

# Knowledge to Action

critical health issues and the work of health philanthropy over 25 years





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With its 2007 annual meeting, Grantmakers In Health celebrates 25 years of service to the field of health philanthropy. As part of our ongoing mission to help grantmakers improve the health of all people and improve the field's effectiveness, we will take time out to reflect on the past with the goal of creating momentum for the future.

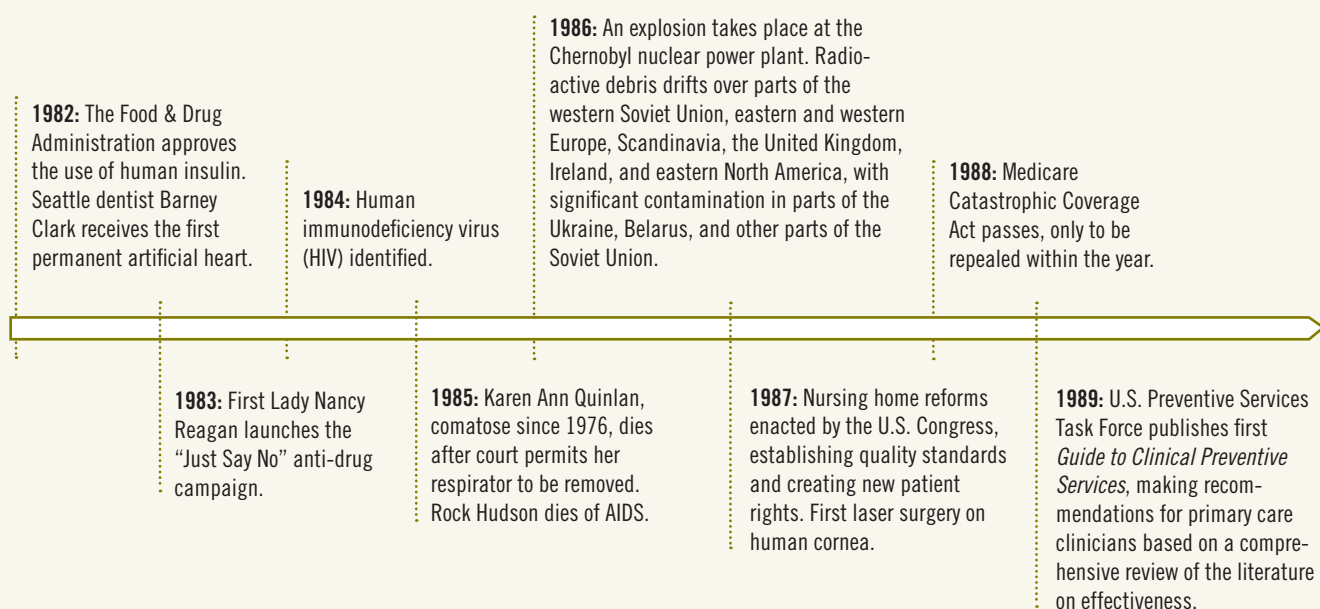
## 2007 marks Grantmakers in Health's 25th year of service to the field of health philanthropy.

As we look back at the past two and a half decades, we can be rightfully proud of the progress made in health and medicine. And if we think in terms of dollars, infrastructure, and

technology, our health system has become the richest, most extensive, and advanced in the world. Yet there is strong evidence that the U.S. lags behind most other industrialized nations on critical measures of health status. Our system often does not deliver the care that people need. In fact, it too frequently harms them. It is myopic in its focus on individual care rather than the public's health. It rations services, not through explicit policy decisions, but by income, race, and immigration status. It emphasizes treatment over prevention. And it leaves millions of people disenfranchised while it wastes billions of dollars on unnecessary care.

Since the early 1980s, we've seen health care costs increase, smoking among youth decline, mental health services move from inpatient

### HEALTH MILESTONES 1982—2006



to outpatient settings, and access to care remain a constant theme. We now must confront how the retirement of the baby boom generation will affect the health care system and how to prepare and respond to

and beyond? How can we be most effective in translating what we've learned into action?

Much of what grantmakers enjoy about our annual meetings comes from the interactions they have with peers, the all-too-rare opportunity to take a time out from the pressures of the office to share and learn with colleagues, but also to think critically about their own work. Yet what many find is that the energy and excitement they take away from that experience dissipates quickly upon returning home. This volume thus provides a companion to the meeting experience, providing a lasting resource on the themes and specific lessons learned through plenaries, breakout sessions, site visits, and networking opportunities.

## What have we learned about health, health care, and the work of health philanthropy? How can we be most effective in translating what we've learned into action?

emerging threats to public health. What have we learned about health, health care, and the work of health philanthropy? What are the lessons from the projects we've funded, the grantees we've worked with, and the experiences of our peers and colleagues within the health sector

**1990:** The federal Human Genome Project gets underway. Ryan White, an Indiana teenager whose struggle with HIV/AIDS and against AIDS-related discrimination helped educate the nation, dies.

**1992:** The National Academy of Sciences reports on the emergence of new and virulent diseases that are resistant to antibiotics.

**1994:** The Clinton Administration's health care reform plans fizzle.

**1996:** Personal Responsibility & Work Opportunity Reconciliation Act ends traditional welfare, making major changes in financing structure of cash assistance and work programs. Congress passes the Mental Health Parity Act of 1996 requiring that annual and lifetime dollar limits on mental health care not be stricter than for other medical care.

**1991:** Magic Johnson reveals that he is HIV positive.

**1993:** The Environmental Protection Agency links secondhand smoke to 3,000 cancer deaths annually.

**1995:** Varicella (chickenpox) vaccine licensed.

**1997:** The State Children's Health Insurance Program (SCHIP) established to provide health coverage to low-income children who live in families with income or assets above Medicaid eligibility levels, yet whose parents cannot afford to purchase private insurance.

Given the breadth of the work of health philanthropy, it is near impossible to fully capture the range of strategies tested and lessons learned across so many areas of endeavor. In choosing the health issues to be covered in-depth, we chose to focus on those where GIH has a significant body of work. We also sought to weave in related issues where possible. We have tried to capture the work of both large funders and small, those working at the local and national level, and those whose focus ranges from direct service delivery to funding academic research and everything in between. Those included here are illustrative of the work of many funders working to make a difference in the health of all people. All told, we have included information of over 50 different grantmaking organizations.

The authors of this book are GIH staff members Elise Desjardins, Brent Ewig, Delia Reid, Osula Rushing, Anne Schwartz, and Kate Treanor. Todd Kutyla, Lauren LeRoy, and Anne Schwartz served as editors. Our thanks to the many health grantmakers who shared their stories with us.

**1998:** Attorneys general and other representatives of 46 states, the District of Columbia, Puerto Rico, and several U.S. territories sign an agreement with the five largest tobacco manufacturers that provides funds to states, allows removal of tobacco billboards, and prohibits targeting youth in tobacco marketing and promotion.

**2000:** *Healthy People 2010* objectives released. Institute of Medicine publishes *To Err is Human*, focusing national attention on medical errors and patient safety.

**2002:** New Freedom Commission convened to conduct a comprehensive study of gaps in the nation's mental health system.

**2004:** PEPFAR, President Bush's Emergency Plan for AIDS Relief, begins first round of funding.

**2006:** Massachusetts enacts law to provide nearly universal health care coverage to state residents.

**1999:** National Center for Health Statistics reports that more than 50 percent of U.S. adults are overweight, and 1 in 5 adults are obese.

**2001:** The September 11th terrorist attacks and anthrax attacks shake Americans' sense of invulnerability. Both events bring into focus the fragility of the nation's public health system.

**2003:** Passage of the Medicare Prescription Drug, Improvement, and Modernization Act creates a new prescription drug benefit for the nation's elderly and disabled. World Health Organization issues first alert for SARS.

**2005:** Hurricane Katrina devastates the Gulf Coast region, drawing attention to income and health inequalities, as well as continuing weaknesses in emergency preparedness at the local, state, and federal levels.



# The Field of Health Philanthropy



# The Field of Health Philanthropy

A priority for many of this country's first philanthropists, health grantmaking has become one of the largest areas of giving, second only to education. Over the past 25 years, the field has experienced a significant period of growth and change with longstanding funders refocusing their efforts, new donors entering the scene or shifting their sights to health issues, the emergence of foundations created after the conversion of nonprofit health organizations, and new issues dominating discussion within the field.

## The Early Years

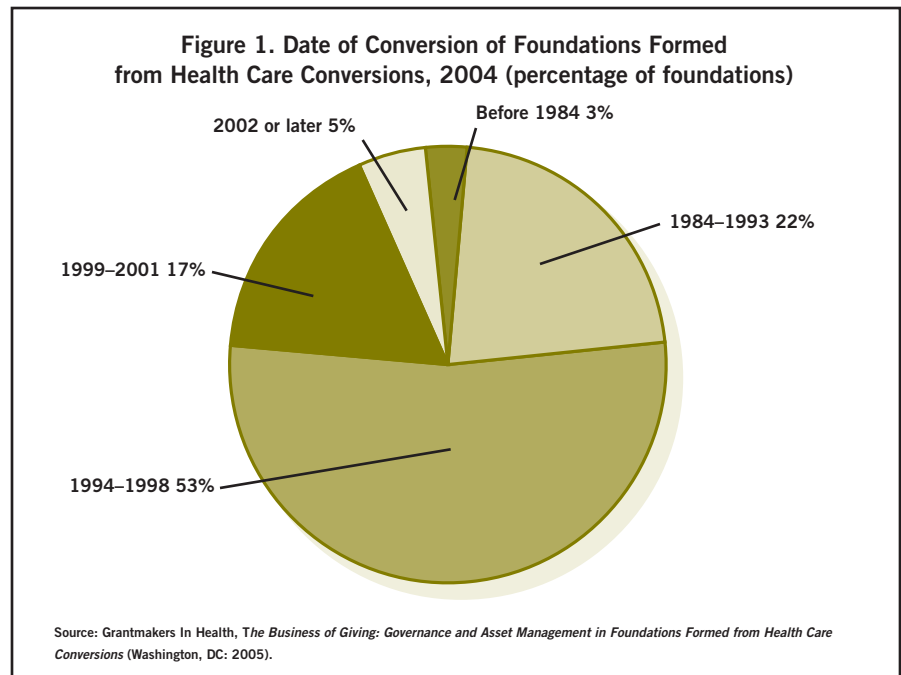
Health philanthropy as we know it today has its roots back in the late 19th and early 20th centuries. As Terrance Keenan noted in his 1992

