

Pennsylvania Health Law Project (PHLP): Making Legal Representation Available to Vulnerable Groups

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Summary

Accessing quality health care has increasingly become a challenge, especially for vulnerable populations not familiar with the health coverage they have. A substantial number of the poor, disabled, and elderly have health insurance but too often are denied a medically necessary service (for example, medication, examination, and equipment). Changing government regulations, complex coverage policies, and lack of adequate legal representation have all resulted in an increasing number of people denied healthcare benefits.

The Pennsylvania Health Law Project (PHLP), headquartered in Philadelphia but with offices in Harrisburg and Pittsburgh, works to secure health rights. PHLP is especially attentive to vulnerable groups who are eligible for (or already rely on) Medicaid. Its unique model of combining free legal representation with a telephone-

based delivery system enables it to achieve statewide coverage and overcome the financial and mobility constraints of the vulnerable groups that it seeks to serve. PHLP is also increasingly working in partnership with national, state, and local organizations, policymakers, and foundations to inform policies that guide Pennsylvania's health system and highlight health care as a social justice issue. PHLP's statewide scale, targeted outreach, innovative model of telephone-based service delivery, and impact on policy-making make it a one-of-its-kind organization in Pennsylvania that is focused on the issue of healthcare coverage and service denials to vulnerable groups in the state. Its efforts are shaped by an overarching goal: the purpose of the healthcare system must be to continuously reduce the impact and burden of illness, injury, and disability, and to improve the health and functioning of the people of Pennsylvania, especially the vulnerable groups, by ensuring that they receive the coverage and services they are eligible for.

PHLP's counsel and actions have ensured a better quality of life for those faced with service denials, at a lower cost to society. Operated at an annual cost of \$1 million, PHLP's Helpline creates more than \$5 million in economic value annually, thereby delivering a social return on investment of more than 400%. Additionally, access to timely, quality health care enables clients to enjoy a superior quality of life and be more productive members of society. Support for PHLP's Helpline comes from the

Pennsylvania Legal Aid Network, the Commonwealth of Pennsylvania, and foundations and individual donations who support their overall mission.

Ruby's Story

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In 2008, Ruby Spencer's story made headlines in Pennsylvania's newspapers after the combination of no insurance, a medical mystery, and the need for an advocate left her with nowhere to go and no one to turn to. Ruby, a petite mother and widow in her early sixties, and her son were living off of \$23,000 per year, somewhat less than double the \$14,570 poverty line for a family of two living in the 48 contiguous states and the District of Columbia. Because of her income level, Ruby was ineligible to get welfare and was left uninsured — she just assumed she would never get sick. Over that summer, she noticed that her stomach was getting increasingly "thicker." Attributing the girth to getting older, Ruby thought nothing of it and continued on with her life as best she could.

But something was really wrong. When Ruby realized this, she found an ad in the paper for a physician's assistant who performed an ultrasound, concluding that Ruby was in desperate need of medical attention. Her "thick" stomach was actually a 35 cm mass — about the size of a football — that needed immediate medical attention. Ruby

was instructed to go to the welfare office to get coverage for her surgery, but once there was turned away because of her income and went to the emergency room for attention. Once at the ER, unfortunately, she again was turned away, this time after seven hours. She had patiently waited, hoping and praying that she was going to find the medical attention she so needed. But once the staff at the hospital realized she did not have health insurance coverage she was immediately sent out the door and instructed to go to a city clinic, which also turned her away. Frustrated and devastated, Ruby and her son felt they were out of options; the country's insurance system had failed them.

The Medicaid Program

The Medicaid Program

When President Lyndon Johnson signed the Medicare-Medicaid bill into law in July 1965, most of the public and media attention focused on the health coverage for the elderly (Medicare), but the architects of Medicaid packed the program with tremendous potential. It has since evolved from a welfare program that primarily paid for health services to individuals receiving cash assistance into an insurance program that fills in some of the gaps in the healthcare financing system and pays for medical and long-term care for eligible low-income American citizens and legal immigrants (U.S. Social Security Administration

2009). It principally serves the nation's most vulnerable citizens, such as children, pregnant women, individuals with disabilities, and seniors. In 2006, approximately 59 million individuals, or about 14 percent of the population, were covered by Medicaid in the United States (Kaiser Family Foundation 2009).

