

Agents of Change:

HEALTH PHILANTHROPY'S ROLE IN TRANSFORMING SYSTEMS

The American health care delivery system is in need of fundamental change. Many patients, doctors, nurses, and health care leaders are concerned that the care delivered is not, essentially, the care we should receive. The frustration levels of both patients and clinicians have probably never been higher. Yet the problems remain. Health care today harms too frequently and routinely fails to deliver its potential benefits.

Crossing the Quality Chasm (Institute of Medicine 2001)

With these opening lines, the Institute of Medicine's Committee on the Quality of Health Care in America called for a transformation of the nation's health care system in its seminal report, *Crossing the Quality Chasm*. Although American ingenuity has profoundly improved both the quality and length of life for millions worldwide through such innovations as the polio vaccine, antibiotics, and open-heart surgery, the system is still lacking. We want a health system that is effective, empowering, equitable, efficient, people centered, and that ensures high-quality care. We observe, however, that costs are high, access is not universal, thousands die annually due to medical errors, and troubling disparities persist. The system as a whole falls short of our expectations of what it should be and how we want to be treated when we are sick and vulnerable.

Although the *Quality Chasm* report spoke primarily about issues related to the medical care system, many of the same issues affect public health. In fact, the two systems often intersect and influence the demands on one another. The balance in roles is often out of kilter, however. The goal should be to create a seamless system to protect and promote health.

This portfolio is designed to help health funders understand both the need for health system transformation and the role of grantmakers, both organizations and individuals, to act as agents of change in making that transformation happen. This framing essay and a series of accompanying articles on specific strategies make the case for what needs to be changed and the various ways foundations and corporate giving programs can both facilitate and champion those changes. A resources document provides a guide to publications and organizations that may be helpful as organizations contemplate how to engage as change agents.

Philanthropic resources are clearly dwarfed by other financing sources for health care. In 2002, when foundations gave \$2.9 billion to health projects, national health expenditures

totaled \$1.5 trillion (Foundation Center 2004; NCHS 2004). Yet health grantmakers can make a difference through the development of a clear mission and a theory of change (a notion of how the actions they take will bring about the goals they seek), and by making investments that foster system change. They must challenge the conventional wisdom and stick with organizations and issues over the long haul. No one philanthropy will change the entire U.S. health system, but collectively, by supporting system changes within institutions, communities, and fields, health funders can contribute to long-lasting changes in the way care is designed, sought, and delivered with attendant changes in health outcomes. Large or small, focused on single issues or health broadly, committed to serving specific communities or the nation, grantmaking organizations can act as agents of change for system transformation.

Addressing systemic problems requires understanding the interactions among health professionals, between providers and patients and their families, between human beings and technology, as well as the complex organizations in which health services are delivered. It demands immersing oneself in the incentives and disincentives associated with existing institutional practices, community norms, public policies, and revenue streams.

GOALS FOR SYSTEM TRANSFORMATION

There are six overarching goals for system transformation: affording access to all, promoting higher quality care, improving efficiency, empowering individuals and communities, designing services to reflect patient values and needs, and addressing the root causes of morbidity and mortality.

► **Afford Access to All** – Access refers to the ability of people to obtain care when they need it. Insurance coverage is the most important determinant of access – nearly 60 percent of the uninsured have no regular source of care. The uninsured – now totaling 45 million people – often do not receive regular preventive and primary care. Smaller proportions of the uninsured are screened for chronic diseases, and mortality rates for cancer, heart disease, and many other conditions are highest among the uninsured. The uninsured who do get care generally rely on a handful of institutions and individual providers who are willing to provide care without compensation. These safety net providers, however, typically are not organized to promote prevention, coordinate services, or spread the financial burden. Rather, systems are often

fragmented, providing uncoordinated care to the most vulnerable. In addition, safety net providers are pressured by a combination of market forces that affect their long-term viability; those who depend on public subsidies are facing great uncertainty regarding the future levels of public funding. Public health agencies are often called upon to fill in gaps in routine services at a time when they are under significant pressure to meet traditional public health needs and strengthen their ability to respond to emergencies.