**The work of early health philanthropists set a tone that continues today: focus on a few strategic goals, look at the root causes of social ills, and foster innovation to meet the health needs of the underserved.**

monograph, *The Promise at Hand: Prospects for Foundation Leadership in the 1990s*, "[Foundations] are the largest single source of private developmental capital in this country for improving our knowledge base and the organizational and financing structures of health and medical care. They have performed this function since the turn of the 20th century when organized philanthropy first materialized as a force for the systematic application of private wealth for the public good." America's industrial giants turned philanthropists, including John D. Rockefeller, Sr., Anna Harkness,

W.K. Kellogg, and James Buchanan Duke, devoted substantial resources to health. Their work at home and abroad set a tone that continues today: focus on a few strategic goals, look at the root causes of social ills, and foster innovation to meet the health needs of the underserved. Health became one of the Rockefeller Foundation's initial priorities when an advisor to John D. Rockefeller, Sr. argued that "disease is the supreme ill in human life." The foundation's first grants, awarded in 1913, supported the American Red Cross, clinical and public health education at The Johns Hopkins University, the Rockefeller Sanitary Commission for Eradication of Hookworm Disease, and research on malaria and yellow fever (The Rockefeller Foundation 2006). Another visionary, Anna Harkness, one of the first women to establish a foundation, set up The Commonwealth Fund in 1918 with the mandate to "do something for the welfare of mankind." The fund's early work helped develop rural hospitals with high standards of care, establish new medical schools to address physician shortages, and bring health care to underserved communities (The Commonwealth Fund 2006). One of the first projects of Will Keith Kellogg's new foundation, created in 1930 to make his giving more focused and purposeful, was the Michigan Community Health Project which targeted education and public health in rural communities (W.K. Kellogg Foundation 2006).

Other philanthropists joined ranks at mid-century. In 1948, shipbuilder Henry J. Kaiser created a family foundation that bears his name. In 1971, Robert Wood Johnson, found-



er of Johnson & Johnson, the health and medical care products conglomerate, left nearly all of his fortune to the Robert Wood Johnson Foundation, becoming the nation's largest philanthropy devoted to improving health and health care.

### Health Conversion Foundations Join the Scene

Perhaps the most profound change in health philanthropy in the past 25 years is the emergence, in the 1980s and 1990s, of a new crop of foundations created with the assets from nonprofit health institutions as opposed to those of wealthy individuals (Figure 1). Changes in the health care delivery system, including the demand for capital by nonprofit organizations and the emergence of a for-profit health care industry, led to an unprecedented number of nonprofit health organizations converting to for-profit status. A major outgrowth of those conversions was the creation of new philanthropic

foundations—often referred to as health care conversion foundations—which were endowed with the charitable assets generated by conversions and concentrated their funding on health-related activities in their communities. Over two decades, over 170 of these new foundations, worth more than \$13 billion collectively, joined the field of health philanthropy (GIH 2005). “Conversions not only affect the health care system, they also represent the largest redeployment of charitable assets in history,” said observer Dennis Beatrice (Nonprofit Sector Research Fund 1999).

The entry of so many new foundations into health philanthropy attracted attention from policymakers, the press, and the public. Policymakers and consumer advocates wanted to know whether these new foundations were contributing to their communities at a level commensurate with the public benefit

provided by the previous nonprofit organization. According to Community Catalyst (2005), “conversion foundations have a uniquely public character and a resulting responsibility to ensure participation by the community they serve.” Researchers wanted to know what impact the foundations had on their communities and whether their grantmaking and other activities differed from older foundations or foundations formed in other ways. Localities where health care conversions were being considered often sought information about the activities of new health foundations to help them assess the potential positive and negative effects of a proposed conversion.

As regulators, advocates, community representatives, and other foundation leaders looked on, new health foundations across the country got to work. Under increased scrutiny and high expectations, these new funders were compelled to be deliberate in how to structure their operations and implement grantmaking programs. They took time to learn from others in philanthropy, engage thought leaders and the public, conduct community needs assessments, test new models for grantmaking, and communicate actively about their process and results.

Reflecting on the first 10 years of grantmaking by The California Endowment, the nation’s largest conversion foundation, president and CEO Robert Ross commented, “Looking back over the early years of the Endowment is akin to watching an oversized toddler taking his or her first steps, inevitably falling over and bumping into furniture—

## The entry of so many new foundations into health philanthropy attracted attention from policymakers, the press, and the public.

but instinctively learning from the falls to walk with skill and assurance” (Ross 2006).

The experiences of new health foundations have resonated throughout the field, particularly as they tackled difficult issues of community engagement, communications, and evaluation. In developing their mission, purpose, and structure, new health foundations often went on the road, listening to stakeholders and recording community residents’ needs, expectations, and ideas for the foundation’s work. Some foundations created ongoing mechanisms for community participation in their work using ad hoc committees, surveys, and regular town hall meetings to inform program design, help with grant review, and provide feedback. Their performance led one long-time foundation critic to recently comment, “strikingly, the foundations that have done the most, albeit still in baby steps, toward involving constituents in their grantmaking decisions have been, in terms of big dollars, the health conversion foundations” (Cohen 2006).

Born under scrutiny, many new health foundations have placed a strong emphasis on communications to make sure that potential grantees, the press, policymakers, and others understand who they are and what they are seeking to accomplish. Under pressure to show that they are using their resources wisely, conversion foundations have worked

closely with grantees to develop outcome measures and evaluate the results of their own work. Early on, effective governance was also a theme as executives learned that trustees of new philanthropies, often holdovers from the converting hospital or health plan, needed orientation and training about their roles and responsibilities. With mandates to have boards representation from the communities they serve, the foundations looked for new ways to bring those voices to the decision-making table.

Many of the issues these new foundations grappled with were not unique. But the conditions under which these foundations were established and the heightened public interest that accompanied their emergence stimulated broader action to strengthen philanthropic practice in engaging communities, communicating about their work, and assessing their performance. As a result, health grantmakers have often been leaders in efforts to strengthen how philanthropy conducts its work.

### A New Age of Giving

In 2000, Bill Gates, chairman of Microsoft and his wife, Melinda French Gates, created the world’s largest private foundation with an endowment now valued at \$31.9 billion and expected to grow with the infusion of assets from Warren Buffett, CEO of Berkshire Hathaway. The Gates Foundation’s global health program now dwarfs the foreign

aid contributions of many nations, giving away about \$800 million annually. Other public figures, including Lee Iacocca, Michael and Susan Dell, and Lance Armstrong, have also created philanthropies focused on health issues. The conversion phenomena also continues; although the heyday of large health plan conversions may be over, foundations continue to be formed from hospital conversions.

When we look across health grantmaking in 2007, we see incredible diversity in the field—types of foundations and donors, assets, geographic funding focus, health priorities, and communities and populations served. Health funders take the form of independent foundations, operating foundations, and public charities; community foundations also have growing health portfolios. Corporate health philanthropy continues to make its mark, moving from matching employee charitable contributions and making product donations to creating strategic grantmaking portfolios. Pharmaceutical companies, such as Pfizer and Merck, are tackling tropical diseases overseas and health literacy at home. Health insurance companies, including the many Blue Cross Blue Shield plans, are actively engaged in giving to improve access to care and the quality of health care services, as well as supporting grassroots service delivery, advocacy, and organizational capacity.

Looking back to 1980, foundations gave \$657 million in health grants, comprising 20.2 percent of all giving (Dooley et al. 1983). That share dipped in the 1990s when health accounted for roughly 17 percent of

grant dollars, but has since rebounded. Health now accounts for 22.3 percent of all giving, second only to grants in education, at nearly \$3.5 billion annually (Foundation Center 2006b). The focus of funding has shifted over the past two decades, however. In 1980, funding was heavily concentrated on hospital construction, biomedical research, and physician education (Dooley et al. 1983). While hospitals, medical care, and biomedical research continue to dominate, public health now accounts for a similar proportion of health grant dollars (Foundation Center 2006b).

### Strategic Choices for Achieving Goals

Despite the field's diversity, all funders struggle with the challenge of making the best use of their resources. Different operational modes have taken hold, including responsive grantmaking, initiative-based grantmaking, foundation-

operated programs, capacity building, and convening. The following illustrative examples show how health foundations have adopted various strategies to achieve the goal of improving health.

### RESPONSIVE GRANTMAKER

The California Wellness Foundation (TCWF) was established in 1992 as a result of Health Net's conversion from nonprofit to for-profit status. A private, independent foundation with assets of \$1 billion located in Woodland Hills, California, its mission is to improve the health of the people of California by making grants for health promotion, wellness education, and disease prevention. The California Wellness Foundation's initial grantmaking strategy was initiative-based grantmaking—the foundation developed specific program ideas and objectives and then selected grantees to implement them. Yet, in 2000, after a two-year strategic planning process, the

### WHAT MAKES FOR A GOOD FOUNDATION?

Components of good practices in building and maintaining a foundation created after the conversion of a nonprofit health organization include:

- a planning process that engages, in a substantial way, the perspective and expertise of consumers and health care advocates;
- a mission statement that dedicates the assets for purposes similar to the converting nonprofit;
- criteria that ensure the governing board will have the appropriate expertise and experience and will be reflective and representative of the diversity of the community served;
- a board selection process that is deliberate, open, and accessible to health care consumers and the broader public, and is free of any conflict of interest; and
- an organizational structure that is open and accountable to the public, coupled with practices that offer many opportunities for community input and ongoing, meaningful community involvement.

Source: Consumers Union of U.S., Inc. and Community Catalyst, *Building and Maintaining Strong Foundations: Creating Community Responsive Philanthropy in Nonprofit Conversions* (San Francisco, CA: 2004).

foundation's board approved a new grantmaking strategy—a responsive grantmaking program. “[Previously], our initiatives focused on ideas that originated at the foundation. We regarded the organizations chosen to implement those ideas as secondary in importance to the goals of the initiatives. In our new approach, we start with organizations whose mission is to improve the health of underserved populations in California. Our conversation with them begins with their mission and how our funding might help them best fulfill it,” stated Gary Yates, foundation president and chief executive officer. “We believe this philanthropic approach is allowing the Foundation to be more flexible in its funding strategies and better able to support the essential efforts of nonprofits working to improve the health of underserved Californians” (Yates 2006). Realizing that the valuable work accomplished by nonprofit organizations is rooted in their ability to meet basic organizational needs, the foundation prioritizes eight issues for funding (diversity in the health professions, environmental health, healthy aging, mental health, teenage pregnancy prevention, violence prevention, women's health, and work and health) and then encourages requests for core operating support under each area. The California Wellness Foundation also focuses on four cross-cutting themes—underserved populations, sustainability, leadership, and public policy—to further build their grantmaking into one cohesive program.