Medicaid is financed jointly by the federal and state governments and is administered by each individual state. The federal government reimburses states for a portion of Medicaid expenditures, with the amount of the federal contribution tied to each state's per capita income (U.S. Social Security Administration 2009). For example, the Federal Medical Assistance Percentage in Pennsylvania in 2009 is 54.39 percent, which means that for every \$100 spent on services and populations covered by Medicaid, the federal government pays \$54.39, and the Commonwealth pays \$46.61. The federal government also pays about 50 percent of the states' costs of administering the Medicaid program.

Governed by federal regulations, states are required to cover a set of mandated services for specific groups of people in order to qualify for federal matching payments. However, subject to these requirements, the states have considerable flexibility in designing their own Medicaid programs. They can broaden Medicaid eligibility by covering individuals that they are allowed, but not required, to cover (for example, women with breast or cervical cancer). Coverage can also be broadened by

raising the income and asset ceilings, expanding the set of covered services, and establishing rules governing the receipt of services (such as imposing limits on the number of services provided). The states can also determine the amounts and methods by which they pay providers for services rendered to Medicaid recipients. Furthermore, they can obtain even greater flexibility by seeking a waiver of certain provisions of Medicaid law. Waivers allow states to do things not otherwise permitted by the Medicaid statute, including both expanding and limiting the program (U.S. Social Security Administration 2009).

The Pennsylvania Medicaid Program

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In Pennsylvania, the Medicaid program is called Medical Assistance, and the Department of Public Welfare (DPW) is responsible for its management. DPW sets eligibility standards and, through local county assistance offices, conducts eligibility determinations and recertifications. DPW also establishes medical benefits, provider payments, and the level of beneficiary cost sharing (Pennsylvania Department of Public Welfare 2009). It also reimburses medical providers and makes payments to health plans. Budget considerations and laws also shape the Medicaid program in Pennsylvania. Medical Assistance provides health insurance coverage for many low-income people, offers long-term care assistance to

individuals who are 65 and older, covers individuals with disabilities, and addresses the gaps in the Medicare program. Consequently, Medical Assistance is a major source of funding for healthcare institutions. Through Medicaid, the Commonwealth is the second largest health insurer in Pennsylvania (after Blue Cross/Blue Shield affiliates). In the average month during 2009, approximately 15 percent of Pennsylvania's population was enrolled in Medicaid. Between July 1, 2008, and June 30, 2009 (the state's fiscal year), Pennsylvania's total Medicaid expenditures were approximately \$16.6 billion. Of this amount, the state paid \$7.5 billion (\$5 billion came from the general fund and \$2 billion from other sources, such as the Tobacco Fund and taxes on providers). The federal government paid \$8 billion, or 54.8 percent of the total cost of the Medicaid program in Pennsylvania (Pennsylvania Department of Public Welfare 2009).

The Problem: Rising Healthcare Delivery Costs, Complicated Coverage Policies, and Lack of Legal Representation Mean More Service Denials

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Pennsylvania's healthcare system, like that of every other state, has experienced rising costs of delivery, lack of adequate staffing, increasing numbers of uninsured, restricted choices, administrative bottlenecks, and lack of safety controls. Moreover, the recent economic downturn, combined with the rising costs of health care, has resulted in cutbacks in state budgets and healthcare delivery. For instance, both operating and overall hospital margins fell during fiscal year 2007-08 (Pennsylvania Health Care Cost Containment Council 2009: 6-8). In addition, lawmakers have proposed significant cuts to hospital payments that will greatly impact patients and communities (Baumgarten 2009).

These developments have resulted in healthcare service denials to those with insurance (private and public) who are eligible to receive health care. The actual numbers of service denials (nationally or in Pennsylvania) are not transparent, but experts such as The Medical Billing Company estimate that 25-40 percent of all claims are either delayed or denied, and 50 percent of denied claims are never refiled. PHLP staff attorney Kyle Fisher states, "We don't know the exact number of people denied services. From the volume of calls PHLP receives and the stories we hear, it's a critical issue that we address daily."