Other factors also compromise the ability to obtain needed care. Over 35 million Americans – some of them insured – live in communities where there is an acute shortage of primary care providers (NACHC 2004). Many poor and rural communities lack service capacity in areas such as specialty care, mental health services, and dental care. Other structural barriers to access include lack of transportation, insufficient evening and weekend hours at many facilities, high premiums and deductibles, and institutional policies requiring payment prior to treatment. Personal barriers may include the role of culture, language and ethnicity; provider attitudes; and lack of social support, knowledge, and awareness.

Affording access to all also demands coordination among different levels of care. The health system currently functions as a set of silos with little support or communication among institutions, professionals, and levels of care. Too little attention is paid to transitions between hospital and home or to other settings such as rehabilitation hospitals and nursing homes. Patients may see several specialists, none of whom ever seem to communicate with each other. And rarely is there sufficient coordination between medical care and social services, or between health care and other systems, including child welfare and criminal justice.

- **Promote Higher Quality of Care** – Much of the national health policy debate has focused on the merits of expanding insurance coverage. While this is an important goal, an equally important goal is improving the quality of care available to both those now covered and those who would gain access to the system under federal or state policy changes.

In the Health Confidence Survey conducted annually by the Employee Benefits Research Institute (EBRI), over half of those surveyed consistently report being extremely or very satisfied with medical care received. Another one-third typically say they are somewhat satisfied (EBRI 2004). But is such confidence warranted? Between 44,000 and 98,000 Americans die annually from medical errors, surpassing the number of deaths related to car accidents, breast cancer, or AIDS. Medical errors are not simply mistakes but rather the “failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim” (IOM 2000).

What causes medical errors and, more importantly, what can be done to prevent them? As the IOM’s report stresses, there is no single solution. Medical errors occur in all sectors of health care and in the provision of all types of care. They are rarely the result of individual misconduct; rather, they are caused by system failures. The solutions can be as simple

as relabeling similarly named medications or including pharmacists on hospital rounds, or as expensive and complex as purchasing and implementing new technologies in institutional settings.

Whatever the nature of the error, the solution depends upon having a systems orientation and a commitment to creating a culture of safety. Health care is a complex industry in which many players must communicate and cooperate. The culture should identify safety as a priority and align organizational objectives and rewards. Creating such a culture also requires establishing a nonpunitive environment in which professionals can report and learn from adverse events and near misses. Institutional leaders, such as trustees and executives, need to make safety a key priority, placing it on the same level as market share and financial performance.

Improving patient safety is only one aspect of quality improvement. A system committed to health care quality also fosters practice based on evidence and ensures that the evidence is disseminated to practitioners and patients. It takes full advantage of information technology to ensure that people with chronic conditions get recommended followup, give health professionals decision support tools to help inform complex diagnostic and treatment decisions, and connect the dots among the myriad actors involved in care processes (Davis 2005). It is staffed by health professionals who are trained to be systems thinkers and change agents. These individuals must be prepared to understand the health care system as a whole, gather and interpret data on outcomes, work effectively across interdisciplinary boundaries, test new approaches rather than cling to status quo, and be good listeners (Berwick 2004).

- **Improve Efficiency** – Health spending per capita is higher in the U.S. than in any other industrialized nation at \$4,631 in 2000. The U.S. now spends 13 percent of its gross domestic product on health care compared to the median of 8.0 percent for other industrialized countries (Anderson et al. 2003). Administrative costs are far higher here in part because private insurers must build the costs of advertising, sales commissions, reserves, and profits into premiums. Churning within the system as individuals gain and lose insurance coverage from different sources also adds significant costs. And hospitals, physicians, and others bear high costs associated with the complex benefits and payment policies of multiple insurance products (Davis 2005).

Inefficiency is also reflected in a system often characterized by excess. Many people receive services for which there is no known scientific benefit. Others remain in hospitals or nursing homes with high per diem costs when care in the home would be cheaper and more conducive to healing and satisfaction. We make heroic efforts to sustain care at the end of life but pay too little attention to pain management and other aspects of palliative care.

Improving efficiency in the public health system will require a clearer definition of roles and responsibilities among agencies, coordination and partnership, and relieving

health departments from the task of filling in where the medical care system has failed. Better use of information technologies for surveillance and communication are also important strategies to improve efficiency.

