade* decision on a “right to privacy,” which some scholars have argued precluded the establishment of a “medical entitlement” to abortion.³² But abortion rights activism could lead to a broader critique of the health care system. In one example, the Young Lords Party, one of the few Puerto Rican nationalist organizations to support abortion access, vocally protested the 1970 death of a Puerto Rican woman during a legal abortion in a New York City hospital. Her treatment at the hands of the public hospital system “proved that legal abortion was not the answer for

poor and Third World women who did not have access to quality health care,” and the Young Lords demanded “community control” of city health care institutions.³³ Reproductive rights activists found that in a stratified health care system, access to safe and legal abortion was a right in name only.

The women’s health movement has greatly influenced campaigns for national health care. In the early 1970s, the labor-led Committee for National Health Insurance held the first conference on women and universal health care. At that and later conferences, feminist perspectives increasingly altered the reform agenda. Women labor leaders and others noted that the majority of the underinsured and uninsured were women, and that employment-based health coverage implicitly discriminated against women, who were heavily concentrated in sectors with no benefits: part-time, temporary, service, and small business employment and homemaking. Feminists criticized the health care system’s emphasis on high-tech hospital treatment at the expense of primary and preventive care. During the Clinton health reform campaign, the Older Women’s League organized a Campaign for Women’s Health to demand that health reform include primary, preventive, and long-term care and coverage for mental health, HIV testing and counseling, domestic violence screening, and full reproductive health care and family planning. Several of the women’s demands were incorporated into the Health Security bill.³⁴

At no time has the connection between grassroots movements and health care reform been more powerful, and more suc-

cessful, than during the AIDS crisis. The activism of people with AIDS and HIV fighting for their very lives led to unprecedented changes in the health care system, including speeded-up drug trials, pharmaceutical price reductions, and large increases in AIDS research and funding. AIDS activists’ targeting of researchers and drug companies has been highly publicized and documented.³⁵ Less noticed has been the AIDS community’s growing concern with inequities in the health care system.

ACT UP, the radical organization of people with AIDS and their supporters founded in 1987, at first protested against health and disability insurance companies with HIV exclusions in their policies. But even when some of this blatant discrimination was curbed, most people with AIDS and HIV still could not get access to private insurance because of its extraordinarily high cost. ACT UP’s New York branch formed an Insurance and Access Committee to fight insurance rate increases, and activists began to target insurance companies with highly visible “street theater” actions, including civil disobedience in front of insurance headquarters in New York and the National Insurance Association in Washington, DC. When increasing numbers of people with AIDS were forced to turn to Medicaid, ACT UP worked to expand Medicaid benefits to include important AIDS services and treatments.³⁶

Activists soon became frustrated with these incremental improvements and began to argue for deeper change in the health care system. At a “People of Color AIDS Activist Conference” in 1990, participants were asked to address the continuing prob-

lem of “PWAs [people with AIDS] being denied access to life saving services and primary health care” and to consider the question, “What are we doing about the establishment of National Health Care?” ACT UP—New York’s Insurance and Access Committee released the statement, “We believe that in a country with as much [*sic*] resources as we have that quality health care is a right,” and in 1991 it launched a publicity campaign featuring a poster that read, “Lack of Insurance Kills People with AIDS: Lack of insurance means lack of access to health care, and lack of health care means death.”³⁷

AIDS activists appeared to have won a major victory in 1990 with the passage of the Ryan White CARE Act, which provided significant financing for

ACT UP Records, 1993, Manuscripts and Archives Division, New York Public Library.

*After You March for
Lesbian, Gay, Bi and Transgender Rights...
Take the Next Step!
National Civil Disobedience at the Capitol*

HEALTH CARE IS A HUMAN RIGHT—NOT A BUSINESS!



- ▼ The Single Payer Plan is the Cure!
- ▼ Women Are Not Expendable—Our Health Care is a Priority!
- ▼ No HIV Borders - Lift the Ban Now!
- ▼ Access = Equality

Clinton's Plan is Not Enough!
—Act Now—
We Can't Afford to Wait!

MONDAY, APRIL 26, 1993
Assemble 9:30 a.m. in Upper Senate Park,
(on Constitution and Delaware Ave., near Union Station)
Rally at 10 a.m., Nonviolent Civil Disobedience to follow.

HUMAN RIGHTS ACTION FOR HEALTH CARE
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AIDS services, including primary health care. But conservatives in Congress initially refused to release the funds, using the argument that “they don’t want to take money away from other people who also need it.” ACT UP, infuriated by the legislators’ stance, called for national health insurance, which “should circumvent this debate by guaranteeing treatment and medical care to every American whatever they need.” Only universal coverage would ensure that patients with different diseases and conditions would not be pitted against each other. “National health care is just morally right,” AIDS activists concluded. “That our country has gone so long without it is a scandal.” ACT UP and other AIDS organizations joined state-level and national health reform coalitions and organized marches on Washington to demand universal health care in 1992 and 1993.³⁸ Winning increased health care rights for some led these grassroots activists to see the need for health care rights for all.

AIDS activists join in the April, 1992, Health Care for All/Philadelphia march. Photograph by Julie Davids. Courtesy of the Institute of Social Medicine and Community Health.



TOWARD A SOCIAL MOVEMENT FOR UNIVERSAL HEALTH CARE

Even though a significant number of grassroots movements have advocated universal health care, until recently national health care reformers have had few connections with these constituencies. The distance between elite and grassroots health campaigns, as we have seen, is partly explained by reform leaders’ lack of knowledge of, lack of interest in, or outright exclusion of popular reform constituencies and grassroots organizing strategies. But much of the explanation also lies with the nature of the social movements themselves. For movement activists, other demands have been more urgent, immediate, and even life-and-death than long-term change in the health care system—the right to organize for the labor movement, desegregation for the civil rights movement, reproductive rights for the feminist movement, disease research and drug access for the AIDS advocacy move-

ment. And immediate, local, and incremental reforms have been more politically feasible than more comprehensive change.

