Helping the Voices of Poverty to Be Heard in the Health Care Reform Debate

Ellen M. Yacknin

Follow this and additional works at: https://brooklynworks.brooklaw.edu/blr

Recommended Citation
Ellen M. Yacknin, Helping the Voices of Poverty to Be Heard in the Health Care Reform Debate, 60 Brook. L. Rev. 143 (1994). Available at: https://brooklynworks.brooklaw.edu/blr/vol60/iss1/6
HELPING THE VOICES OF POVERTY TO BE HEARD IN THE HEALTH CARE REFORM DEBATE

Ellen M. Yacknin*

INTRODUCTION

The law, in its majestic equality, forbids the rich as well as the poor to sleep under bridges, to beg in the street, and to steal bread.¹

Written about France in 1894, these grim words have long inspired advocates for the rights of the poor throughout the United States.² Ninety years later, Justice John Paul Stevens modified Anatole France's lament as he denounced the Supreme Court's interpretation of one facet of the American health care system. Deploring the majority's decision that required four Medicare patients in need of major surgery to exhaust all administrative remedies before challenging the government's refusal to pay for the surgery, Justice Stevens wrote:

To sanction such a ruthless consequence . . . would justify a latter-day Anatole France to add one more item to his ironic comments on the 'majestic equality' of the law. . . . On the majority's view it would appear the rich and the poor alike also have the right to front the money for major surgery. I cannot believe that is what Congress intended, or what our precedents require.³

* Health Law and Litigation Specialist, Greater Upstate Law Project, Rochester, New York. This paper is a revised version of the author's presentation at the Brooklyn Law School Symposium: Ensuring (E)qual(ity) Health Care for Poor Americans (Dec. 3-4, 1993).

¹ ANATOLE FRANCE, Le Lys Rouge, in 5 WORKS OF ANATOLE FRANCE 91 (W. Stephens trans. 1924).


Notwithstanding his incredulity, the two-tiered inequitable nature of health care identified by Justice Stevens is a deeply imbedded American tradition. The United States is one of only two industrialized nations in the world that does not have a health care system that provides universal coverage. Access to quality health care in America is contingent upon access to money: those who can afford health insurance and medical care can obtain it; those who cannot afford them go without.

Unfortunately, the cost of health care in America is not cheap. On the contrary, the United States spends more dollars on health care—both per capita and as a percentage of the Gross National Product—than any other country worldwide.

—

and dissenting in part). Justice Stevens was joined by Justices Brennan and Marshall.


5 South Africa and the United States are the only two industrialized countries in the world that do not have some form of a national health care program. Citizen Action, Health Care Security for All: The Single-Payer Answer V-1 (1992).

6 Senator Edward Kennedy has described the American health care system as one where “the state of a family’s health is determined by the size of a family’s wealth.” Citizen Action, National Health Care: An American Priority 9 (Jan. 1990). The data are incontrovertible and alarming. As of 1992, there were 37 million persons in the United States, nearly 15% of the population, who had no health insurance at all. This number grew by 2 million between 1991 and 1992, and by 40% in the last decade. During a 28-month period between 1986 and 1988, roughly 25% of all Americans were uninsured for at least one month. It is also estimated that between 50 and 70 million Americans have such inadequate insurance that a major health crisis would lead to their financial ruin. David U. Himmelstein & Steffie Woolhandler, The National Health Program Book 22-23, 33 (1994).

According to a Robert Wood Johnson Foundation survey, 12% of Americans under age 65 experienced a serious financial problem due to serious illness in 1986. Increasing numbers of Americans report avoiding health care because of costs, from 27% in 1981 to 36% in 1987. In 1989, 21% of Americans reported an inability to pay for health care, a 40% increase from 1974. Id. at 36-37.

7 In 1993, the United States spent over $900 billion on health care, 14.4% of
This disparity in access to health care is not without consequence. In the United States, health indicators prove that the percentage of poor people in good health is far less than the percentage of wealthy people in good health, confirming the Inverse Care Theory: "Health care is distributed inversely to need."8

Struggling against tradition and theory, health care and anti-poverty advocates like Ed Sparer, the "Welfare Law Guru,"9 have long battled for an American health care system that provides quality health care to all, regardless of financial status.10 Fortunately, tradition is not always immutable.

The Inverse Care Theory was articulated by the eminent British general practitioner, Dr. Julian Tudor Hart. See HIMMELSTEIN & WOOLHANDLER, supra note 6, at 75. Roughly 23% of persons with incomes of less than $7000 income are considered to be in poor health, while roughly 8% of persons with incomes of more than $25,000 are considered to be in poor health. Only 38% of children in households with incomes of less than $10,000 are considered to be in excellent health, compared to 63% of children in households with incomes of more than $35,000. Id. at 74-75.

As might be expected, the numbers of persons in poverty and poor health are highly correlated to minority racial status. See HIMMELSTEIN & WOOLHANDLER, supra note 6, at 61-77;Racial Poverty Gap Predicted to Grow, News and Blues Forum, Oct. 19, 1993, available in HANDSNET; U.S. Census: Households Are Poorer, News and Blues Forum, Jan. 25, 1994, available in HANDSNET. See infra note 64 for a description of the HANDSNET communications network.


In Gordian Knots: The Situation of Health Care Advocacy for the Poor Today, Ed Sparer critically analyzed efforts to equalize access to health care by poor Americans through expansion of governmental health care benefits programs and questioned whether such efforts led to an equalization of the health status of the poor. Sparer, supra note 4, at 16-21. Nevertheless, Gordian Knots sets forth a list of principles for reformed health care advocacy by poverty rights advocates, and concludes that health care advocacy has the potential to make a significant differ-
Shortly after his 1992 inauguration, President Bill Clinton proclaimed his commitment to reform America's health care system by guaranteeing universal coverage. The President followed his promise with the creation of Hillary Rodham Clinton's Health Care Reform Task Force, and the presentation of his health care reform proposal to Congress and the nation on September 22, 1993. The President's subsequent vow to veto any congressional proposal that does not guarantee coverage for all exalted his political promise to a tangible possibility.