#### CAPACITY BUILDER

With assets of \$70 million, the Foundation for Seacoast Health is

one of the largest private foundations in New Hampshire. Created in 1984 with private endowments and the proceeds of the sale of the Portsmouth Hospital franchise to Hospital Corporation of America, the foundation is charged with two primary responsibilities: monitoring Portsmouth Regional Hospital to ensure that Seacoast citizens get high quality medical care in a first rate facility at competitive prices and to use the foundation's resources to fund health-related programs for citizens in the Seacoast communities of Portsmouth, Greenland, Rye, Newington, New Castle, and North Hampton, New Hampshire; and Kittery, Eliot, and York, Maine. In the mid 1990s, the foundation was confronted with the decision of whether to buy or build a new home for a foundation-funded program that was in desperate need of a new facility. The foundation soon discovered that several other grantees were in a similar situation, including a community health center, a preschool program for learning-delayed youngsters, and the community's Head Start program. “What was originally a crisis for space-hungry nonprofits turned into a unique opportunity for the foundation:

Different operational modes have taken hold, including responsive grantmaking, initiative-based grantmaking, foundation-operated programs, capacity building, and convening.

how to address the inefficiency of providing health, educational, and social services to many of the same children and families at different sites,” said Susan Bunting, presi-



dent and CEO of the Foundation for Seacoast Health. The foundation decided to develop one large facility to house those agencies and others, with the caveat “that they work and plan together to reduce duplication of services, increase resource sharing, and maximize program effectiveness” (Bunting 2001). The Community Campus is now home to the foundation as well as health-related nonprofits and public programs that use common intake and outcome assessment tools and personnel procedures.

#### INITIATIVE-BASED GRANTMAKER

The Colorado Trust was established as an independent foundation in 1985 and endowed with \$191 million from the proceeds of the sale of PSL Healthcare Corporation; it now holds over \$450 million in assets. The trust utilizes an initiative-based grantmaking strategy to focus on advancing the health and well-being of the people of Colorado. The grantmaking style blends together several elements—researching and understanding the needs of the people of Colorado, creating a strategy to meet those needs, making grants, evaluating effectiveness and impact, and strategically communicating what the foundation learns—to bring about defined changes or improvements. The process begins with the foundation learning about current and emerging issues faced by Colorado citizens and communities. Staff then design initiatives and obtain approval from the board. Potential grantees are then asked to respond to a formal request for proposals. A key feature of all trust initiatives is the offering of technical assistance and networking opportunities for all grantees. The trust

evaluates all of its initiatives with the goal of learning for itself, sharing knowledge among grantees and others, and creating mechanisms for program sustainability.

By taking this approach, rather than considering unsolicited proposals, The Colorado Trust has found that it is able to support grantees over longer-than-usual periods of time and maximize their ability to bring about positive, sustainable change. For example, in 2000, the trust began its five-year, \$11 million After-School Initiative, with the goal of developing and supporting after-school programming strategies that capitalize on strengths of young people, families, and communities. The initiative provided funding, training, and tailored technical assistance services to 32 grantee after-school programs across the state. An independent evaluation of the initiative showed that it served more than 12,000 youth. Youth reported improvements in their positive life choices, sense of self, core values, cultural competency, life skills, community involvement, and academic success as a result of participating in the after-school programs. The initiative, in part, also led to the development of the Colorado After School Network, a statewide network that provides ongoing support for after-school programs. Current initiatives include increasing the number of health care professionals, providing equality in health care, strengthening immigrant integration, preventing suicide, advancing mental health care, supporting early child development and care, and preventing bullying.

#### FOUNDATION-OPERATED PROGRAMS

In 1995, St. Luke’s Health Initiatives (SLHI) sold all of its hospital facilities to OrNda HealthCorp. Since selling its hospital facilities, SLHI has become a public foundation focusing primarily on Maricopa County, the greater Phoenix, Arizona metropolitan area. Over the years, the foundation used its assets to fund charitable activities and engage in public education activities. The leadership realized, however, that the foundation could offer more than general grants; they could become directly involved with the issues and the individuals. “In this way, we evolved into a quasi-operating foundation; a strategic blend of community grantmaking with SLHI-driven and produced policy analysis and research, community engagement and technical assistance, and targeted community development projects,” noted foundation CEO Roger Hughes in *Beyond Grantmaking: On Attraction, Promotion and Resilience*. “Grants became one of several means to effect our mission, and not always the first or best choice, given shifting conditions and opportunities on the ground.” One of the foundation’s main ventures has been creating and running Arizona Health Futures, SLHI’s health policy and education arm. Its purpose is to conduct relevant and timely policy research; provide balanced, nonpartisan information and perspectives on health issues in Arizona; serve as a convener and forum for the critical discussion of those issues in an independent and policy-neutral setting; and translate good ideas into action through the support of community-based initiatives.

In the early 1990s, trustees of The Henry J. Kaiser Family Foundation stopped usual business to reconsider how the foundation could use its resources (some \$30 to \$40 million annually) to maximum effect. With approximately \$600 million in assets, the trustees decided that distributing 5 percent in grants to a huge health care system was “not a recipe for playing a special national role.” “Nor were we large enough to try to change things through direct action—by undertaking large, multisite demonstration programs; supporting large numbers of community organizations; or bankrolling the development of new independent national institutions, as some larger foundations do,” noted Drew Altman, president and CEO in his 1998 message, *The Kaiser Family Foundation’s Role in Today’s Health Care System*. The leadership saw the need for an independent, trusted, credible source of information to provide analysis, balanced discussion, and expert commentary on the major health care issues facing the nation. To fill this void, the Foundation has changed its tax status from a private foundation to an operating foundation, seeing its essential role as providing research and information for policymakers, the media, the health care community, and the general public.

### Moving Forward for Health Grantmakers

Against a backdrop of the technology and Internet booms of the 1990s, the year 2000 and Y2K, the 9/11 terrorist attacks, natural disasters, critical health issues facing our society, and heightened scrutiny of the nonprofit sector, health funders have been challenged to keep their

balance over the past few decades. In the years ahead, health foundations will continue to face significant challenges.

### ACCOUNTABILITY AND TRANSPARENCY

In an effort to rebuild public trust in the corporate sector, the Sarbanes-Oxley Act was put into place in 2002, requiring publicly traded companies to follow new standards in financial transactions and audit procedures. As policymakers looked for ways in which the law could apply to the nonprofit sector as well, funders and nonprofits have been urged to examine their own practices and put new policies in place (Independent Sector 2006). “The only way for foundations to protect

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the freedom, creativity, and flexibility they now enjoy – and which they need if they are to serve society to their fullest potential,” argues Duke University professor Joel Fleishman (2007), “is to open their doors and windows to the world so that all can see what they are doing and how they are doing it.”

Foundations have made some first steps with about one-third of the nation’s largest foundations making changes in their policies in such areas as conflict of interest, review

of tax returns, and establishing audit committees (Center for Effective Philanthropy 2005).

#### DIVERSITY AND CULTURAL COMPETENCY

As the racial and ethnic makeup of the U.S. population changes, foundations must work to ensure that their boards and staff reflect this diversity. Over the last 20 years, philanthropy has evolved from a field dominated by white men to one where two-thirds of the professional staff are women, and people of color make up a fifth of all staff. These changes, however, have not carried over to foundation boards. Men comprise 69

the measures. Based on a series of interviews with foundation leaders, the Urban Institute found that “all too often, foundations have failed to institutionalize a process to establish standards of effectiveness and regularly assess themselves in relation to these standards...foundations need to clarify and specify what they believe it means to be effective. There are multiple approaches to effectiveness, and foundations need to choose one that is appropriate for themselves—but they must be clear about the choice they make” (Ostrower 2004).

#### LEADERSHIP

Philanthropy and the rest of the nonprofit sector are on the precipice of a leadership crisis; many of today’s foundation leaders are likely to catch the retirement wave that will rise with the baby boom during the next 10 years and staff among nonprofits are being stretched to a breaking point. In *Daring to Lead*, a joint research project by CompassPoint Nonprofit Services and the Meyer Foundation, nearly 2,000 nonprofit executive directors in eight cities were questioned about their current and future work in the nonprofit sector. Results showed that “three quarters don’t plan on being in their current jobs five years from now, and nine percent are currently in the process of leaving. Frustrations with boards of directors and institutional funders, lack of management and administrative support, and below-market compensation add stress to a role that can be challenging even in the best circumstances” (Bell et al. 2006). Health foundations cannot achieve their goals without effective staff and leaders within both their own

### Grantmakers continue to grapple with how best to measure a foundation’s overall effectiveness and gauge its impact.

percent of foundation boards, and 89 percent of board members are white. Moreover, minorities continue to be greatly underrepresented among CEOs. Men of color appear to be having greater success than minority women; but, in both cases, they are concentrated in certain types of foundations and less frequently reach higher-level positions (Joint Affinity Groups 2002).

#### EFFECTIVENESS AND IMPACT

Grantmakers continue to grapple with how best to measure a foundation’s overall effectiveness and gauge its impact. Grantmaking takes place in a complex social environment and is rarely the only factor affecting how things turn out. Capturing what truly matters, however, and figuring out what can inform future work often requires looking deeper into the stories behind

organizations and those they fund; efforts to provide nurturing, support, and professional development for existing and potential leaders must be increased.

## Moving Ahead

Over the past twenty-five years, health grantmakers have learned that funding change is hard and requires the long view. As Steven Schroeder, former president of Robert Wood Johnson Foundation stated, “maintaining a long perspective while being battered by the winds of change will take all the knowledge, imagination and nerve we can muster.” Funders have also been leaders in a reconceptualization of the role of philanthropy from, in the words of Annie E. Casey Foundation CEO Doug Nelson, “funder of charitable transactions or the patron of civic and cultural institutions to seeing themselves as agents or catalysts for social, economic, cultural, and scientific progress” (Foundation Center 2006a). Accordingly, The California Endowment’s Robert Ross recently challenged colleagues to lead and drive change by respecting community-driven ideas, adopting a broad, holistic view of health, funding policy advocacy, relying on partnership and collaboration, building community capacity, and recognizing the importance of foundation tools beyond grants (Ross 2006).

The work ahead is daunting but the field can make a difference. Over a decade ago, Terrance Keenan, who inspired the Grantmakers In Health leadership award that bears his name, articulated for health funders the special capacities they enjoy to serve the public welfare: freedom

to invest in innovation; freedom to fail; time to anticipate the future; unequalled flexibility and speed; the freedom to persist; the power to pioneer new fields of knowledge; the freedom to develop new institutions or institutional systems for confronting major needs; and the ability to convene (Keenan 1992). Armed with the insights and lessons the past few decades of work provide, the field is poised to seize this tremendous opportunity to improve the health of all people.