- **Empower Individuals and Communities** – Health professionals alone do not hold the reins in a transformed health system. Instead patients and their families are true partners in care, making decisions about prevention, diagnosis, and treatment. Currently, lack of information and power keeps many people from being engaged in decisions about their health. A transformed system would give individuals access to their own medical information and the tools to make important choices about health behaviors, select health plans and providers, and have a say in decisions that ultimately affect their health, whether these relate to the location of a hazardous waste site or how and where they die.

An estimated 90 million Americans struggle with low health literacy: the ability to read, understand, and obtain health information to make appropriate health care decisions and follow instructions. Even patients with above-average reading skills and education report difficulty understanding insurance forms, interpreting test results, and understanding complex diagnostic and treatment options. The consequences of low health literacy are no joke; they include poor health outcomes, medication errors, preventable emergency room visits, and hospitalizations.

Empowering individuals to understand their medical conditions and facilitate their ability to make important decisions demands system-level responses. These include training physicians and other health professionals on communicating treatment details and risks to patients and their families, integrating communications techniques into health professions education, and providing incentives (or at least removing disincentives) for providers to spend time with patients. Changes are also needed to help patients communicate with providers to get answers to clinical questions, find accurate information on the Web, and better understand the content of direct-to-consumer advertising.

Patient centeredness is one of the six aims for health care quality improvement identified by the Institute of Medicine. According to the IOM, this approach provides care that is “respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions.” Patient centeredness focuses on the patient’s experience of illness, as well as the system that meets the patient’s needs. In addition to coordination and integration, and information and communication discussed above, the key dimensions of patient-centered care include respect for patients’ values, preferences, and expressed needs; physical comfort; emotional support; and involvement of family and friends in all aspects of the planning and delivery of health care (IOM 2001).

Empowering consumers means involving them in program and policy development, quality improvement initiatives, facility design planning, and program evaluation.

Moreover, providers and health systems must learn to view health information from the patient’s perspective and recognize that everyone’s knowledge of the system is different. Empowering communities means involving residents, including those who have no formal voice, in identifying the health issues that are important to them and developing the solutions that best meet those needs given community norms and strengths.

- **Design Services to Reflect Patient Values and Needs** – Currently, the health care system takes a “one size fits all” approach. But the U.S. population is diverse in many ways. Customizing care to meet the unique needs of different population groups and individual patients is a critical element of a strategy to ensure both the delivery of high-quality care and equity of health outcomes, not just greater equity in the provision of services.

Racial and ethnic disparities in health care have been well-documented since the federal government first committed itself to their elimination in 1998. Many barriers are systemic. Hispanics and African Americans are the most likely to be uninsured. Those who do enter the health care system may have difficulty in receiving culturally competent services. In part, this reflects the low supply of minority health professionals. The lack of culturally competent services fuels the perceptions that many minorities have about discrimination in the system. These perceptions can exacerbate barriers by reducing individuals’ willingness to access care that is available. Racial and ethnic minorities also face disproportionate levels of air and water pollution, a lack of green space and parks, decrepit housing and schools, and dumping of chemical waste close to their homes.

Nearly 47 million people in the U.S. speak a language other than English at home; over 21 million have limited proficiency in English. For these individuals, language and cultural barriers have real consequences including decreased access to health care, diminished patient comprehension, decreased patient satisfaction, compromised quality of care, and increased costs and inefficiency in the health care system. In its 2002 report, *Unequal Treatment*, the IOM stated that “language mismatches are a fertile soil for racial and ethnic disparities in care.”

Other populations have also been overlooked. Only 70 percent of gay, lesbian, bisexual, and transgender adults have health insurance coverage (an important facilitator of health care access) compared to 86 percent of nongay adults. Lesbians may be less likely than the general population of women to get early intervention and preventive services such as regular Pap smears or breast examinations. Moreover, in a 2002 survey of gay, lesbian, bisexual, and transgender individuals, nearly half of those responding said they had not discussed their sexual orientation with their provider. Lack of disclosure can limit the receipt of services. For example, many providers underestimate the extent to which lesbians may be at risk for sexually transmitted diseases and other gynecological infections. It also limits providers’ understand-

ing of all the factors affecting their patients' health (Harris Interactive and Witek-Combs Communications 2002; The Medical Foundation 1997).