In those moments, the dream that the United States would join the ranks of enlightened nations, at least in terms of health care, became a thrilling prospect for anti-poverty and health law advocates. For the last three and one-half decades, those advocates used their legal skills to protect the rights of their clients in the courts. Hundreds of successfully litigated

---

11 The President's health care reform package was presented in bill form to Congress on October 27, 1993. See President Clinton's Health Care Reform Proposal and Health Security Act, Medicare & Medicaid Guide (CCH) No. 773 (Nov. 1, 1993). With some revisions, the President's plan was presented to Congress in bill form (H.R. 3600/S. 1757) on November 20, 1993. See President Clinton's Health Security Act, Medicare & Medicaid Guide (CCH) No. 778 (Dec. 2, 1993).

12 In his State of the Union Address on January 25, 1994, President Clinton stressed:

I want to make this very clear. . . . If you send me legislation that does not guarantee every American private health insurance that can never be taken away, you will force me to take this pen, veto that legislation and we'll come right back here and start over again.


cases over the last several years forced hospitals to provide free health care to the poor under the Hill-Burton Act, protected the due process rights of Medicaid recipients, secured Medicaid recipients' right to medically necessary treatment, and prevented or stalled Medicaid cutbacks in the face of federal and state budget deficits.\textsuperscript{14}

Health care litigation, however, can only accomplish so much. Successful trials and appeals decisions have been unable to change the stark reality for hundreds of thousands of Medicaid recipients who cannot find doctors willing to accept them as patients,\textsuperscript{15} or the 37 million Americans who have no health insurance\textsuperscript{16} and, therefore, live on the brink of poverty should a medical crisis occur.\textsuperscript{17}

For the first time in years, President Clinton's declared goal of universal health care coverage in the United States presents a different challenge to anti-poverty law advocates, one that is simultaneously exhilarating in its possibilities and daunting in its obstacles. The challenge involves using our legal skills in ways that were particularly unthinkable during the Reagan and Bush eras; namely, to work within the federal political process to help the voices of the poor to be heard in the health care debate.

Whether this challenge merits the necessary time, energy and resources hinges on the answers to several questions: Is it really that important to ensure that poor persons' voices are heard? Do we, as legal advocates for the poor, have any power to help the voices of the poor be heard over the other voices? Do legal advocates for the poor have anything worthwhile to contribute? Can we possibly make a difference in the outcome of health care reform?

The answer to these troublesome questions is unconditionally yes. This article explores why the answer is yes by ad-

\textsuperscript{14} Many of these cases are compiled in the following publications of the National Health Law Program: JANE PERKINS & MICHÈLE MEULDEN, AN ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM (1991); ARMIN FREIFELD, THE RIGHT TO HEALTH CARE: AN ADVOCATE'S GUIDE TO THE HILL-BURTON UNCOMPENSATED CARE AND COMMUNITY SERVICES REQUIREMENTS (1986).

\textsuperscript{15} See infra notes 26-28 and accompanying text.

\textsuperscript{16} See supra note 6.

\textsuperscript{17} The limitations of health care litigation to achieve access to quality health care are thoughtfully discussed in Sparer, supra note 4.
dressing these fundamental questions: Who are the voices of poverty that must be heard in the health care reform debate? Why should anti-poverty legal advocates help ensure that the voices of poverty are heard in the debate? What are the issues that are critical to poor people in the debate? What power do the poor and their advocates have to ensure that their voices are heard? How can poor people's legal advocates use their power to help their clients' voices be heard? and, Will helping the voices of poverty to be heard in the health care reform debate make any difference?

WHO ARE THE VOICES OF POVERTY THAT MUST BE HEARD IN THE HEALTH CARE REFORM DEBATE?

The voices of poverty are all of our clients, and a lot of us. The number of people living in poverty in America has swelled dramatically in the last fifteen years. In 1977, 11.5% of all Americans had incomes below the federal poverty level. In 1992, the percentage had escalated to 36.9 million, or 14.5% of all Americans. Increasingly, the poor in the United States are women and children. In 1992, one-sixth of all households were headed by women, but these households accounted for 52.4% of all poor families.

And despite American mythology, a job is not a guaranteed path out of poverty. Overall, 18% of full-time, full-year workers earned less than the federal poverty level in 1990. About 40% of poor Americans older than age 16, or 9.4 million people, worked at least some time during 1992.

Contrary to another Great American Myth, being poor does not automatically entitle a family to Medicaid, the

---

18 In the United States, the standard measure of poverty is the federal poverty level, established each year by various designated governmental departments. In 1994, the federal poverty level, as set by the Department of Health and Human Services, is $7360 for a one-person household, $9840 for a two-person household, $12,320 for a three-person household, and $14,800 for a four-person household. Meeting Notice, 59 Fed. Reg. 6,277 (1994).

19 Paulette Thomas, Poverty in the U.S. Worsened Last Year While the Richest Group Became Richer, WALL ST. J., Oct. 5, 1993, at A2. In sharp contrast, the rich have continued to get richer. The wealthiest 20% of households accounted for 46.9% of the nation's wealth in 1992, up from 46.5% in 1991. Id.

20 HIMMELSTEIN & WOOLHANDLER, supra note 6, at 46.

21 Thomas, supra note 19, at A2.
nation's health care financing program for poor single-parent families and poor disabled persons. The financial eligibility levels for Medicaid differ state by state, and no state's Medicaid financial eligibility guidelines meet the federal poverty level. Moreover, even if they qualify financially for Medicaid, childless adults and disabled adults who do not meet the criteria for Supplemental Security Income, are provided state-funded medical assistance in roughly only two-thirds of all states.

