

About NHeLP

Imagine a United States in which all citizens suffering pain, struggling to cope with disabilities, or unable to afford preventive care such as eye exams and childhood immunizations could access medical services with ease. Imagine a public health program readily available and responsive to those for whom the system was created. Imagine families with incomes too low for private insurance and too high to be eligible for public programs being able to tap into a consistent source of health care, the same as everyone else.

These yearnings gave rise to the National Legal Program on Health Problems of the Poor—known today as the National Health Law Program. The National Health Law Program (NHeLP) is a non-profit public interest organization working for justice in health care on behalf of low-income individuals. Since our inception in a basement on the UCLA campus more than 30 years ago, NHeLP has fought many hard battles, often behind the scenes. For example, NHeLP fought for the right for people of all races and economic backgrounds to receive emergency medical care. Because of NHeLP's work in passing this law, emergency rooms in hospitals which receive federal funding cannot refuse to see a patient simply because the patient cannot pay. This is a right many now take for granted. NHeLP's work made it possible.

Today, NHeLP continues to fight for justice in health care. It has gone to court to win the right for institutionalized children to receive care in their homes. It represents low-income women trying to access reproductive services. It works on behalf of people of all races, ethnic backgrounds and nationalities to obtain culturally sensitive and appropriate care. It has given a needed voice to the underrepresented before Congress and state legislatures, in administrative hearings, and in the courts. It is due, in large part, to the persistence of NHeLP that millions of people have the health care rights they have today.

At first glance it might seem unusual that an organization devoted to health justice is concerned

with campaign finance reform. We thought so too, until we realized that justice in health care would never be achieved so long as health policy is controlled by the monied interests. That is why NHeLP launched our project, *Their Money or Your Health*.

Contacts:

Laurence M. Lavin, *Director*

Los Angeles Office: (310) 204-6010

Brendan McTaggart, *Communications Director*

D.C. Office: (202) 289-7661

NHeLP projects include:

Children's Health

David, an 8-year-old boy in Michigan, has spina bifida, lead poisoning and learning disabilities. He has never been treated for high lead blood levels or been provided with case management services. His sister suffers from seizures and has not been tested for blood lead levels. His brother, suffering from hearing loss, seizures and developmental disabilities, has received only limited services. The state's Medicaid managed care program has failed to provide David and his siblings with the services they need—despite the fact that these services are required under federal law.

April is a 16-year-old girl in West Virginia with cerebral palsy and a seizure disorder. Her family wants her to remain at home instead of in an institution, but, because her medical needs are so intense, her family needs a little bit of help with her daily care. Her doctor and the Medicaid program have approved care for April in her home, but April and her family have waited more than three years to receive it. Other children in her state have waited more than ten years after the care had been approved.

NHeLP works on behalf of David and April and thousands like them to make sure that children receive the services they need—when they need them. Through the Medicaid program, we have been able to keep children whose needs could be better and more efficiently served in their homes and communities out of institutions. We have obtained such services as substance abuse treatment for adolescents, dental services for low-income children, speech therapy for autistic children and blood level screens for at-risk children. In the past two years alone we have worked in over 42 states to ensure that children receive the services they need.

Contacts:

Jane Perkins, *Director of Legal Affairs*
N.C. Office: (919) 968-6308
Manjusha Kulkarni, *Staff Attorney*
Los Angeles Office: (310) 204-6010
Sarah Somers, *Staff Attorney*
N.C. Office: (919) 968-6771

Reproductive Rights

Maria, a young mother of seven children, pregnant with her eighth, wanted a tubal ligation but MediCal (California's version of Medicaid) would only pay for her baby's delivery in the Catholic hospital with which the state contracted. Since the hospital refused to provide a tubal ligation, Maria would have to obtain the procedure at another hospital following her delivery. Medi-Cal would pay for the second procedure, but Maria, who had to struggle just to feed her family, could not take more time off her job as a migrant farmworker. As a result, she never got the family planning services she needed.