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# Fast Facts

## Funding Trends

There are close to 68,000 foundations in the United States (Foundation Center 2006a).

Giving by the nation's grantmaking foundations grew 5.5 percent to \$33.6 billion in 2005, following two consecutive down years (Foundation Center 2006a).

By region, the West posted the fastest growth in giving in 2004 and surpassed Southern foundations by share of overall giving for the first time on record (Foundation Center 2006a).

Foundations in the Northeast, Midwest, and South favored education in 2004; funders in the West made health a priority (Foundation Center 2006b).

Health's share of overall giving reached a record 22.3 percent in 2004, helped by a \$750 million ten-year grant from the Bill & Melinda Gates Foundation (Foundation Center 2006b).

The largest percentage of grant dollars in health supported public health (35 percent), followed by hospitals and medical care, (21 percent); medical research, (15 percent); and specific diseases, (13 percent) (Foundation Center 2006c).

The health field still receives most of its funding in the form of program support. In 2004, 63.7 percent of all grants for health represented program support, compared to 46.8 percent for overall grant dollars (Foundation Center 2006c).

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## Foundations Created From Conversions

Grantmakers In Health (GIH) has identified more than 170 foundations that were either newly formed with the assets from health care conversions or received assets generated by conversions. These foundations held approximately \$18.3 billion in assets in 2004 (GIH 2005).

New health foundations distributed more than \$280 million in grants in 2004 (Foundation Center 2006d); 68 percent of these foundations fund solely in health (GIH 2005).

Approximately two-thirds of new health foundations were created through hospital conversions. About 17 percent resulted from health plan conversions, 10 percent from health systems conversions, and 2 percent from conversions of other entities such as nursing homes (GIH 2005).

Foundations formed from health care conversions are located in 37 states and the District of Columbia with the largest numbers in California (20), Ohio (17), Pennsylvania (15), Missouri (10), and Florida (10) (GIH 2005).

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## Challenges For The Field

Three-quarters of the nation's largest foundations have addressed implications of the Sarbanes-Oxley Act, one-third of which have made changes in policies regarding conflicts of interest, review of tax returns, and establishing audit committees (Center for Effective Philanthropy 2005).

Over the last 25 years, philanthropy has evolved from a field dominated by white men to a field where women are the majority and a fifth of staff are people of color (Joint Affinity Groups 2002).

Board diversity for foundations formed from health care conversions improved modestly from 2001 to 2004. In approximately 7 percent of new health foundations, board members from racial and ethnic minority groups represent 50 percent or more of the entire board. In 2004, however, almost one-fourth of foundations had no minority board members (GIH 2005).

In studying how foundation leaders understand effectiveness, it was found that foundations typically define effectiveness in broad and general terms—good grantmaking or attaining goals—and considerable variation exists among grantmakers. In order to make effectiveness a priority, many foundations need to clarify and specify what they believe it means to be effective (Ostrower 2004).

On average, more than one in ten executive director jobs turns over each year. That number is projected to climb by 15 percent or more as the baby-boomer generation—many of whom founded core organizations in their communities 20 to 30 years ago—begin to reach retirement age (TransitionGuides 2006).

Nonprofit executive directors cite boards of directors and funders as contributing to their burnout, wishing that boards would help more with fundraising and that funders would provide increased general operating support and multi-year support (Bell, Moyers, and Wolfred 2006).



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Bell, Jeanne, Richard Moyers, and Timothy Wolfred, *Daring to Lead 2006: A National Study of Nonprofit Executive Leadership* (San Francisco, CA: CompassPoint Nonprofit Services, 2006).

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## Recommended Reading

Association of Small Foundations, *The New Foundation Guidebook: Building a Strong Foundation* (Bethesda, MD: 2003). Available on-line at <http://www.smallfoundations.org>.

The report addresses key concerns in creating a new foundation and speaks to the many issues that must be considered when devising the structure and operations of the foundations.

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Bell, Jeanne, Richard Moyers, and Timothy Wolfred, *Daring to Lead 2006: A National Study of Nonprofit Executive Leadership* (San Francisco, CA: CompassPoint Nonprofit Services, 2006). Available on-line at [http://www.compasspoint.org/assets/194\\_daringtolead06final.pdf](http://www.compasspoint.org/assets/194_daringtolead06final.pdf).

This report presents findings from a national survey of nonprofit leaders. The data raise important questions about the future executive leadership of nonprofit organizations and suggest the need for boards of directors, grantmakers, and other nonprofit sector stakeholders to focus on supporting and sustaining the best current executives, developing the next cohort of leaders, and preparing for inevitable executive transitions.

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Blumenthal, Barbara, *Investing in Capacity Building: A Guide to High-Impact Approaches* (Washington, DC: Foundation Center, 2003). Available on-line at <http://www.fdncenter.org>.

This book is geared to help grantmakers and consultants plan better methods to help nonprofits, while showing nonprofit managers how to get more effective support. It identifies which strategies help nonprofit organizations achieve efficiency, stability, and effectiveness—and which ones do not. Based on interviews with more than 100 grantmakers, intermediaries, and consultants.

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Bowen, William G., *Inside the Boardroom: Governance by Directors and Trustees* (New York, NY: John Wiley & Sons, Inc., 1994). Available on-line at <http://www.wiley.com>.

William Bowen explores the role of the board of directors in for-profit and nonprofit corporations and offers his recommendations on how boards can better serve the interests of organizations and their stakeholders. Bowen provides detailed answers to a number of crucial questions, such as do boards really matter? To what extent do external checks and constraints preordain outcomes? In what ways is a board's ability to act effectively influenced by the type of information reported to it and by the reporting mechanisms themselves? Is there an optimal board size and an optimum balance between inside and outside members?

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Buchanan, Phil, Ellie Bateau, Sarah DiTroia, et al., *Beyond Compliance: The Trustee Viewpoint on Effective Foundation Governance* (Cambridge, MA: Center for Effective Philanthropy, 2005). Available on-line at [http://www.effectivephilanthropy.org/images/pdfs/CEP\\_Beyond\\_Compliance.pdf](http://www.effectivephilanthropy.org/images/pdfs/CEP_Beyond_Compliance.pdf).

This report summarizes the findings from a survey of foundation boards of directors. It sets forth a definition of board effectiveness, challenges faced by foundation boards, and key components of effective governance.

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The California Wellness Foundation, *Evaluations and Lessons Learned from our Grantmaking* (Woodland Hills, CA: 2003). Available on-line at <http://www.tcwf.org/publications/evaluations.htm>.

This is a Web-based series in which foundation staff, grantees, and contractors share lessons learned and information gleaned from grantmaking programs and strategies. The foundation presents these publications three or four times a year.

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*Reflections* is a series produced by The California Wellness Foundation to share lessons learned and information gleaned from its grantmaking practices and strategies. The foundation publishes the series three or four times a year.

Clotfelter, Charles T., and Thomas Ehrlich, *Philanthropy and the Nonprofit Sector in a Changing America* (Bloomington, IN: Indiana University Press, 2001). Available on-line at <http://www.iupress.indiana.edu/catalog/>.

This volume of essays suggests how philanthropy and the nonprofit sector might respond to a society which is seeing not only the devolution of federal programs to the state and local levels, but also the blurring of lines between nonprofit and for-profit organizations, globalization, tax and other regulatory reform, and the rise of privatization and market models, among other sea changes.

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Connolly, Paul, and Carol Lukas, *Strengthening Nonprofit Performance: A Funder's Guide to Capacity Building* (St. Paul, MN: Fieldstone Alliance, 2005). Available on-line at <http://www.fieldstonealliance.org>.

This guide synthesizes recent capacity building practice and research into a collection of strategies, steps, and examples. It includes capacity-building strategies; cost ranges; and a process for planning, implementing, and evaluating a capacity-building funding effort.

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Consumers Union of The U.S., Inc., and Community Catalyst *Building and Maintaining Strong Foundations: Creating Community Responsive Philanthropy in Nonprofit Conversions* (San Francisco, CA: 2004). Available on-line at <http://www.consumersunion.org/pdf/buildreport.pdf>.

This handbook examines how community members and advocates can become involved in the creation and on-going operation of new health foundations in order to address the health needs of their locality, state, or region.

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Council on Foundations, *Grantmaking Basics: A Field Guide for Funders* (Washington, DC: 2005). Available on-line at <http://www.cof.org>.

This book outlines grantmaker roles and responsibilities, including reviewing grant proposals, conducting site visits and interviews, improving fiscal accounting expertise, and increasing communication skills and effectiveness.

Council on Foundations, *Grantmaking Basics II: A Field Guide for Funders* (Washington, DC: 2004). Available on-line at <http://www.cof.org>.

This volume offers additional information, guidance and tips from the field intended to further educate people involved in giving away money.

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Council on Foundations, *The Handbook on Private Foundations, Third Edition* (Washington, DC: 2005). Available on-line at <http://www.cof.org>.

This handbook and its comprehensive bibliography have been updated to serve foundation managers, from newcomers to veterans. Beginning with a brief history of foundations in the United States, this handbook guides the reader through every aspect of managing a private foundation, including legal issues, public relations, investment management, grantmaking basics and more.

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Council on Foundations, *Philanthropic Foundations in the United States: An Introduction* (Washington, DC: 2000). Available online at <http://www.cof.org>.

This primer explores the sources, motivations and goals of foundation giving in the United States. It answers questions such as, "Why do foundations exist? How do they operate? How are they regulated?" This book is particularly valuable for those looking for a deeper understanding of American philanthropy.

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This publication examines how leadership development drives organizational effectiveness and how grantmakers are beginning to invest in new and more robust leadership models to help their grantees reach their goals.

Foundation Center, *Practice Matters Series* (Washington, DC). Available on-line at <http://www.fdncenter.org>.

The Practice Matters project represents a collective field-building effort involving more than 150 grantmakers, scholars, and other experts who set out to fill the gap in knowledge about the fundamental foundation practices that lead to good grantmaking. Titles include *The Evaluation Conversation: A Path to Impact for Foundation Boards and Executives*; *Philanthropies Working Together: Myths and Realities*; *Communications for Social Good*; *The Capacity Building Challenge*; *Ideas in Philanthropic Field Building: Where They Come from and How They Are Translated into Actions*; *Experienced Grantmakers at Work: When Creativity Comes Into Play*; *Foundation Strategies for Attracting and Managing Talent*; *Toward Greater Effectiveness in Community Change: Challenges and Responses for Philanthropy*; *Acts of Commission: Lessons from an Informal Study*; and *Toward More Effective Use of Intermediaries*.