Likewise, being eligible for Medicaid does not guarantee a recipient's access to health care. The Medicaid program is an elaborate health care financing system; it simply pays health care providers who agree to accept Medicaid recipients as patients, and who meet Medicaid's myriad and complicated eligibility requirements. In no state do the Medicaid rates to outpatient providers come close to their private billing rates. In

---

22 The Medicaid Act, Subchapter XIX of the Social Security Act, 42 U.S.C. §§ 1396a-1396d (1991), was adopted by Congress in 1965 to enable the poor to have access to the health care system. Medicaid was originally conceived of as a program that ultimately would: assur[e] ... complete, continuous, family-centered medical care of high quality to persons who are unable to pay for it themselves. The law aims much higher than the mere paying of medical bills, and States, in order to achieve its high purpose, will need to assume responsibility for planning and establishing systems of high quality medical care, comprehensive in scope and wide in coverage. 

Sparer, supra note 4, at 3 (quoting UNITED STATES DEP'T OF HEALTH, EDUC. & WELFARE, FEDERAL HANDBOOK OF PUBLIC ASSISTANCE 5140 (Supp. D. 1967)). According to the Act, this "comprehensiveness" goal, set forth in § 1903(e), was to be achieved by 1975. Due to political pressure, however, § 1903(e) was first delayed, and then repealed altogether in 1972. See Sparer, supra note 4, at 3.

23 In New York State, for example, the 1994 Medicaid income eligibility level is $9,400 for a family of three. New York State Department of Social Services, 92 Administrative Directive-2 (Feb. 9, 1994). In contrast, the Federal Poverty Level for a family of three in 1994 is $12,320. Meeting Notice, 59 Fed. Reg. 6,277 (1994). New York's Medicaid income eligibility levels are among this nation's highest. More than half the states set the Medicaid income level at less than 50% of the federal poverty level, while four set them below 25% of poverty. See DIANE ROWLAND ET AL., A REPORT OF THE KAISER COMMISSION ON THE FUTURE OF MEDICAID: MEDICAID AT THE CROSSROADS 39 (1992).


most states, Medicaid outpatient provider rates do not even match the provider’s administrative costs.\textsuperscript{26} It is no surprise, then, that few private physicians will treat Medicaid recipients.\textsuperscript{27} It is also no surprise that Medicaid recipients in large numbers are forced to use extremely expensive hospital emergency rooms as their primary health care providers.\textsuperscript{28}

**WHY SHOULD ANTI-POVERTY LAW ADVOCATES HELP ENSURE THAT THE VOICES OF POVERTY ARE HEARD IN THE HEALTH CARE DEBATE?**

There are countless debates surrounding every aspect of health care reform system. What is undebatable is that the current political climate presents a window of opportunity for health care reform unlike any other in recent history.\textsuperscript{29} As

---

\textsuperscript{26} In New York, for example, private physicians are reimbursed at the rate of $11 per office visit.

\textsuperscript{27} Medicaid does not guarantee health care coverage to its recipients. Instead, it guarantees only that health care providers will be paid if they volunteer to participate as Medicaid providers.

Under federal Medicaid law, states have broad discretion to set outpatient provider rates. Historically, these rates have been far lower than private physician rates or Medicare rates. The average Medicaid payment for a physician’s visit, for example, is 60% of the average Medicare payment. As a result of this and other factors, such as complicated paperwork, only about one-third of the nation’s physicians participate without restrictions in the Medicaid program. Another one-third limit the number of Medicaid patients they will see. See Rowland \textit{et al.}, \textit{supra} note 23, at 21, 43-45.

\textsuperscript{28} Id. at 45.

\textsuperscript{29} Comprehensive health care reform in the United States has been proposed before in this century. In 1943, the Wagner-Murray-Dingell National Health Insurance Bill was introduced in Congress. The bill called for payroll taxes on employees and employers, and for government-paid doctors. Although introduced in some form or another for 14 years, the bill never made it to the floor of either chamber.

In 1943, President Franklin Roosevelt publicly promised to deliver national health care reform, but died before he was able to do so. His successor, President Harry Truman, backed legislation similar to the Wagner-Murray-Dingell Proposal, and a huge public debate ensued in 1949-1950. In the meantime, the Korean War overwhelmed, and eventually killed, health care reform efforts.

The Kerr-Mills Plan, which required the federal government to match state funds to care for the elderly poor, was passed in 1958. Seven years later, through a compromise between Representative Wilbur Mills and President Lyndon Johnson, Medicare, which covered senior citizens, and Medicaid, which covered the poor, were adopted.

The last comprehensive health reform plan in this century before the present debate was proposed by President Richard Nixon in 1974. Under the Comprehen-
commentators have observed, President Clinton has staked his presidency on the passage of a universal health care coverage package. The popular media has assiduously kept the health care reform debate before the public. If nothing else, the millions of dollars already spent by lobbyists and interest groups on advertising and campaign contributions warrant at least some action by Congress.

Nevertheless, even if health reform becomes reality, it is entirely conceivable that poor people will not benefit from it. Unless the voices of poverty prevail, health reform might result in universal coverage that is so costly to individuals that the guarantee of universality will be illusory. Unless the voices of poverty are heard, the informally created two-tier health care system that exists today will be institutionalized as a legitimate form of discrimination and inequality.

Among the chorus of health care lobbyists, several voices...
have spoken out for meaningful universal coverage for years, and they continue to do so. None, however, focuses on the plight and the health care needs of the poor. As Ed Sparer constantly reminded us, the most effective voices for the poor are those of the poor themselves. Unfortunately, groups of people in poverty who are organized to speak out exist today only on a small scale and in few communities.