A religious Medicaid managed care plan in New York City expands beyond its home base to

other parts of the state, taking over the Medicaid business of another health plan. The lack of sufficient and effective disclosure to Medicaid beneficiaries about the merger's impact on patients' access to reproductive health services means that women, men and their families are unable to make an informed choice about whether to stay in their health plan or choose another option. It also means that the plan's enrollees are unaware of their option to access out-of-plan family planning services.

Our campaign championing reproductive rights for women began with our 1973 amicus brief on behalf of poor women in the cases decided by the U.S. Supreme Court legalizing abortion. Today, we continue to protect and advance reproductive health services for low-income women in the face of ongoing challenges by market changes and the spread of managed care organizations.

Religious hospitals—including those that limit family planning services—are rapidly replacing or merging with their nonsectarian counterparts. Catholic institutions control more than 600 hospitals, 140,000 hospital beds, and \$40 billion in revenue. Four of the ten largest health care systems in the nation restrict family planning services because of their Catholic affiliations. As state Medicaid programs and HMOs increasingly contract with religious hospitals, women and men are losing their right to the full scope of reproductive health services. NHeLP has been active in ensuring that these rights are not lost. One example of NHeLP's work: during the 1999-2000 legislative session NHeLP attorneys worked with the California Assembly's Judiciary Committee in drafting cutting-edge legislative language requiring disclosure to Medicaid and private managed care consumers of potential restrictions on access to reproductive health services. In addition, through the work of NHeLP and the California Women's Law Center, the American Public Health Association adopted a resolution to

ensure that access to reproductive health services is maintained during mergers and affiliations with religious health systems.

Contacts:

Lourdes Rivera, *Project Director*
Los Angeles Office: (310) 204-6010
Mara Youdelman, *Staff Attorney*
D.C. Office: (202) 289-7661

Civil Rights

In 1998, a hospital in South Carolina decided not to provide epidurals to women in labor who could not speak English. Without an interpreter to communicate warning signs between the mother and physician, the hospital was concerned that an epidural gone wrong could kill the mother and her baby. Instead of hiring an interpreter, as required by federal law, the hospital simply stopped providing epidurals to these women. The hospital insisted that the practice was not discriminatory since it applied equally to all women: women unable to communicate because of a stroke or other disability were also denied services.

Shortly after NHeLP filed a complaint with the Office for Civil Rights, the hospital changed its policy. Now all pregnant women, regardless of their language, are able to receive the full scope of services. Yet, this is not an isolated example. In Oregon, a migrant worker who spoke a rare Indian dialect was committed to a state psychiatric ward for two years before it was discovered that, when diagnosed in his own language, he was perfectly sane. Another patient underwent a battery of expensive tests for angina after a physician misunderstood his complaint of “urgina”, Russian for sore throat.

Linguistic access is just one of many problems that arise in the context of civil rights. Consider the following:

According to the Health Care Financing Administration, in 1998 the Medicaid program spent an average of \$4,609 per white Medicaid recipient, \$3,297 per American Indian, \$2,836 per black recipient, \$1,925 per Asian/Pacific Islander, and \$1,842 per Hispanic recipient.

While these numbers alone do not prove discrimination, they certainly raise troubling questions, particularly when combined with other evidence. For example, the United States Commission on Civil Rights concluded in their 1999 report that “the evidence of discrimination by health care providers and insurers is overwhelming.” At the same time, the Commission found that the federal government has failed to enforce its civil rights laws in the area of health care. NHeLP is working to fill this gap.

Contacts:

Erica Berry, *Staff Attorney*
D.C. Office: (202) 289-7661
Mara Youdelman, *Staff Attorney*
D.C. Office: (202) 289-7661
Doreena Wong, *Staff Attorney*
Los Angeles Office: (310) 204-6010
Jane Perkins, *Director of Legal Affairs*
N.C. Office: (919) 968-6308

For information about the Americans with Disabilities Act:

Randy Boyle, *Staff Attorney*
Los Angeles Office: (310) 204-6010

Legal Rights of Medicaid Beneficiaries

Luke, a Colorado Medicaid beneficiary, was given less than a year to live without a life-saving bone marrow transplant. When a utilization review organization working for the state denied the transplant, Luke’s doctor immediately

appealed. Luke faced two risks: first, the decision might come down against him. Second, and of equal concern, was the risk that the decision might be in his favor, but too late to do him any good. Two months after the doctor filed the appeal, an administrative law judge decided in Luke's favor. The state, however, appealed the decision. Luke waited another month and a half. Finally, four months after the initial appeal, a second decision came down, again in Luke's favor. Fortunately for Luke, he was still alive to take advantage of it. Sadly, this is not always the case.