But the distance between expert and grassroots health reform has not been insurmountable. Since the social upheavals of the 1960s, health care reform organizations have increasingly recognized the importance of grassroots participation to their cause. From the Health Policy Advisory Center, founded by New Left activists, to today’s Universal Health Care Action Network (UHCAN), created in the aftermath of the Clinton health debate, health reformers have either emerged from or worked closely with grassroots groups and have incorporated community-organizing techniques to build support. Reform proposals are still generated primarily by professional advocacy organizations, but these have increasingly gone beyond the labor–reformer coalition to embrace other popular constituencies, including public health and social workers, nurses, seniors, religious activists, and people with particular diseases or disabilities. While physician health reformers from the 1910s through the 1950s based their appeals on their expert status rather than popular mobilization, reformist doctors now reach out to the wider community as much as to their fellow professionals. The most prominent medical reform organization, Physicians for a National Health Program, founded in 1987 to advocate a single-payer health system, emphasizes its members’ efforts to “work closely with grassroots consumers’, seniors’, and disability rights organizations.”³⁹

Since the end of the Clinton health care campaign, public discontent with the medical system

and frustration with traditional reform efforts have led to an upsurge in state-level grassroots activism. Health reform movements are currently active in over a dozen states, from California to Maryland.⁴⁰ These ballot initiatives and political campaigns for universal coverage appeal to an increasingly diverse support base. Organizers of Oregon's single-payer Health Care for All initiative, for example, have won the endorsements of groups representing teachers, medical students, churches, tenants, seniors, African Americans, alternative health practitioners, women, and environmentalists, as well as labor unions.⁴¹

Even as they expand their constituencies, most state reform campaigns continue to emphasize coalitions of professional advocacy groups as the centerpiece of their organizing strategies.⁴² In contrast, the activists of Maine's Citizen's Health Initiative have chosen to build membership through door-to-door canvassing of individuals rather than the endorsements of the already organized. Maine reformers used these organizing methods, based in the US social movement tradition, to win a major victory: in November 2001, Portland voters approved, 52% to 48%, a non-binding referendum calling for universal health care in the state. The referendum passed even though opponents, as usual, greatly outspent supporters. The Maine health care reform movement has also adopted ACT UP-style street actions to dramatize its call for universal coverage. When Anthem Blue Cross/Blue Shield of Maine created an insurance-industry front group to fight health reform, activists staged a "raucous" march and rally in front of the company's Portland

headquarters. "Shouting and carrying signs," the "largely young crowd" chanted "Hey hey, ho ho, corporate health care's got to go" and booed life-size puppets of insurance executives. Although statewide single-payer legislation failed, Maine legislators plan to reintroduce it in 2003.⁴³

Today's health care reform movement is diverse in organizing style, membership, and tactics, and even in its goals. Although most campaigns push for a single-payer system, some, including UHCAN and the Maryland Citizens' Health Initiative, argue that universal coverage could be achieved by other financing methods.⁴⁴ Whatever their differences, state and national reform groups all agree that a movement for universal health care must rely on grassroots mobilization and the support and participation of local activists. This recurring theme appears in a recent UHCAN announcement: "One key lesson UHCAN has learned in our ten years is that to change the health care system, we need a nationally coordinated movement with deep roots all over the country—roots that extend into the faith community, the labor movement, the health provider sector, and other places where people come together who care about health care justice."⁴⁵

Advocates also agree that the constituency for universal access is growing as changes in the health care system break down some of the forces that have fragmented popular support for reform. Employer cutbacks and layoffs are heightening the instability of job-based health coverage. Medicare's limitations are increasingly obvious as more people enter the system, as health maintenance organizations (HMOs)

have dropped Medicare enrollees, and as some doctors have begun to reject Medicare patients as too costly. State budget crises are forcing drastic cuts in Medicaid.⁴⁶ The workers, seniors, and poor families who were formerly protected by job benefits, Medicare, and Medicaid now have more in common with the uninsured and the underinsured.

State-level campaigns for universal coverage have greater potential for grassroots mobilization than the "patients' rights" proposals currently languishing in Congress. While patients' rights has been described as a "consumer movement" of HMO members, this simply points to its limitations. Consumer identity can be a powerful organizing force,⁴⁷ but basing health care demands on people's roles as consumers still narrows the constituency for reform: to consume health care, one must have access to it. A consumer-based movement is not necessarily more inclusive than a movement of seniors, of welfare participants, of AIDS or breast cancer patients, or even of the uninsured and underinsured. Like other piecemeal reforms, patients' rights only leads to the question of why some, but not all, deserve access to health care. State-level reform campaigns, wielding slogans like "Health Care for All" and "Everybody In, Nobody Out," are working to unify, rather than separate, their potential supporters. "You can't build a social movement with a Band-Aid philosophy," argues 73-year-old Ohio single-payer activist and former civil rights worker Jerry Gordon. "Where would civil rights be, with that kind of attitude?"⁴⁸ ■

About the Author

Beatrix Hoffman is with the Department of History, Northern Illinois University, DeKalb.

Requests for reprints should be sent to Beatrix Hoffman, PhD, Dept of History, Northern Illinois University, DeKalb, IL 60115 (e-mail: beatrix@niu.edu).

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