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GrantCraft, *GrantCraft Guides* (New York, NY). Available on-line at <http://www.grantcraft.org>.

A project of the Ford Foundation, GrantCraft produces a series of guides, each focused on a different grantmaking topic. These guides are based on actual grantmaker experiences and told in their voices. They offer a wide range of actions, interventions, and strategies that grantmakers use to be more effective. Titles include *Executive Transitions*; *Program-Related Investing*; *Advocacy Funding*; *Working with the Business Sector*; *International Grant Making*; *Working with Start-Ups*; *Grant Making with a Gender Lens*; *World Summits and Conferences*; *Providing for the Long Term*; *When Projects Flounder*; *Building Community Inside & Out*; *Using Competitions & RFPs*; *Personal Strategy*; *Scanning the Landscape*; and *Saying Yes/Saying No to Applicants*.

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Grantmakers In Health, *Building Relationships in Health: How Philanthropy and Government Can Work Together* (Washington, DC: 2003). Available on-line at [http://www.gih.org/usr\\_doc/gih\\_build\\_relations.pdf](http://www.gih.org/usr_doc/gih_build_relations.pdf).

Philanthropy and government have many mutual interests. While differences in culture, time frame, and expectations can make building relationships difficult, there are many successful partnerships that together are greater than the sum of their parts. This publication presents what GIH has learned from colleagues in both sectors about the range of options for those interested in collaboration and the lessons they have learned in building those relationships.

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Grantmakers In Health, *The Business of Giving: Governance and Asset Management in Foundations Formed From Health Care Conversions* (Washington, DC: 2005). Available on-line at [http://www.gih.org/usr\\_doc/Conversion\\_Report\\_2005.pdf](http://www.gih.org/usr_doc/Conversion_Report_2005.pdf).

This report looks at the composition and function of boards of directors in foundations formed from health care conversions, as well as how the foundations manage the investment of their assets. This report is the latest in GIH's series of reports on these foundations.

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Grantmakers In Health, *Strategies for Shaping Public Policy: A Guide for Health Funders* (Washington, DC: January 2000). Available on-line at [http://www.gih.org/usr\\_doc/53198.pdf](http://www.gih.org/usr_doc/53198.pdf).

Many foundations have shied away from funding in public policy in part because of confusion over federal tax rules governing lobbying for nonprofit organizations. As a guide to foundations on funding in health policy, this publication is intended to clear up some of the misconceptions and help funders engage in public policy work. It also presents examples of the range of public policy activities now being undertaken by health funders.

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Hubbard, Betsy, *Investing in Leadership: A Grantmaker's Framework for Understanding Nonprofit Leadership Development* (Washington, DC: Grantmakers for Effective Organizations, 2005). Available on-line at [http://www.geofunders.org/\\_uploads/documents/live/FINAL-InvestinLeadership%20Vol1.pdf](http://www.geofunders.org/_uploads/documents/live/FINAL-InvestinLeadership%20Vol1.pdf).



This paper examines the link between strong executive leadership and organizational performance, as well as how this link plays a leading role in shaping foundation grantmaking.

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Independent Sector, *Building Value Together: Guidelines for the Funding of Nonprofit Organizations* (Washington, DC: 2006). Available on-line at <http://www.independentsector.org/issues/buildingvalue/opsupport.html>.

Concerned about the health and vitality of the nonprofit sector and about the state of foundation-nonprofit relationships, the Independent Sector board of directors unanimously endorsed a statement calling on funders and nonprofit organizations to adopt a reciprocal commitment to working together constructively, to enhanced performance and to effectiveness.

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Independent Sector, *Statement of Values and Code of Ethics for Charitable and Philanthropic Organizations* (Washington, DC: 2004). Available on-line at [http://www.independentsector.org/PDFs/code\\_ethics.pdf](http://www.independentsector.org/PDFs/code_ethics.pdf).

This document presents the statement of values and code of ethics that Independent Sector will use for its own work. In addition, the organization encourages its members, and the field as a whole, to use this document in either drafting or adopting statements of values and codes of ethics.

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Independent Sector, *Strengthening Transparency, Governance, and Accountability of Charitable Organizations: A Supplement to the Final Report to Congress and the Nonprofit Sector* (Washington, DC: 2006). Available on-line at <http://www.nonprofitpanel.org/final>.

This publication reports on the recommendations developed by the Panel on the Nonprofit Sector, a committee of those involved with charities and foundations, on the sector's governance, transparency, and standards. The recommendations provide approaches that maintain the balance between legitimate oversight and protecting the independence that charitable organizations need to remain innovative and effective.

Prager, Denis J., *Raising the Value of Philanthropy: a Synthesis of Informal Interviews with Foundation Executives and Observers of Philanthropy* (Washington, DC: Grantmakers in Health, 1999). Available on-line at [http://www.gih.org/usr\\_doc/54151.pdf](http://www.gih.org/usr_doc/54151.pdf).

This report, based on a series of interviews with leaders in health philanthropy, focuses on the characteristics of foundation programs and assessment strategies that appear to be most effective. It considers some of the seminal challenges facing the field and offers insights on operational structures and styles

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Raymond, Susan U., *The Future of Philanthropy: Economics, Ethics, and Management* (New York, NY: John Wiley & Sons, Inc., 2004). Available on-line at <http://www.wiley.com>.

This book is a collection of essays on ethical and management issues facing foundations and nonprofit organizations.

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Schwartz, James R., and Chester H. Horn, *Health Care Alliances and Conversions: A Handbook for Nonprofit Directors and Trustees* (San Francisco, CA: Jossey-Bass, 1999). Available on-line at <http://www.josseybass.com>.

This publication examines governance issues involved when a nonprofit health care organization converts, or considers converting, to for-profit status.

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Yates, Gary L., and Thomas G. David, "Don't Call Us 'Conversion Foundations'...Please" Views From the Field, *GIH Bulletin*, February 28, 2000. Available on-line at [http://www.gih.org/usr\\_doc/53190.pdf](http://www.gih.org/usr_doc/53190.pdf).

This Views from the Field piece—an occasional series offered by GIH as a forum for health grantmakers to share insights and experiences—comments on the term and implications of being labeled a "conversion foundation."

Access

There have been immense changes in our health system over the past two decades. In the 1980s, an economic recession focused payers' attention on cost control, spurring the growth of managed care, a model that integrated the financing and delivery of health care services. In the early 1990s, the managed care industry experimented with integrated delivery systems and new payment arrangements that would give providers tools and incentives to control the costs and improve quality. By 1996, more than three-fourths of all U.S. residents with employer coverage were covered by managed care plans (Ginsburg and Lesser 2006; Rovner 2000).

### There have been immense changes in our health system over the past two decades.

In the late 1990s, however, as more Americans enrolled in managed care—many because this was the only type of coverage offered by their employers—the industry experienced a backlash. Consumers became anxious about what seemed to be needless limits on their care. Physicians opposed limits on care and payment rate restrictions. The media began to cover stories about care being postponed or refused by some managed care companies. Confronted with public outrage about practices such as so-called drive-through deliveries, state and federal legislators responded by passing laws that guaranteed minimum levels of care. With the economy booming and employers competing for workers and aware of the plummeting popularity of managed care, employers

largely abandoned the managed care model, choosing instead to pass the responsibility for containing costs to their employees through higher patient cost sharing (Ginsburg and Lesser 2006; Rovner 2000).

Most recently, an emphasis on market solutions has dominated the thinking about health care. Hospitals and physicians have moved to raise revenues, focusing their investments on more profitable services. The vision of integrated delivery has been replaced with the consumer-driven health care model, which proposes giving consumers a sizeable financial stake in the cost of care and detailed cost and quality information, in the hopes that they will help to control costs and compel quality improvement. This broader economic and political climate has major implications for discussions of access to health care, with growing attention being given to controversial proposals such as limited benefit plans and consumer-directed health plans, which pair high-deductible health plans with health savings accounts. Skeptics warn that this reliance on market solutions may lead to a segmentation of the market and result in higher cost-sharing requirements, placing low-income populations at risk (Ginsburg and Lesser 2006; Ginsburg 2005).

### Access to Health Care

In an influential 1974 article, Lu Ann Aday and Ron Andersen developed a framework for studying access to care in which the potential for access is measured by characteristics of the health care delivery system and the population at risk, and the realization of access is measured by

## COMPONENTS OF HEALTH CARE ACCESS

### Attaining good access to care requires three discrete steps:

- Gaining entry into the health care system.
- Getting access to sites of care where patients can receive needed services.
- Finding providers who meet the needs of individual patients and with whom patients can develop a relationship based on mutual communication and trust.

### Health care access is measured in several ways including:

- Structural measures of the presence or absence of specific resources that facilitate health care, such as having health insurance or a usual source of care.
- Assessments by patients of how easily they are able to gain access to health care.
- Utilization measures of the ultimate outcome of good access to care—that is, the successful receipt of needed services.

Source: Agency for Healthcare Research and Quality, 2005 *National Health Care Disparities Report* (Rockville, MD: 2005).

utilization of and consumer satisfaction with health care services. The Aday-Andersen framework has been the basis of much of the research, policy, and practice related to access to care since then. Access is still defined by the presence (or absence) of resources that facilitate health care, such as having health insurance or a usual source of care, patient assessments of how easily they are able to secure health care, and measures that indicate whether needed health services are used (Berk and Schur 1997; AHRQ 2005).

Today, most of us receive the health care we need. Access to a broad array of primary and specialty care services has improved for sizeable numbers of Americans. But these successes mask certain realities. Research has consistently shown that particular groups of people fare far worse than others when attempting to gain access to the health care system, and that there are particular health care services, such as oral and mental health, for which problem-

atic barriers still exist (Berk and Schur 1997).

Against this backdrop, two main approaches to improving access to health care have emerged: removing financial barriers to care by broadening insurance coverage, and removing nonfinancial barriers to care by redesigning the delivery system (Meyer and Silow-Carroll 2000).

### Broadening Health Insurance Coverage

Health insurance coverage is one of the strongest predictors of access to care. Insurance coverage reduces the out-of-pocket costs of health care, providing entrée into the health care system and shielding people from the economic hardships that an unexpected injury or illness can create (Lewit et al. 2003). With the steady erosion of employer coverage, the number of people without health insurance has grown, up to 46 million in 2005 (U.S. Census Bureau 2006; Kaiser Commission on Medicaid and the Uninsured 2006).