Donald showed up at an emergency room in Mississippi with early stage pneumonia. The pneumonia could have been treated with a \$45 antibiotic prescribed by the emergency room doctor, but the drugstore informed Donald that Medicaid would not pay for it. Mississippi, like a number of other states, limits the number of prescription drugs for non-hospitalized Medicaid beneficiaries. Donald could have appealed the limit, but he did not know he had this right. Unable to pay for the drug, Donald went home. Three days later, after becoming progressively sicker, he returned to the hospital where he accrued a bill of \$4,900 before he died. The Medicaid agency paid the \$4,900 hospital bill.

Since its inception, Medicaid has been an entitlement, promising an array of services to the most vulnerable among us. In the famous *Goldberg v. Kelly* case decided in 1970, the United States Supreme Court held that Medicaid beneficiaries have certain constitutional rights, including the right to an appeal, if medical care is denied. These rights, however, are only meaningful if Medicaid beneficiaries are informed of their rights and if the state and its agents—such as HMOs—ensure that these rights are provided.

These rights have become all the more meaningful in recent years as Medicaid agencies increasingly turn to managed care organizations to solve budgetary shortfalls. Although the majority of patients enrolled in HMOs never experience serious problems, the critical question is what happens to those who do. While managed care organizations risk their money, Medicaid beneficiaries, who cannot afford to access care out-of-plan, risk their health—and sometimes even their lives. Yet, despite the importance of these rights, there have been continued efforts to curtail them. NHeLP is working to ensure that these rights are maintained and that Medicaid beneficiaries are informed of and able to avail themselves of the full scope of their rights.

Contacts:

Jane Perkins, *Director of Legal Affairs*

N.C. Office: (919) 968-6308

Steve Hitov, *Managing Attorney*

D.C. Office: (202) 289-7661

Lourdes Rivera, *Managing Attorney*

Los Angeles Office: (310) 204-6010

Health Consumer Alliance

A retiree suffering from asbestosis needs a “breathing machine” to keep his lungs from collapsing. When his machine is stolen, he calls his HMO to get another one. The customer service representative informs him that the HMO is unlikely to provide a replacement, and gives him another phone number to call. After days of unanswered calls and busy signals, he is literally gasping for breath. Terrified, he calls San Diego's Consumer Center for Health Education and Advocacy, a member of NHeLP's Health Consumer Alliance. The next day, he gets his machine. He can breathe again. An uninsured child living in San Francisco was enrolled in Healthy Families, California's

Children's Health Insurance Program, in 1998. In November 1999, his family's income increased, and the state, using outdated eligibility guidelines, terminated the child's coverage. Staff at the San Francisco Community Health Action Project, a member of NHeLP's Health Consumer Alliance, convinced state officials that they had erroneously failed to apply new, federally-approved income guidelines for Healthy Families, and the child's coverage was restored. In addition, state staff agreed to review up to 6,000 case files to identify other California children whose coverage may have been improperly terminated for the same reason, and to restore their Healthy Families coverage based on proper income standards. Thanks to this work, numerous uninsured children around the state had their Healthy Families coverage restored.

The Health Consumer Alliance, launched by NHeLP in 1998 with funding from The California Endowment, is one of the largest health consumer assistance programs in the United States. HCA's overriding goal is to help low-income people resolve problems impeding their access to health care services and to help them become more informed activists about their legal rights. HCA's eight legal services and health policy groups from six of California's poorest counties have helped over 10,000 low-income consumers with legal advice on individual health access problems ranging from Medi-Cal eligibility to lack of health insurance and medical debt.

Contacts:

Laurence M. Lavin, *Director*
Los Angeles Office: (310) 204-6010
Lorraine Jones, *Staff Attorney*
Oakland Office: (510) 302-0445