Second in potency to the voices of the poor themselves are the voices of those who speak on their behalf. Foremost among them are anti-poverty lawyers. There is, of course, no guarantee that the voices of the poor, via their advocates, will be heeded in the health care debate. However, unless anti-poverty lawyers advocate vigorously for the rights of their clients in the federal legislative arena, just as we have always done in the judicial arena, it is certain that the voices of poverty will be ignored.

WHAT ARE THE ISSUES THAT ARE CRITICAL TO POOR PEOPLE IN THE HEALTH CARE REFORM DEBATE?

Beyond the polemics of managed competition, financing mechanisms, and health alliances, the voices of poverty demand three components in a health care system to make it accessible in reality as well as in name: a single health care

---

33 Among the more prominent organizations are Families USA, Physicians for National Health Reform, and Citizen Action.

34 See Sparer, supra note 4 at 22-23; DAVIS, supra note 9, at 30-31, 144-45; see also Michael J. Fox, Some Rules for Community Lawyers, 14 CLEARINGHOUSE REV. 1 (1980); White, supra note 13, at 884-87.

35 See DAVIS, supra note 9, at 133-41; FRANCES F. PIVEN & RICHARD A. CLOWARD, POOR PEOPLE'S MOVEMENTS: WHY THEY SUCCEED, HOW THEY FAIL 289-53 (1977); NICK KOTZ & MARY L. KOTZ, A PASSION FOR EQUALITY: GEORGE A. WILEY AND THE MOVEMENT 285-306 (1977); see also Houseman, A Short Review, supra note 13, at 1514, 1518, 1520; Fox, supra note 34, at 1.

36 See Fox, supra note 34, at 1; Sparer, supra note 4, at 22-23; White, supra note 13, at 884-87.

37 Poverty law advocates in offices funded by the Legal Services Corporation have a history, albeit a modest one, of federal legislative advocacy. See Houseman, A Short Review, supra note 13, at 1517-18. The pointedly aloof reactions of the Reagan and Bush Administrations to the concerns of the poor made federal legislative advocacy a low priority. Legislative advocacy by legal services' advocates is governed by 45 C.F.R. § 1612 (1992). See Alan W. Houseman, Questions and Answers on Legislative and Administrative Advocacy, Training and Organizing (Oct. 1991) (on file with author).
card and a seamless system for everyone, regardless of income,\textsuperscript{38} premiums and point-of-service costs that are truly affordable,\textsuperscript{39} and comprehensive health care benefits.

Of all the elements of a universal health care system, the right to have the same health care card as everyone else is vital to the poor. For too long, and in too many ways, the poor have been stigmatized publicly by their welfare cards, their food stamps and their Medicaid cards. The humiliation felt by public assistance recipients as they pull out their badges of poverty should not be underestimated.\textsuperscript{40}

A single health care card has far more than symbolic meaning to the poor, however. It means that poor health care consumers will never again be turned away by a doctor's office

\textsuperscript{38} Advocates for the immigrant community do not disagree with the concept of a single unified health care system. They are worried, however, about a system that requires a card to gain access to it and rules that bar undocumented immigrants from obtaining the cards. See \textit{National Health L. Program, Making Health Care Work for All: A Perspective from Legal Services Health Advocates for Low-Income People} 35 (1993); \textit{New York State Health L. Task Force, Universal Health Care Coverage: To Be Universal, Health Care Coverage Must Include Everyone} (1993).

\textsuperscript{39} A co-payment is generally a fixed amount of money that health care patients must pay at the time they receive service. President Clinton's Health Security Act, for example, requires Aid to Families with Dependent Children ("AFDC") and Social Security Insurance ("SSI") recipients to pay a $2 co-payment for each physician's visit, and all others to pay a $10 co-payment for each physician's visit. President Clinton's Health Care Reform Proposal: Health Security Act, 103d Cong., 1st Sess. § 1135(a) (Oct. 27, 1993) [hereinafter HSA].

\textsuperscript{40} A deductible is generally a percentage of the cost of the particular health care service that consumers must pay at the time they receive service. President Clinton's Health Security Act, for example, requires the payment of at least a 20% deductible when a consumer receives treatment from a provider who is outside the consumer's designated health care plan. HSA § 1132 (b)(1)(A).


\textsuperscript{40} See \textit{National Health L. Program, supra} note 38, at 29-30.
simply because they are Medicaid recipients. It means that the health care options to impoverished consumers will be expanded dramatically, as providers will not deprive them of care. A single, unified system of health care means that hospital emergency rooms will be used primarily for emergency care, that Medicaid bills may disappear, and that the discrimination in quality of care will wane.

As Justice Stevens portended,\textsuperscript{41} universal health coverage means little if its cost precludes the poor from receiving necessary health care. In 1994, a mother of two children who works 40 hours a week at minimum wage\textsuperscript{42} and takes no unpaid vacation or sick time earns $8,840 a year, close to two-thirds of the federal poverty level.\textsuperscript{43} After paying for her family's food, clothing and rent, this mom has absolutely no disposable income to pay for health care premiums, or point-of-service co-payments or deductibles.\textsuperscript{44}

If a reformed health care system requires individuals to pay for insurance, premiums and point-of-service payments should not be charged to those with incomes of less than 200% of the federal poverty level. For those with incomes greater than 200% of the federal poverty level, payments should be indexed according to income, and capped at an affordable percentage of income.\textsuperscript{45} To demand more would be tantamount to a perpetuation of a system that rations health care to those who can afford it rather than those who need it.\textsuperscript{46}

\textsuperscript{41} See supra note 3 and accompanying text.