Research has shown that the uninsured and those faced with service denials are four times more likely to delay or forgo needed care than the insured, more likely to be hospitalized for avoidable conditions, and less likely to

manage chronic conditions or seek preventive care (Kaiser Family Foundation 2008a). Researchers at the Kaiser Family Foundation (2008b) have also estimated that continuous health coverage could decrease premature mortality rates by up to 25 percent among uninsured adults. Denial of healthcare benefits and the resulting lack of access to quality care are urgent issues.

The Solution: Provide Education and Legal Representation to Vulnerable Groups

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PHLP uses the law to secure health rights through direct representation, community education, and systemic advocacy on behalf of low-income Pennsylvanians. Through its two decades of advocacy, PHLP has developed a deep understanding of the interface (in eligibility, payment liability, covered services, and provider networks) among the many programs as well as the federal, state, and local laws, regulations, policy directives, and contracts that define its clients' healthcare rights.

PHLP's free legal services make it easy for consumers to seek individual representation when they are denied coverage. All Helpline callers receive careful legal counsel to help them through their problems, including verbal

advice, written materials and resources, communications with health programs and providers, and representation at various types of hearings in the healthcare setting.

Through its Helpline, newsletters, list serves, public trainings and presentations, website, brochures, and flyers, PHLP breaks down the barriers that prevent consumers from receiving health care coverage and services. The most innovative components of PHLP's model include:

- *Scale*: PHLP offers statewide coverage across Pennsylvania and assists several national-level organizations.
- *Focus*: PHLP's programs and initiatives focus on service denials to vulnerable groups such as the poor, disabled, and elderly.
- *Reach*: PHLP has developed innovative mechanisms to access its target constituents in cost-effective and focused ways.
- *Delivery*: PHLP's unique telephone-based service delivery model is tailored to overcome the financial and mobility constraints of its target constituents.
- *Impact*: In recent years, PHLP has elevated health care as a social justice issue.

Scale

PHLP's constituency includes the 2.1 million low-income Pennsylvanians on Medicaid, more than 174,000 low-income children enrolled in the Children's Health

Insurance Program, and over 54,000 adults in the adultBasic program. PHLP also receives calls from uninsured Pennsylvanians. In a typical year, more than 3,000 Pennsylvanians call PHLP's Helpline for individual counseling and representation. Federal healthcare reform will increase the needs for PHLP's services.

While PHLP's services focus on Pennsylvanians, it has been a resource for national-level organizations. For instance, PHLP assisted the National Academy of Child Advocacy in writing their Child Health Advocacy manual. On behalf of their clients, PHLP worked closely with the Children's Defense Fund, the American Association of Retired Persons, and Families USA on national healthcare issues. PHLP also worked with the National Health Law Project during the intense congressional debate over universal health insurance, to analyze the Clinton Plan from the perspective of low-income consumers. Additionally, PHLP attorneys have testified before congressional committees.

Focus

PHLP specifically focuses on issues and individuals that fall beyond the purview of other aid organizations. In its early years, PHLP identified a key shortcoming in the state's healthcare delivery system. PHLP's Executive Director Laval Miller-Wilson explains, "There were large numbers of people who had trouble accessing publicly funded healthcare services — in other words, people who

were eligible for Medicaid but were being denied medically necessary services. Other legal aid programs could get people eligible for Medicaid, but there wasn't enough legal help available to those who had a service denied, reduced, or terminated. We realized that someone needs to step in to plug this gap." PHLP is the only legal service organization that focuses exclusively on healthcare coverage eligibility and service denials.

PHLP serves customers who are both above and below the federal poverty level. By advocating for a range of clients, PHLP addresses the needs of those citizens who are ineligible for the local legal aid service agencies such as Pennsylvania Legal Aid and Community Legal Services. PHLP's Helpline benefits Pennsylvanians who find it difficult to obtain counsel for their grievances.

Additionally, such consumers are typically declined services by private legal service providers because of their low income and low profitability. The only alternative available to consumers faced with service denials has been to approach member advocates who face a conflict of interest, as the insurance companies employ these advocates.