The disabled are also often neglected by the health care system. People with disabilities frequently experience physical, financial, and attitudinal barriers to care. Insured people with disabilities are four times more likely than their nondisabled peers to need equipment and services not covered by their health insurance (National Organization on Disability 2004). They need health professionals who can understand the experience of disability in order to obtain the type of care that lets them live full and productive lives.

- **Address the Root Causes of Illness** – Finally, system transformation must involve a reorientation of resources towards prevention and the social determinants of health. The development and progression of many chronic diseases are linked to unhealthy behaviors, particularly cigarette smoking and use of other tobacco products, poor diet, and lack of regular exercise. Behavioral change models can be effective in addressing these risk factors if they help people develop new skills, provide comprehensive and sustained interventions, and ensure access to social and other supports that help people maintain behavioral changes. Similarly, changes in product design and public policy could prevent many injuries that now add substantially to the nation's health care bill as well as to human suffering.

Developing strategies to address the root causes of illness

is a complicated task. In addition to work to reduce unhealthy behaviors, it demands thoughtful attention to the other factors that affect health including: the condition of the environments where people live and work, including the quality of the air and exposure to other environmental hazards; and the condition of the social environment, including racism, poverty, economic opportunities, and the availability of safe and affordable housing. These are tough issues, requiring major commitment of resources, sustained attention, and partnerships with those outside of the health system. Work is also needed to strengthen the public health infrastructure, with attention to its organizational capacity, information and data collection systems, and workforce.

LOOKING AHEAD

The IOM's Committee on the Quality of Health Care in America was not sanguine on the prospects for revolutionary changes in the U.S. health system. But their words provide reassurance that the task is not only worth engaging but eminently do-able: "American health care is beset by serious problems, but they are not intractable. Perfect care may be a long way off, but much better care is within our grasp. The committee envisions a system that uses the best knowledge, that is focused intensely on patients, and that works across health care providers and settings...achieving such a system is both possible and necessary" (IOM 2001).

This article is part of GIH's portfolio, Agents of Change: Health Philanthropy's Role in Transforming Systems. Each article focuses on an approach grantmakers are using to promote systemic or social change. The entire portfolio is available on GIH's Web site www.gih.org.

SOURCES

- Anderson, Gerard F., Uwe E Rehnardt, Peter S Hussey, and Varduhi Petrosyan "It's The Prices, Stupid: Why The United States Is So Different From Other Countries," *Health Affairs* 22 (3): 89-105, September 2003.
- Berwick, Donald M., *Escape Fire: Designs for the Future of Health Care* (San Francisco, CA: Jossey-Bass, 2004).
- Davis, Karen, "Transformational Change: A Ten-Point Strategy to Achieve Better Health Care for All," in *2004 Annual Report* (New York, NY: The Commonwealth Fund, 2005).
- Employee Benefits Research Institute, "Health Confidence Survey. 2004 Results," <<http://www.ebri.org/hcs/2004/index.htm>> accessed on January 24, 2005.
- Foundation Center, *Foundation Giving Trends: Update on Funding Priorities* (New York, NY: 2004).
- Harris Interactive and Witek-Combs Communications, "Fewer Than Half of All Lesbian, Gay, Bisexual and Transgender Adults Surveyed Say They Have Disclosed Their Sexual Orientation to Their Health Care Provider," press release, December 17, 2002.
- Institute of Medicine, *Crossing the Quality Chasm: A New Health Care System for the 21st Century* (Washington, DC: National Academy Press, 2001).
- Institute of Medicine, *To Err is Human: Building a Safer Health System* (Washington, DC: National Academy Press, 2000).
- Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities* (Washington, DC: National Academy Press, 2002).
- National Association of Community Health Centers, *A Nation's Health at Risk: A National Report on America's 36 Million People Without a Regular Healthcare Provider* (Washington, DC: 2004).
- National Center for Health Statistics, *Health, United States, 2004* (Washington, DC: U.S. Department of Health and Human Services, 2004).
- National Organization on Disability "Access to Health Insurance," <<http://www.nod.org/content.cfm?id=135>>, accessed on January 5, 2005.
- The Medical Foundation, *Health Concerns of the Gay, Lesbian, Bisexual, and Transgender Community*, 2nd edition (Boston, MA: June 1997).