\textsuperscript{42} The federal minimum wage was last raised in 1991 to $4.25 per hour. See Study: Minimum Wage Hike Small Benefit to Poor, News and Blues Forum, Mar. 10, 1994, available in HANDSNET.

\textsuperscript{43} See supra note 18.

\textsuperscript{44} At the federal poverty level, a family of three has $11.25 per person per day to pay for all household expenses, including housing, utilities, food, clothing, transportation, personal care items, household furnishings and all other expenses of life. See supra note 18. There is general agreement that households with incomes of twice the federal poverty level amount have no disposable income with which to pay for health care. See NATIONAL HEALTH L. PROGRAM, supra note 38, at 19-33.

\textsuperscript{45} See NATIONAL HEALTH L. PROGRAM, supra note 38, at 19-33; NEW YORK STATE HEALTH L. TASK FORCE, supra note 38.

\textsuperscript{46} Representative Claude Pepper aptly observed:

For the elderly poor, a fifty cent co-payment which seems insignificant to most of us can mean the difference between a needed prescription and a quart of milk or a loaf of bread. What right do we have to ask them to make this choice?

\textbf{HOUSE SELECT COMM. ON AGING, H.R. Doc. No. 181, 96th Cong., 1st Sess. 28}
Finally, covered health care services must be comprehensive to ensure that the poor and the wealthy alike obtain the health care they need. Americans with multiple health problems are often poor because they cannot work at higher paying jobs. These same individuals often need specialized medical and rehabilitative services more frequently than others. Moreover, without wrap-around and supportive services, such as transportation and translation services, necessary health care for the poor will remain inaccessible.

A single, unified system, affordability, and comprehensive benefits, then, are the three linchpins of a truly universal health care system. Without these assurances, the guarantee of universality will be as meaningful as the right to sleep under bridges.

**WHAT POWER DO THE POOR AND THEIR ADVOCATES HAVE TO ENSURE THAT THEIR VOICES ARE HEARD IN THE HEALTH CARE REFORM DEBATE?**

The national health care debate has become, if nothing else, extraordinarily loud. The voices of the insurance companies, big businesses, small businesses, health care conglomerates, physicians, state governments, Republicans and Democrats are all vying with each other for attention. To help the voices of poverty join the din, not to mention to be heard, unquestionably will be demanding.

Several obstacles muffle the voices of poverty. To be heard in the political arena requires the power to influence legislation. Poor people, though, simply lack the types of power that powerbrokers classically use to underscore their positions.

(1979).

For a family making under $5000 a year, which is true for 1 in 20 American households, a $10 co-payment would be equivalent to a $75 co-payment for a household with an average income of $37,400. *See New York State Health L. Task Force, supra* note 38.

According to a study released in January 1994, 24 million people—or one in ten—are severely disabled. Further, about 30% of all severely disabled working-age adults have incomes below the federal poverty level. *See A Third of Disabled Adults Are Poor*, News and Blues Forum, Jan. 28, 1994, *available in HANDSNET*. See *infra* note 64 for a description of the HANDSNET communications network.

*See National Health L. Program, supra* note 38, at 7-18.

For an analysis of political power that is not shared by the poor, see *Piven*
In the first place, interest groups and lobbyists effectively use the very thing poor people don’t have: money. Corporations, professional associations and interest groups often have full-time salaried lobbyists on staff, enabling them to make the steady and close connections with legislators and their staff that are essential to being heard. Furthermore, the expenditure of money to influence the health care reform debate, both in campaign contributions and in lobbying activities, is enormous. When legislative action occurs on a federal scale, as is happening in the health care reform debate, money becomes even more important to pay for Washington trips, lobbying literature, national media campaigns and political contributions.\(^5\)

Second, poor people historically do not have access to the “old-boy network” of important political connections. “Access” is key to legislative advocacy, because without access to decisionmakers, there is no one to hear the message, let alone be persuaded by it. Professional lobbyists spend careers building and nurturing their contacts so that decisionmakers will listen to them at key moments. Poor people, on the other hand, spend much of their lives trying to survive. Learning how to “make friends and exert influence” in Congress is simply not a top-priority goal.

Interest groups without money and connections often wield an alternative source of power in their advocacy activities: the power of the vote. While a single vote may seem inconsequential, legislators are, with rare exceptions, extremely sensitive to the views of their voting constituency. Although lawmakers obviously cannot be responsive to all constituents on all occasions, they will nonetheless go to surprising lengths to listen to the views of the electorate.

Despite their burgeoning numbers, however, poor people have not made effective use of the power of their ballots. A major obstacle to doing so is that electoral power is as much perceived as it is actual. In other words, a constituent who is perceived to be a voter will carry more weight than a constituent who is perceived to be a non-voter, regardless of whether either of them actually votes. When constituents write, call

\& CLOWARD, supra note 35, at 1-5. See also Fox, supra note 34, at 1.

\(^5\) See supra note 32.
and fax messages to their congressional representatives, the tacit message is that they may vote against their representative if the representative doesn't come through. Constituents who have no contact with their legislators are regarded as non-voters, and hence their power is minimal.

Finally, unlike other interest groups, poor people today have no organizational structure to help amplify their voices. The power of an organization is that it can speak as one voice on behalf of many, and the "many" are inevitably believed to be more in number than reality. For these reasons, the perceived power of a unified front is often stronger than the actual power of individuals. In the absence of a group structure, poor people must fend for themselves individually and with little support from their peers. Alone, the effort to make one's voice heard is great, but the resultant power of the voice is small.

Despite the numerous barriers to poor people's ability to organize to champion their interests, poor people's movements in the United States are not unprecedented. The potential strength of poor people's organizational efforts is best illustrated by the National Welfare Rights Organization that endured throughout the 1960s and early 1970s and, at its peak, had 20,000 members nationwide. In the 1990s, though, no national poor people's organization exists, and smaller community poor people's groups are few. To the extent that poor people speak out, they do so primarily as individuals.