The poor, disabled, and elderly are especially vulnerable to service denials. Their inability to afford legal representation or get around made it particularly difficult for them to access healthcare benefits that they were eligible for. PHLP's service model is specifically geared towards serving these groups. The aid PHLP offers makes

it possible for low-income groups to obtain knowledgeable counsel, while its over-the-phone legal service delivery model enables the disabled and elderly to overcome their mobility constraints. In this way PHLP has carved out a unique niche.

Reach

PHLP pioneered an effective way to reach its target constituents by convincing the Department of Public Welfare to make it mandatory to put its Helpline information on denial forms. As a result, those who get a written denial from the Medical Assistance program automatically are informed about PHLP's free legal representation for appealing the decision and receive PHLP's contact information. This is a highly effective, targeted, and low-cost way to reach those who are denied healthcare coverage and inform them about PHLP's services. Additionally, PHLP has developed several touch-points to reach and educate those who face service denials. These include in-person access through its three offices (Philadelphia, Harrisburg, and Pittsburgh), education seminars organized periodically in various counties across the state, and several print and online newsletters and publications. Miller-Wilson states that "our services are only as effective as our ability to reach those who need them. We strive to get the word out about our program, whether it be through our Helpline, website, or publications. It is encouraging to see what we have

achieved without spending a single dollar on advertising, but we are always looking to reach more and more people who are in need."

Delivery

A key feature of PHLP's model has been the organization's ability to provide legal representation over the phone.

Those denied services and who wish to appeal the decision can call PHLP's toll-free Helpline, speak with a PHLP representative, and fax over the relevant documents. PHLP attorneys then conduct legal consultations over the phone, with everything from legal arguments, case documentation, and expert testimony provided over the phone or by fax. In most instances, the entire process of providing legal representation takes place without any in-person contact between the plaintiff, PHLP attorneys, insurance agents, doctors, judges, or other healthcare experts.

PHLP's innovative approach of delivering legal aid over the phone has enabled information, education, and a helping hand to reach inaccessible geographies and customer groups. The Helpline allows PHLP to have a statewide presence and reach people in remote areas where families may not have easy access to the offices of their local legal aid service providers. Similarly, the Helpline makes it easy for the elderly and the disabled to access legal services. Says Miller-Wilson, "We are forever on the lookout for ways in which more people can access

our services. Our legal services delivery over the phone was a result of this search and continues to bring more and more people to our Helpline every day."

Impact

Impact litigation and policy influence are cornerstones of PHLP's impact strategy. Through class-action lawsuits and representation on government policy-making committees, PHLP ensures quality health care. Thus, in addition to the individual representation described above, PHLP seeks systemic change to prevent the same case from happening again and again.

PHLP has seen some early signs of success with this new strategy of litigating class-action suits. For instance, PHLP brought litigation that resulted in the addition of hundreds of modern medical procedures to Medicaid's fee schedule when Pennsylvania's Medicaid program refused to pay for over 800 procedures, including ultrasounds for pregnant women, because the fee schedule had not been updated in nearly 20 years. In the case of the ultrasounds, the state had contended that x-rays were an acceptable alternative (*Simpson v. Schweiker*). PHLP successfully litigated a class action that restored care to thousands of nursing home patients when the state tried to reduce services (*Troutman v. Cohen*). PHLP co-counseled the case that restored benefits for hundreds of poor, seriously ill persons, including payment for life-sustaining medication that the state had denied (*Lind v. Snider*). And

PHLP brought the case seeking consumer safeguards when Pennsylvania sought to impose a mandatory managed care program on 650,000 Medicaid recipients without any regulatory protections (*Hernandez v. Houstoun*).

PHLP has also made significant headway in getting its voice heard within policy-making circles. It serves as staff for the Consumer Subcommittee of the Medical Assistance Advisory Committee that is the voice of Pennsylvania's 2.1 million Medicaid recipients before the DPW, which administers the Medicaid program. In this role, PHLP analyzes every proposed regulation, bulletin, and policy initiative that has the potential to affect the delivery of health care to the poor. PHLP also facilitates dialogue between recipients and DPW, the Hospital Association, the Medical Society, and the many other healthcare providers under Medicaid. PHLP drafted the legislation that established the Children's Health Insurance Program, a Pennsylvania law that expanded health coverage for tens of thousands of low-income children. PHLP also helped the federal Health Care Financing Administration with its guide for Medicare beneficiaries, which compares HMOs offering Medicare coverage.