Low-income Americans are in the greatest danger of being uninsured, despite the fact that most are in working families, because they are less likely to be offered employer coverage or able to afford individual coverage (Figure 1) (Kaiser Commission on Medicaid and the Uninsured 2005).

There are costs and consequences—to individuals and to society—of uninsurance. People without health insurance have poorer health and earlier deaths than those with insurance, often because they postpone care and have later diagnoses of serious illnesses. People without health insurance pay more than a third of their medical bills themselves, often going into debt to do so (Figure 2). The other costs of uncompensated care are covered by taxpayers, through financial support for hospitals and clinics. The economic

performance of individual communities and the nation as a whole is diminished by the worse health, earlier death, and more likely disability of the uninsured (IOM 2004).

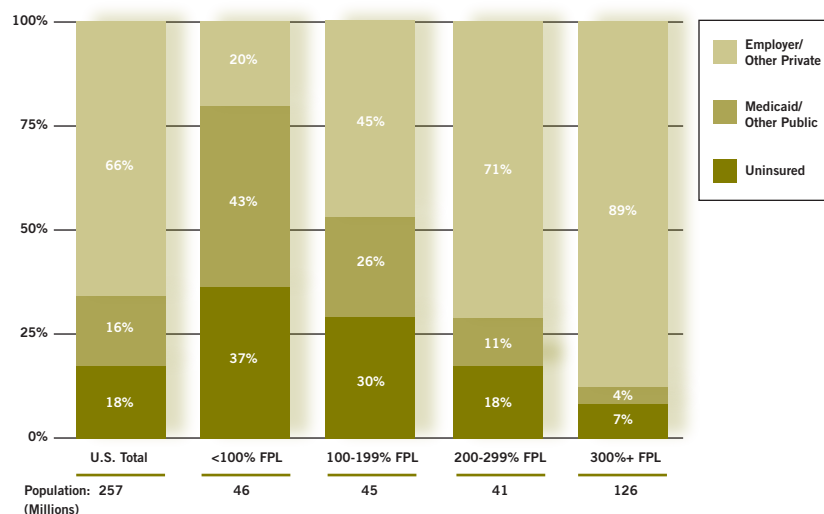
The federal response to this problem has been to make incremental expansions to one population group at a time. In 1965, Medicaid and Medicare considerably expanded coverage to the poor and the elderly. These programs have evolved over time, adding coverage for specific services or populations. Most recently, Medicaid expansions and the enactment of the State Children's Health Insurance Program (SCHIP) have improved coverage rates among lower-income children (IOM 2004). In fact, as private coverage has eroded, the number of uninsured has held steady only because public coverage has grown (Ginsburg and Lesser 2006).

These government expansions have been accompanied by attempts by funders, health care experts, and community leaders to increase the enrollment of eligible populations into government-funded programs, expand employer coverage (especially among small businesses), and make individual coverage more affordable. The inroads made, however, have not succeeded in eliminating uninsurance for several reasons. Strained state and federal budgets threaten Medicaid and SCHIP expansions (GIH 2006). A large number of children eligible for Medicaid and SCHIP remain unenrolled. It has proven difficult to design plans to increase coverage in small firms (Rosenblatt 2006). And it has proven increasingly difficult to design an affordable individual benefit plan.

## Redesigning the Health Care Delivery System

The existence of insurance alone does not eradicate all of the barriers to access, of course (IOM 1998). Many people with insurance are considered underinsured, because they forgo services due to deductibles and copayments that are unaffordable. And not all insurance plans are created equal, with many not providing adequate coverage for prescription drugs, dental care, or preventive or emergency care services (Chung and Schuster 2004). Even among those with insurance (and especially for those without it), an array of delivery system barriers prevent timely access to health care, including the availability and capacity of providers, their cultural and linguistic competence, and the existence of referral services.

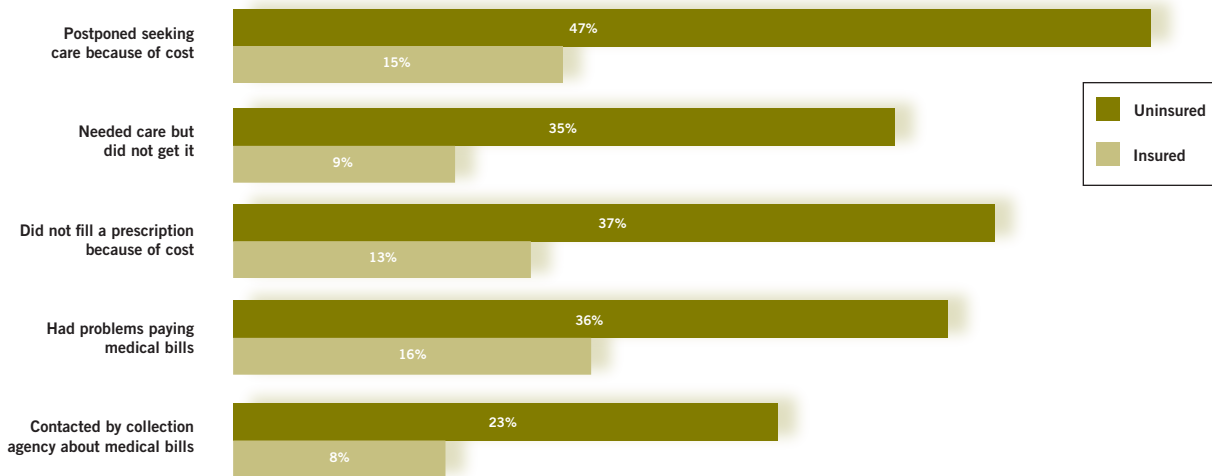
**Figure 1. Health Insurance Coverage of the Nonelderly by Federal Poverty Level, 2005**  
(percentage covered and number in millions)



Source: Kaiser Commission on Medicaid and the Uninsured, *The Uninsured and Their Access to Health Care* (Washington, DC: The Henry J. Kaiser Family Foundation, 2005).



**Figure 2. People Experiencing Barriers to Health Care in the Past Year, by Type of Insurance Coverage (percentage)**



Source: Kaiser Commission on Medicaid and the Uninsured, *The Uninsured and Their Access to Health Care* (Washington, DC: The Henry J. Kaiser Family Foundation, 2005).

Low-income people tend to rely on an extended but stressed network of safety net providers: those community health centers, public hospitals, individual practitioners, public health departments, and others that provide health care for the uninsured and underinsured, regardless of their insurance coverage, ability to pay, or immigration status (IOM 1998). Safety net providers are often applauded for their essential efforts to ensure access to the underserved, their leadership in developing and delivering culturally and linguistically competent health care, and the prevention-oriented primary care services that they provide (The California Endowment 2004). But there are problems with relying on the safety net to provide care to the 16 percent of Americans without health insurance coverage. Communities vary in their concentration and capacity of safety net providers (Cunningham and Hadley 2004). Primary care providers often find it

difficult to locate specialists willing to provide uncompensated care to low-income people. And when they do, it is difficult to coordinate care between several different safety net providers, even in one community, which can lead to duplicated tests, treatment errors, frustrated families, and discouraged providers. Perhaps most importantly, there is no sole or sure source of financial support for safety net providers. Though this is true for all providers, safety net providers have fewer sources they can rely on to raise the revenue needed to provide a growing number of services to uninsured patients who are unable to pay for them (Regenstein and Huang 2005).

There have been valiant attempts by states, counties, and cities to reorganize safety net care in order to provide health care services to more of their uninsured and underinsured residents, reimburse providers who have been offering uncom-

pensated care, and integrate care across fragmented health care settings and systems at the local level (Silow-Carroll et al. 2004; Taylor et al. 2006; Harvard Interfaculty Program for Health Systems Improvement 2006). These community access programs, though undeniably valuable, struggle with sustainability and expansion because of inherent financing challenges. Without federal help, few states and local communities have the wherewithal to provide health care to all who need it (Taylor et al. 2006). And even if they did, depending on scattered, diverse, small-scale efforts to cover the nation's uninsured would result in uneven access and a system of care highly susceptible to cutbacks during tough economic times (Meyer et al. 2004).

So what are we to do? There are huge differences of opinion about how to solve access problems, many of them ideologically based. The

debate about how to pay for access to care for more people is made more difficult by the relentless rise in health care costs. And there is a disheartening lack of public, and therefore political, will to make any fundamental change to our health care system. Universal coverage has been the subject of national debate at least six times in this country—during the First World War, during the Depression, during the Truman and Johnson Administrations, in the U.S. Senate in the 1970s, and during the Clinton Administration—and each time the proposals have been defeated. Every effort to enact broad reform has ended in a political skirmish over who should be covered and who should pay for it (Gladwell 2005).

And yet the status quo is unacceptable. The number of uninsured continues to grow, with another 16 million estimated to be underinsured. Hurricanes Katrina and Rita drew attention to holes in the nation's safety net. Rising health care costs are putting increased pressure on low- and middle-income consumers, particularly the growing number citing trouble paying off medical debt, and on employers and public payers. Growing Medicaid costs have become a focal point for state and federal officials looking to close their budget gaps (The Commonwealth Fund 2006).

### Grantmaker Activity

As these issues have evolved over the past two decades, the ways health philanthropy has chosen to intervene have changed. Funders have supported a number of access-related successes over the years: increasing enrollment in Medicaid and SCHIP, building networks of

community clinics, investing in school health centers, stimulating state experimentation, producing replicable models, supporting key research studies, and keeping attention focused on access issues. But there have also been major disappointments. Steven Schroeder, former president of Robert Wood Johnson Foundation, has called the inability to achieve stable, affordable health coverage for all Americans a heartbreaking failure (Rosenblatt 2006). As the field moves forward, its main challenges will be determining how to do thoughtful state and local work on a national problem, how the myriad incremental solutions that funders have supported over the years can be knitted together, and how to build the political will necessary to address these issues on a broader scale (GIH 2006).

**Steven Schroeder, former president of Robert Wood Johnson Foundation, has called the inability to achieve stable, affordable health coverage for all Americans a heartbreaking failure.**

With an eye on lessons learned, many funders are focusing their attention on encouraging and evaluating state attempts at health reform, building public support for change, and promoting delivery system innovation. A few illustrative examples of this work follow.

### ENCOURAGING AND EVALUATING STATE ATTEMPTS AT HEALTH REFORM

States have come to doubt that the federal government will address the rising number of uninsured in the near future, and are preparing to take the lead (Avalere Health LLC 2006).