Despite their lack of conventional sources of political power, poor people are not powerless to assert their voices. Especially in the health care reform debate, poor people's nontypical sources of power have the potential to enable their voices to be heeded.

More than anything else, poor people possess the power of their compelling stories. Virtually every poor person who...
needs medical care in this country has a story to tell. Poor people have suffered the daily tragedies of foregoing dental care for their families because no dentist within 100 miles will accept Medicaid patients; of being turned away from hospitals because they have no health insurance; of splitting their prescription pills in half because their limited incomes must be used for their children’s food and clothing; of being found ineligible for Medicaid because their incomes are a few dollars over the Medicaid financial eligibility level; and of being forced to quit a job with no health insurance so as to qualify for Medicaid. These are the stories that dictate a single system of universal and comprehensive health care coverage. These are the stories that lawmakers are too embarrassed to ignore.

Besides their stories, poor people also have substantial experience with complex benefits systems and bureaucracies. While providers bemoan the bureaucratic hassles of dealing with insurance companies, poor people are intimately familiar with the complexities of dealing with governmental systems. They know what it’s like to deal with caseworkers, complicated and varied benefit systems and requirements, financial eligibility paperwork, appeals and grievance procedures, and complicated application and recertification procedures and documentation. This information is invaluable to legislators who are concerned about creating a health care system that reduces rather than increases governmental red tape.

Poor people also have the intangible power of being right in their goal of universal health care coverage. Being right obviously carries no warranty of victory. But it is much more difficult to be persuasive on behalf of causes that are unjust or that serve the few at the expense of the majority. Despite its historically enormous political power, for example, the tobacco industry is finding it harder and harder to advance credible arguments on its own behalf.

recipients themselves. As Judge Patricia Wald of the D.C. Circuit recently implored a legal services audience, “We judges want to know the facts, the real-life conditions, the actual practices underlying a legal challenge . . . . Judges search for meaning in what we do. You need to convince us that the law or the regulation is important in poor people’s lives.” Patricia Wald, Ten Admonitions for Legal Services Advocates Contemplating Federal Litigation, 27 CLEARINGHOUSE REV. 11, 13 (1993).
Beyond being right, poor people in the health care reform debate have the power of having their interests coincide with the interests of financial savings. As the President persistently proselytizes, and as governmental studies have found, universal health care coverage will save this country billions of dollars. This form of power is a rare bonus to poor people, whose interests, given their poverty, more often than not clash with the interests of saving money. While saving money, like being right, will not ensure success, it is an ability that is far more valuable to have than not.

Poor people also have the power of numbers. The number of people living in poverty continues to grow, as does the number of people without health insurance coverage. More importantly, in the context of the health care reform debate, health is the great equalizer: medical crises strike the affluent as well as the poor, the employed as well as the jobless, without discretion, potentially forcing them out of their jobs and into destitution.

That the unpredictable mutability of life puts everyone in the identical position of needing comprehensive health care coverage regardless of work status, regardless of health status, and regardless of financial class is becoming more apparent. Thus, the numbers of people who recognize that they, too, could be impoverished as a direct result of an unforeseeable medical crisis or the unanticipated loss of adequate health insurance coverage swell the ranks of those who, like the poor, demand meaningful universal health care reform.

53 The Congressional Budget Office ("CBO") recently found that the President's Health Security Act will cost more initially than the President maintained. On the other hand, according to the CBO, the HSA will lead to a long term deficit reduction after 2004, and reduction in national health expenditures of perhaps $413 billion over 5 years, beginning in 2000. Businesses would see their health care costs reduced by as much as $20 billion per year by the year 2000. See 2 American Health Line: An APN Daily News Briefing 1, American Healthline Forum, Feb. 10, 1994, available in HANDSNET. See infra note 64 for a description of the HANDSNET communications network. Other governmental studies have found that a single-payer national health care system will save billions of dollars immediately. See supra note 39.

54 See supra notes 18-21 and accompanying text.

55 See supra notes 6-7, 22-28 and accompanying text.

56 For a fascinating discussion of the rights and interests of communities, as analyzed through peoples' relations, contrasted with the rights and interests of individuals, see Joseph W. Singer, The Reliance Interest in Property, 40 STAN. L.
Besides their direct power, poor people in the 1990s also have access to collateral sources of political power in the health care reform campaign. Chief among them are those sources possessed by legal advocates for the poor. Similar to their clients' power of being right, anti-poverty advocates retain the impalpable power of having no ulterior self-interest in promoting the interests of the poor. This source of power is shared by few other interest groups in the health care reform dialectic. Regardless of whether their clients' interests are ultimately protected by health reform, poor people's lawyers will neither make nor lose money, their jobs will be no more or less secure, and their current access to the health care system will be no better or worse.\footnote{This proposition is qualified by the proposition, discussed earlier, that the unexpected whims of life keep us all one step ahead of a pink slip or hospital bed and, therefore, one step away from the ranks of the poor.}

The unquantifiable power of the absence of self-interest translates into the power of enhanced credibility. Whether expressed or not, the credibility of the American Medical Association, for example, is qualified by its unstated interest in retaining physicians' high salaries and fees. And the credibility of the National Insurance Association is qualified by its unstated interest in retaining high health care insurance profits. The credibility of poor persons' legal advocates, on the other hand, is qualified by no interest other than the explicit goal of universal health care coverage for all.