Miller-Wilson says, "Our grassroots presence and years of service have equipped us with a deep understanding of what the issues are, where they exist, and how they can be addressed. We want to take this knowledge and serve

as a bridge between the people and the policy makers. By seeking representation on policy-making committees or by counseling them, we want to share what we are hearing on the ground, inform government policies regarding medical assistance, and magnify the impact of our efforts."

The scale and reach of PHLP, its focus on vulnerable groups, and unique mode of contactless legal services delivery have all enabled PHLP to make a difference in the lives of those who have been denied services that they are eligible for.

Ruby's Story: The Conclusion

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While Ruby and her son felt lost and devastated, help was just a phone call away. Introduced to the struggling family through the *Philadelphia Inquirer*, PHLP attorneys used their experience and expertise to find Ruby a health insurance plan that would work. PHLP managed the entire process of ascertaining Ruby's eligibility, connecting her with the relevant insurance and medical experts, developing a plan for her, and making sure that Ruby understood the fullest benefits of the coverage she was getting. This task would have been impossible without PHLP's help. Ruby's income level made her ineligible for welfare, and private legal service providers were not interested in Ruby's case. PHLP plugged this gap by

offering its free services to Ruby and working patiently with her to meet her needs. The vast array of insurance plans offered in the United States is unfeasible to dig through without an advocate, and thanks to PHLP a solution was created that no other agency had previously been able to see. Through the plan she was eligible for, Ruby was able to get the coverage and care she needed in order to get her life back. Instead of being sick and incapacitated, Ruby now enjoys a healthy life.

Social Return on Investment

Social Return on Investment

There are hundreds more people like Ruby who are now contributing members of society because of the help and assistance they have received from PHLP. The use of PHLP's resources has the potential to save society hundreds of millions of dollars in uncompensated care.

According to the Kaiser Family Foundation, the annual cost of uncompensated care for 40 million uninsured Americans in 2004 was \$100 billion, meaning that one uninsured person equals about \$2,500 in uncompensated economic value. With an economic investment of about \$1 million annually, PHLP provides services or publicly funded insurance to about 2,000 of the 3,000 clients contacted. According to the Foundation, the cost to insure one person through Medicaid in the state of Pennsylvania is about \$4,832. Although this number when

compared to \$2,500 seems to be higher, in actuality insuring these citizens saves society a huge cost, as insuring these 2,000 people will create a cost of \$9,664,000 in compensated care, which is not a throw-out cost as it would be if these people were uninsured (Kaiser Family Foundation 2009).

A study by the Kaiser Commission on Medicaid and the Uninsured (2004: 7) estimated the annual economic value of foregone health per uninsured person to be \$2,500. By ensuring that 2,000 of its clients receive the healthcare benefits they are eligible for, PHLP generates economic value of up to \$5 million. Given that the annual cost of running the Helpline is \$1 million, PHLP's services generate an annual social return of approximately 400%.

In addition, it's been proven that people with insurance have a tendency to have stronger relationships with healthcare providers and have better health outcomes. PHLP's counsel and actions thus ensure a better quality of life for those faced with service denials, at a lower cost to society.

Towards the Future

Towards the Future

PHLP has achieved significant success in making a difference with its Helpline, but the organization has set its sights on even higher goals. PHLP staff attorney Kyle

Fisher states, "It is satisfying to see the impact we have had on the lives of those whom we have helped. But there is a lot more to be done and we realize that." Going forward, PHLP has set its sights on several objectives, including:

- Growing the number of people served through the Helpline from the current 3,000 cases per year
- Providing legal counsel not just to Medicare and Medicaid users, but also to those who use commercial insurance
- Using the platform provided by the Consumer Subcommittee of Pennsylvania's Medical Assistance Advisory Committee to drive critical changes in delivery of health care
- Positioning health care as a social justice issue and influencing policy through impact litigation and advisory roles

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