**Dirigo Health Reform:** Maine led the recent charge with the enactment of the Dirigo Health Reform Act in 2003. The purpose of the act is to make quality, affordable health care available to every Maine citizen by 2009. The plan's centerpiece is an insurance subsidy program, DirigoChoice, which offers affordable health insurance to small businesses and to families with low to moderate income (The Commonwealth Fund 2006).

States have come to doubt that the federal government will address the rising number of uninsured in the near future, and are preparing to take the lead.

The Maine Health Access Foundation encouraged state reform as early as 2002, meeting with the governor's staff to determine the resources that would be needed to move comprehensive health care reform forward; providing a grant to the nonpartisan National Academy for State Health Policy for research and technical support; and supporting consultants, staff, and technical assistance for the state's health action team, which was made up of key stakeholders and health care policy experts and was charged with helping the governor's Office of Health Policy and Finance develop the comprehensive reform plan. After the act was approved by the state legislature, the foundation awarded several targeted strategic advocacy grants to insure that it would be implemented as intended (GIH 2006).

The Commonwealth Fund has provided support for Dirigo's evaluation, to measure the effects of the insurance subsidy on three groups: low- to moderate-income individuals, small employers, and public and private payers. The evaluation, which will cover the program's first two years, will provide state and federal policymakers with information on the impact and replicability of Maine's unique approach to broadening insurance coverage (The Commonwealth Fund 2006).

**The Massachusetts Health Care Reform Plan:** In April 2006, Massachusetts enacted a law that could provide nearly universal health care coverage to state residents. The bipartisan legislation requires the participation of both individuals and employers. It mandates everyone in the state to purchase health insurance by July 1, 2007 (with government subsidies to ensure affordability) and will impose financial penalties of up to 50 percent of the cost of a health insurance plan on those who do not via income tax filings. It also includes a requirement that employers with more than 10 employees provide health insurance coverage or pay a so-called fair share contribution of up to \$295 annually per employee (Kaiser Commission on Medicaid and the Uninsured 2006).

Blue Cross Blue Shield of Massachusetts Foundation played an important role in efforts that led to passage of the state's sweeping health reform law. In 2003, the foundation convened a summit on the uninsured that drew 350 leaders from politics, health care, business, labor, and consumer advocacy. That meeting is credited with changing

the debate on the uninsured, creating the momentum that prodded state leaders to take action, and building public support for reform. After the meeting, the foundation funded a series of policy studies on specific aspects of reform, under its Roadmap to Coverage initiative. The studies, which were carried out by researchers at the Urban Institute, analyzed what it cost to care for the uninsured in Massachusetts, who paid for it, and what full coverage would add to the state's spending. The study also presented options for expansion. Foundation staff met with stakeholders in a series of meetings to help them understand the options, the costs of the current system, and the implications of reform. Finally, the foundation provided grant support to most of the advocacy organizations working for health reform in Massachusetts. These combined efforts prevented the intense political maneuvering that has blocked past health reform efforts in the state (GIH 2006).

Other states are watching the Massachusetts reform carefully for three key reasons. First, the Massachusetts reform relies very heavily on federal Medicaid funds to finance the plan, and many states intend to use Medicaid as a central component of their strategies to increase access. Second, it has so far been difficult to construct affordable health plans offering comprehensive coverage, so many are interested in how Massachusetts will address that challenge. Third, the plan combines different strategies from across the political spectrum, making elements of the plan—as well as the strategy for reaching political agreement—of interest to a wide range of observers

(Kaiser Commission on Medicaid and the Uninsured 2006; Avalere Health LLC 2006). Blue Cross Blue Shield Foundation of Massachusetts is committed to playing a role in assessing and communicating what unfolds.

#### Health Reform in California:

Blue Shield of California Foundation, The California Endowment, California HealthCare Foundation (CHCF), The David and Lucile Packard Foundation, and other California funders have been working in concert for years on an ambitious effort to enable health coverage for all of the state's children (GIH 2006). Many of these funders have long believed that this work could help build the public's interest in the larger goal of providing access to quality, affordable health care for everyone, and would help identify coverage expansions and system fixes that could later benefit adults. That time may be near. There is currently a great deal of energy and enthusiasm on the topic of health reform in the state capitol. In January 2007, Governor Schwarzenegger announced a plan to expand coverage to Californian's 6.5 million uninsured residents. In addition, state senator Don Perata has released a coverage expansion proposal in the legislature, and a number of other proposals are expected from other members of the state assembly and senate.

CHCF is currently working to support development and analysis of several coverage expansion scenarios. Led by the Institute for Health Policy Solutions (IHPS), results from that work were released in October 2006 and presented in Sac-

ramento in late November 2006. In December 2006, the CHCF board approved \$2.5 million over two years to support continued work in the coverage expansion arena, including ongoing work by IHPS. This work builds on CHCF's efforts to expand health insurance to uninsured Californians; foster informed public and private sector decisionmaking toward expanding and improving coverage; and focusing stakeholder attention on tradeoffs among cost, benefits, and coverage (Yegian 2006).

At the same time that this state-level work is taking place, reform efforts are also underway in San Francisco. In February 2006, San Francisco mayor Gavin Newsom created a Universal Healthcare Council (UHC) to develop a plan to provide access to health care for San Francisco's 82,000 uninsured adults. The council included representatives from the health care, business, labor, philanthropy, and research communities, including Crystal Hayling of Blue Shield of California Foundation, Mark Smith of California HealthCare Foundation, and co-chair Sandra Hernández of The San Francisco Foundation. In June 2006, the council recommended the development of a San Francisco Health Access Program (SF HAP). Shortly thereafter, San Francisco passed the Worker Health Care Security Ordinance, which calls for implementation of SF HAP in tandem with an employer spending requirement. SF HAP is not health insurance; it will instead provide a primary medical home to participants, allowing a greater focus on preventive care, as well as a specialty care, urgent and emergency care, mental health care, substance abuse services, laboratory,

inpatient hospitalization, radiology, and pharmaceuticals. SF HAP will be administered by San Francisco Health Plan (SFHP) in partnership with the San Francisco Department of Public Health (DPH). To be

## Public perception and opinion can drive change or block it.

eligible for SF HAP, an individual must be uninsured, live in San Francisco, and be ineligible for other government-subsidized health benefits programs such as Medi-Cal, the Healthy Families Program, or Healthy Kids & Young Adults. SF HAP has a first phase implementation goal of July 2007.

### BUILDING PUBLIC SUPPORT FOR CHANGE

Public perception and opinion can drive change, or block it. One need only think back to the “Harry and Louise” advertising campaign of the 1990s (in which a middle-class couple lamented the complexity of Clinton’s plan and the menace of a new bureaucracy) to realize that policymakers will need to advance proposals that can gain the support of the American public if they want them to succeed (Ginsburg and Lesser 2006; Sourcewatch 2006).

**Cover the Uninsured Week:** Robert Wood Johnson Foundation has used three strategies for addressing access issues. It has supported efforts at major reform, worked to expand insurance coverage incrementally, and funded research to inform policy decisions (Rosenblatt 2006). In the mid-1990s, when the Clinton Administration’s national health

reform effort failed, foundation staff took away the message that neither the public nor policymakers had an appetite for pursuing universal coverage in the near term and shifted their strategy from building infrastructure to expanding access for specific population groups. The foundation refocused its strategy toward the actions of states, which were beginning to expand Medicaid coverage through federal waivers and other means, as the best opportunity to increase access (GIH 2006).

Although states have been the locus of most recent coverage innovations, foundation staff members recognize the problems in sustaining state and local initiatives. They therefore are again setting their sights on a national solution. Since 2000, Robert Wood Johnson Foundation has invested heavily in a national awareness campaign to inform the public and national leaders about the need to expand health care coverage. The multimillion dollar Cover the Uninsured Week campaign—which is also supported by The California Endowment, California HealthCare Foundation, The Colorado Health Foundation, W.K. Kellogg Foundation, Missouri Foundation for Health, and Rose Community Foundation—is an attempt to instigate a national debate on the access issue and encourage business, labor, health, and consumer representatives to join together to find a consensus solution. Through various national and local campaigns that occur at the same time each year, the Cover the Uninsured campaign has used survey data and other research to raise public awareness about gaps in coverage and help people understand that most of the nation’s



uninsured are working Americans who cannot afford coverage. With the campaign in its fifth year, Robert Wood Johnson Foundation staff acknowledge that advocates are growing impatient for the campaign to focus less on the problem and more on solutions. The foundation is unlikely to back a specific solution, but can use the foundation's convening power to push stakeholders to consider viable options (GIH 2006).

**The Herndon Alliance:** In May 2005, 56 people from 48 organizations interested in comprehensive health care reform met for 3 days in Herndon, VA to explore more creative ways of achieving their goal of quality affordable health care for all. The initial participants were composed of leaders of national and state organizations, faith based groups, minority groups and organized labor. At their first meeting, the participants concluded that the six attempts since 1917 to achieve universal access to health care in the U.S. had all been characterized by being underfunded, uncoordinated, and ultimately unsuccessful. The group concluded at its initial meeting that what was needed was a shared entity to develop broadscale grassroots support and coordinate efforts for an extended period of time. It also concluded that what was needed was not another health care plan on which organizations might differ, but instead for groups to work together to create demand for universal access (Herndon Alliance 2006).

With the support of The California Endowment, The Nathan Cummings Foundation, Missouri Foundation for Health, and Public

## It is difficult for many low-income people to find a provider who accepts their coverage or will treat uninsured patients.

Welfare Foundation, the alliance is using values research, marketing data, and polling to develop messaging, narratives, and initiatives that resonate with a majority of Americans and promote support for affordable health care for all. Through communications and coordination resources and policy development, the alliance engages with partners to customize and refine the messaging and initiatives for public discussion at the local and national levels. Their goal is to have these issues in public discussion in twenty states and nationally over the next year and a half, with the goal of broadening the base of American voters who support health care reform (Herndon Alliance 2006).

Interestingly, it may be the cost question that leads to public support for health care reform. One can imagine that if patient cost-sharing continues to rise, the public (and employers who know they cannot continue indefinitely to shift costs to employees) might be more open to a national conversation on the tough choices necessary to provide quality, affordable health care for all Americans (Ginsburg 2006).

### PROMOTING DELIVERY SYSTEM INNOVATION

It is difficult for many low-income people—whether privately insured, publicly insured, or uninsured—to find a provider who is conveniently located, with hours that accommodate a family's work schedule, who

has the linguistic skills and cultural sensitivity necessary to provide quality care, and who accepts their coverage or will treat uninsured patients (Lewit et al. 2003). Many of these issues would remain even if universal coverage were to be achieved.