Anti-poverty advocates also possess the power of expertise, acquired through years of experience, in understanding the complex systems that affect the poor in general, and the health care systems that affect our clients in particular. Having represented hundreds of thousands of clients in health-related cases over the years, we collectively know more than any lawmaker or lobbyist about the intricacies of the American health care system and its impact on the poor. We are recognized authorities on the theories and implementation of procedural due process rights as they affect the poor. We are masters of the minutiae of eligibility criteria and procedures in governmental
benefits programs. Most importantly, we have learned which policies and procedures work, which should be discarded, and which can be altered to make them work better. It is knowledge such as this that is invaluable to policy architects and legislators as they attempt to graft comparable policies and procedures onto their health care reform proposals.\textsuperscript{58}

We also have become skilled at the art of advocacy on behalf of poor people. Through innumerable briefs, we have learned how to communicate our clients' lives on paper, and to compel judges and others to acknowledge their pain. While we have honed our skills primarily in the courts, in recent years many of us have also become adept at legislative and administrative advocacy in state legislatures across the country. Our power to tell our clients' stories, and to use their stories to compel action is easily transferable to the halls of Congress.\textsuperscript{59}

Like our clients, lawyers for poor people historically have not been privy to the political networks that provide access to

\textsuperscript{58} The legal knowledge of legal services' advocates is immeasurable. Over the years, for example, legal services attorneys have become proficient authorities on the Medicaid Act, which courts have variously called a "Serbionian bog," Feld v. Berger, 424 F. Supp. 1356, 1357 (S.D.N.Y. 1976), an "impenetrable thicket of legalese and gobbledygook," Lamore v. Ives, No. 90-0092-B, 1991 WL 193601, at *2 n.2 (D. Me. July 19, 1991), aff'd, 977 F.2d 713 (1st Cir. 1992), and "almost unintelligible to the uninitiated." Friedman v. Berger, 547 F.2d 724, 727 n.7 (2d Cir. 1976), cert. denied, 430 U.S. 984 (1977).

\textsuperscript{59} Conveying our clients' stories to legislative powerbrokers is no different than conveying them to a judge. For example, 68-year old Helen M. of Rochester, New York, receives $528 a month in Supplemental Security Income and Social Security Retirement benefits as her sole source of income. Ms. M. is an insulin-dependent diabetic who also suffers from chronic psoriasis, hypertension, arthritis, and kidney and thyroid conditions, all of which require intensive medications and medical care to prevent her from being hospitalized. Ms. M. relies on Medicaid to pay for her health care.

In 1992, Ms. M. received a notice from the New York State Department of Social Services stating that she would now have to pay so-called "minimal" co-payments for her medications and doctor visits. When the notice was explained to her, Ms. M. broke down and cried. She explained that she had $2.72 in the bank and could not possibly afford the co-payments for her medical care.

With the help of her legal services attorney, Ms. M. submitted an affidavit relating her story in a lawsuit to enjoin the co-payments. Although plaintiffs succeeded in stopping the co-payments for over a year, plaintiffs ultimately lost. See Sweeney v. Bane, 996 F.2d 1384, 1390 (2d Cir. 1993).

In the meantime, however, Ms. M. agreed to allow her legal services lawyer to tell her story in support of an universal health care system that helps poor people. See NATIONAL HEALTH L. PROGRAM, supra note 38, at 21. Ms. M.'s story is now known by many congressional representatives and their staff.
decisionmakers, especially during the Reagan-Bush years. During the Clinton Administration, however, our access has expanded dramatically, at least with respect to health care reform. There are three principal reasons for this expanded access. First, the Clinton Administration has publicly adopted as national goals the same universal health care coverage principles that poor people and their advocates espouse. Second, on a related but more politically pragmatic level, many of our colleagues are now in positions of governmental authority themselves, giving us access simply because we know them; in other words, the "old-boys network" finally includes some of us. Third, over the years, poor people's legal services have connected with, or themselves joined, more established organizations that have nurtured access to federal administrations. Though indirect, these connections with policymakers are not inconsequential.

A less indirect source of strength derives from poor people's linkages with other segments of society that have more political clout. Increasingly, women's organizations, associations of racial minorities, and unions and other workers' groups have significant interests that coincide with poor people's interests in the health care reform debate. Women's groups have become more conscious of the dramatic "feminization of poverty" during the last two decades. Moreover, low-wage uninsured workers are more and more frequently confronted with the painful Hobson's choice of retaining their jobs

---

60 Two former staff attorneys with the Legal Services Corporations' National Health Law Program instantly come to mind. Andreas Schneider is counsel to Congressman Henry Waxman, Chair of the Health and Environment Subcommittee of the House Committee on Energy and Commerce, and one of Congress' leading proponents of health reform. Sara Rosenbaum was counsel to the White House's Health Reform Task Force and remains active in the Administration's health reform efforts.

and foregoing health care, or quitting and going on welfare to get Medicaid. Women, African Americans and Latinos account for large percentages of these low-wage workers. While universality, affordability and comprehensive benefits may not be among the foremost health care reform priorities of these groups, they must be, simply by virtue of their memberships, goals shared by them all.

A final source of collateral power is one that poor people lack directly—the power of organization. Under the umbrella of the Legal Services Corporation, anti-poverty advocates across the nation have connected with each other in several ways: at trainings and conferences, through shared written materials, via the Corporation's publication, Clearinghouse Review, by way of the all-important telephone, and, more recently, by way of the modern miracle of communication: modems and HANDSNET. While decidedly not on par with the National Welfare Rights movement, the legal services community has become an organization for the 1990s; namely, a national network with the ability to share information instantly.

**How Can Poor People's Legal Advocates Use Their Power to Help Their Clients' Voices Be Heard?**

Possessing political power is meaningless if the power is not used. By exercising our power and that of our clients, legal advocates for the poor have the potential to make a difference on behalf of our clients in the efforts to reform the health care system. There are several actions we can take.

---

62 Between 1974 and 1990, the percentage of full time, full year workers with earnings of less than the poverty level had increased from 13.8% to 22.4% for African American men, from 24.5% to 28.5% for African American women, from 12.1% to 28.2% for Latino men, and from 32.6% to 37.0% for Latina women. Overall, 18% of all full-time, full-year workers earned less than the poverty level in 1990. HIMMELSTEIN & WOOLHANDLER, supra note 6, at 46; see also George C. Galster, Polarization, Place, and Race, 71 N.C. L. REV. 1421, 1437 (1993).

63 For a discussion of the importance to anti-poverty advocates of working with coalitions to achieve social change on behalf of low-income persons, see Jane Hardin, Alliances and Coalitions: Building Associations for Mutual Benefit, 27 CLEARINGHOUSE REV. 766 (1993).

64 HANDSNET is an electronic bulletin board and mail system that targets as its users primarily public interest organizations and legal services offices. Several consumer-oriented health care reform groups participate on the HANDSNET communications network.
clients' stories. Poor people have the compelling stories; we have access to them. It is our clients' stories that must be used as the litmus test to determine which health reform plans will fulfill the principles and meet the needs of our clients. Will the President's proposal help Mrs. Smith obtain the health care she desperately needs despite her meager income? Will the Chaffee proposal ensure that quality health care is available to Ms. Jones' multiply-disabled son? Will the Cooper proposal enable Mr. Anderson to retain his family's health care coverage if he takes another job? As advocates for the poor, we can help our clients exert their political power by using ours to put our clients' stories on paper, compile them, and provide them to congressional representatives in support of the principles that are critical to poor people.

We can also educate our clients and the public about the health care reform debate and the issues that affect them. Information and knowledge are, as discussed above, their own sources of power. Through the legal services network, advocates have instantaneous access to substantial information about the pending health reform proposals. Using our own local contacts, we can share this information, and therefore political power, with clients and groups throughout our communities.65

To the extent possible, we can also help our clients speak for themselves. We can invite them to meetings, make appointments with and accompany them to meetings with legislators, arrange for them to speak at public health care events and legislative hearings, and help them make their views known through the media.

On a more analytical level, as poor people's advocates we can use our legal skills to analyze the various proposals' impact on poor people. We can use our political power to work with amenable representatives and congressional staffers to draft legislative amendments of the various bills as they wind their way through committees.

65 The National Health Law Program has prepared a slide show and accompanying script that describes the various health reform proposals and their impact on the lives of poor people. The show is available from the National Health Law Program, 1815 H Street, Suite 705, Washington, D.C. 20006, (202) 887-5310.
HELPING THE VOICES OF POVERTY

WILL HELPING THE VOICES OF POVERTY TO BE HEARD IN THE HEALTH CARE REFORM DEBATE MAKE ANY DIFFERENCE?

Undeniably, helping the voices of the poor to be heard in the health care reform debate will require time, energy and resources. Our efforts will require forms of advocacy different than those with which we have become comfortable over the previous several years. Moreover, competing to be heard, let alone heeded, among the hundreds of other voices who have far more political clout than we or our clients do is, at best, a challenge. So the inevitable question becomes, "Are the time, energy and resources that we will have to expend to help our clients' voices to be heard make any difference?" There are, it seems, two answers to the question.

The first answer is that the work that poor people's legal advocates have already done has, indeed made a difference. Under the tireless leadership of the staff of the National Health Law Program, legal services advocates around the country are organized to analyze health reform bills, write legislative advocacy position papers, draft legislative language on various issues at the request of representatives, and conduct legislative advocacy on behalf of our clients.

As a result of these efforts, the President's proposal includes the "blended rate" structure that, if adopted, will provide that health care providers are paid the same for treating all patients regardless of their income—guaranteeing, in effect, the eradication of this country's two-tier health care system. Also as a result of these efforts, the President's bill provides for reduced co-payments for cash assistance beneficiaries, a provision not included in his preliminary draft.66 Finally, congressional representatives and their aides have been quick to ask for drafting input from legal services advocates as the legislative process ensues. These success stories, minor as they may be, give credence to the ability of advocates for the poor to make a difference.

The second answer to the question, "Will our work make a

66 Although legal services advocates are not satisfied with the limited scope of the reduced co-payment rates, the rates are far better than those proposed in the President's initial plan. See NATIONAL HEALTH L. PROGRAM, supra note 38, at 19-33.
difference?” is that we will never know for certain. The fact is that in many respects the answer is no different than it is in litigation. If we win a case, we can never know whether a certain motion or a specific legal argument or a particular strategy decision was responsible for the legal victory, or whether we would have won regardless of the issues we raised or the cases we cited. Conversely, the loss of an important case does not prove that the hundreds of hours spent on it were an utter waste of time for our clients.

Likewise, assuming that a truly universal system of affordable and comprehensive health care coverage emerges from committee, let alone becomes law, we will never know for certain what, if anything, we did that contributed to the passage of meaningful health care reform. Similarly, the failure of meaningful health reform to become law will not constitute definitive proof that our efforts were a waste of time, energy and resources.67

What is certain, though, is that health care reform is now at the top of the national agenda, a place it may never be again in our lifetimes. What is also certain is that if anti-poverty legal advocates do not participate in the debate, the voices of poverty will have no chance of being heard.

Given the passion with which he approached poor people’s advocacy, particularly in the domain of health care, it is impossible to imagine that Ed Sparer would not have confronted this challenge.68 For our principles and our clients, we should do no less.

---


68 In Gordian Knots: The Situation of Health Care Advocacy for the Poor Today, Ed Sparer expressed his categorical support for unrestricted medical care for all and his belief that advocacy for health care reform on behalf of the poor, while complicated and difficult, must nonetheless be tried. Sparer, supra note 4, at 6-7, 22-23.