**CarePartners:** In 1999, a group of health care stakeholders in Maine set out to redesign uncompensated care to be delivered in a more logical and efficient manner for both patients and providers. With initial support from the Bingham Program and Robert Wood Johnson Foundation, the group developed CarePartners, in which physician visits, hospital services, pharmacy benefits and case management are provided through the donated in-kind services of physicians and hospitals. The program differs from many other donated care programs in that a local health system also provides substantial funding for administrative and support services. CarePartners has grown in to a nationally-recognized, award-winning program. The program has served approximately 1,000 low-income adults per year in three counties in southern Maine since 2001 and has been shown to reduce emergency department use and medical and pharmacy costs of enrollees over time.

A recent evaluation of the program, funded by Maine Health Access Foundation, offers valuable lessons for other communities considering

developing a managed uncompensated care program. Engaging primary and specialty providers to donate their services relies heavily on their good will and proves challenging at a time when providers feel squeezed by low reimbursements from public programs. Costs and service utilization rapidly decrease for those who remain in the program more than one year and continue to decline. Pharmacy benefits require considerable resources, and aggressively pursuing free pharmacy programs offered by pharmaceutical companies is time-consuming work. Tracking the value of donated care by multiple organizations and providers is vital to measuring program performance and providing information to make timely programmatic decisions. And finally, small safety net programs, sandwiched between large public and private programs, require a flexible program design that can be adjusted quickly to be responsive to external changes (Ormond and Gerrish 2006).

CarePartners was initially conceived of as a temporary safety net program, to serve as a stop gap until either the state's Medicaid eligibility levels were expanded or a national or state universal coverage program was established. Even after the introduction of DirigoChoice, however, the demand for CarePartners has been high, because many of those eligible for DirigoChoice cannot afford the premium, co-pays, and deductibles. As a result, CarePartners currently exceeds the capacity of the donated services network, and the sites have reluctantly implemented enrollment caps and waiting lists (Healthcare Financial Management Association 2006;

Ormond and Gerrish 2006; Taylor et al. 2006). Like other programs of its kind, CarePartners is of enormous value to enrollees but can provide coverage or care to no more than a small percentage of the community's uninsured residents, and is therefore no substitute for broad national reform.

**Palm Beach County Community Health Alliance:** Communities have a choice: to meet all of the needs of some uninsured people, or to meet some of the needs of all of them. In a Palm Beach County, Florida replication of an Austin, Texas program, the Quantum Foundation is attempting the latter approach. With the foundation's support, the Palm Beach County Community Health Alliance (PBCCHA) is working directly with safety net providers to build a coordinated system of care for uninsured and other low-income people. This new system of care links providers through collaborative initiatives, with the aim of either reducing their cost of serving historically uninsured patients, or increasing the service revenue they receive through medical assistance and other third-party funded programs.

The alliance's package of collaborative initiatives includes the creation of a communitywide shared electronic health record, the implementation of a common eligibility program, a network of health care and mental health care providers, a donated care program, expansion of the delivery of free health care throughout the area, reduction of primary care burden on free clinics and hospital emergency depart-

ments, an increase in the number and capacity of federally qualified health centers, and efforts to improve language access. All of the county's safety net providers, including public and private hospitals, the county health department and health care district, multiple free clinics, the local medical society, and mental health centers, actively participate in PBCCHA. Two key attributes have helped to garner support for the alliance's efforts: they do not require large, complicated administrative structures or new coverage programs, and they do not require new behavior by patients or providers at the outset. Foundation leaders hope that if their replication succeeds, the same model will be adopted in similar areas across the country. Their recommendations to others who consider replicating their effort are to get the right people in the room when creating the common vision, choose strategies that two or more of the collaborating partners will embrace, only ask partners to do what they have the time and resource to do, and stay true to the mission (Quantum Foundation 2006).

### Regional Primary Care Access

**Initiative:** The Health Foundation of Greater Cincinnati has shifted course from trying to help individual organizations develop primary care resources to leading a regional initiative to revamp the region's health care system (GIH 2006). The foundation launched the 20-county Regional Primary Care Access Initiative (RPCAI) in September 2005. Over 50 executive leaders from the business, non-profit, insurer, primary care, and hospital sectors committed to developing a three-year workplan to achieve full access to

primary care for the uninsured, low-income, and underinsured residents of the region.

The RPCAI steering committee determined that there are critical connections and infrastructure improvements that must be in place as part of restructuring the delivery of primary care. The committee prioritized five areas of fast-track projects for its first round of invited proposal funding in order to build these connections and improvements. The five areas are:

- developing pathways to quality primary care (with a focus on reducing inappropriate emergency department visits),
- building access to health care coverage for small businesses and low-wage uninsured employees,
- creating community health outreach connections for high-risk populations,
- integrating private practice physicians into primary care networks for the uninsured, and
- building the information system support.

Foundation staff hope that this multipronged approach will help jumpstart activities and realign services on multiple fronts as opposed to focusing on one area at a time. The foundation invited a limited number of organizations to submit proposals who were deemed to be capable of responding to this fast-track project funding opportunity. These grants are not for single-entity projects; they are for systemic

change in the region. A key criterion for submission was an organization's ability to show involvement from multiple providers and organizations in planning or implementing a truly collaborative project. The foundation will be announcing the fast-track grants in early 2007.

The launch of the RPCAI has generated considerable interest and support from the business community, hospitals, and public officials who are either grappling with the rising costs of their health insurance plans or seeking to maintain an adequate safety net for the uninsured. For example, RPCAI is a key component of the Cincinnati Chamber of Commerce's Vision 2015 effort, a long-term plan for the community (Warren 2006).

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# Fast Facts

## Definition

Access to health care is the degree to which individuals and groups are able to obtain needed services from the health care system (IOM 1993).

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## Health Care Utilization

Twenty-one percent of U.S. residents with family incomes below the federal poverty level had no health care visit in 2003-2004. That number rose to 47 percent for those who were uninsured (HHS 2006).

Thirty-six percent of nonelderly adults had no dental visit in 2004. That number rose to 56 percent for those with family incomes below the federal poverty level (HHS 2006).

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## Affordability

In 2004, 40 percent of U.S. adults reported that they went without care because of costs (Schoen et al. 2006).

Only 58 percent of the nonelderly population lives in a state where employer insurance premiums average less than 15 percent of the population's median household income (Schoen et al. 2006).

One-third of nonelderly adults report having problems with medical bills, collection agencies, or medical debt (Schoen et al. 2006).

High out-of-pocket and premium costs compared to income affect 17 percent of all nonelderly families (Schoen et al. 2006).

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## Health Insurance Coverage

Most Americans under the age of 65 receive health insurance coverage as an employer benefit. In 2006, 61 percent of firms offered health benefits to at least some of their employees, down from 69 percent in 2000 (Kaiser Commission on Medicaid and the Uninsured 2006b).

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## People without Health Insurance Coverage

In 2005, 46.6 million people were without health insurance coverage, up from 45.3 million people in 2004 (U.S. Census Bureau 2006).

The uninsured are largely low-income adults in working families, for whom coverage is either unavailable or unaffordable (Kaiser Commission on Medicaid and the Uninsured 2006b).

The percentage of people without health insurance coverage increased from 15.6 percent in 2004 to 15.9 percent in 2005 (U.S. Census Bureau 2006).

The percentage and number of children (people under 18 years old) without health insurance increased between 2004 and 2005, from 10.8 percent to 11.2 percent and from 7.9 million to 8.3 million, respectively. With an uninsured rate of 19.0 percent in 2005, children in poverty were more likely to be uninsured than all children (U.S. Census Bureau 2006).

Uninsured people are more likely to receive too little medical care and to receive it too late, to be sicker, and to die sooner (IOM 2004).

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## Societal Costs of Uninsurance

People who were uninsured for part or all of 2001 received health care services valued at about \$99 billion. If they became insured, total health costs for those who now lack coverage would be expected to increase by an estimated \$34 to \$69 billion each year (IOM 2003).

The potential economic value to be gained in better health outcomes from continuous coverage for all Americans, however, is estimated to be between \$65 to \$130 billion each year, assuming the uninsured will use health care as do those who now have health insurance (IOM 2003).

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## People with Inadequate Health Insurance Coverage

Nearly 16 million people ages 19-64 are underinsured, which is defined as being insured all year but without adequate financial protection because of exposure to out-of-pocket costs that are high relative to income (Schoen et al. 2005).



Underinsured adults are more likely to forgo needed care than those with more adequate coverage and have rates of financial stress similar to those of the uninsured (Schoen et al. 2005).

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### The Role of Public Coverage

The Medicaid program provides health coverage and long-term care assistance to over 41 million people in low-income families and 14 million elderly people and persons with disabilities (Kaiser Commission on Medicaid and the Uninsured October 2006a).

Over the last few years, every state has implemented policies to freeze or reduce provider payments and to control prescription drug spending. Some states also implemented policies to restrict benefits or eligibility to slow Medicaid spending (Kaiser Commission on Medicaid and the Uninsured 2006a).

Despite broad Medicaid and SCHIP eligibility for low-income children, many eligible children are not enrolled in the programs. As many as 75 percent of uninsured children are eligible for Medicaid or SCHIP but are not enrolled (Kaiser Commission on Medicaid and the Uninsured 2006).

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### Delivery System Barriers

The proportion of U.S. physicians accepting Medicaid patients has decreased slightly over the past decade. In 2004-05, 14.6 percent of physicians reported that they received no revenue from Medicaid, an increase from 12.9 percent in 1996-97 (Cunningham and May 2006b).

The proportion of U.S. physicians providing charity care dropped more dramatically over the past decade, to 68 percent in 2004-05 from 76 percent in 1996-97 (Cunningham and May 2006a).

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## Recommended Reading

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This influential 1974 article developed a framework for studying access to care in which the potential for access is measured by characteristics of the health care delivery system and the population at risk, and the realization of access is measured by utilization of and consumer satisfaction with health care services.

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Cunningham, Peter, and Jack Hadley, "Expanding Care Versus Expanding Coverage: How to Improve Access to Care," *Health Affairs* 23(4): 234-244, July/August 2004. Available at <http://content.healthaffairs.org/cgi/content/abstract/23/4/234>.

This study examines the relative effects of insurance coverage and community health center (CHC) capacity on access to care, finding that communities that have both high insurance coverage and extensive CHC capacity tend to have the best access, although the former appears more important. The authors conclude that funding of insurance coverage expansions is likely to produce greater gains in access than if an equivalent level of funding were invested in CHCs, and recommend that policymakers consider CHC expansions as complementary to insurance coverage expansions rather than as a substitute.

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Institute of Medicine, *America's Health Care Safety Net: Intact but Endangered* (Washington, DC: National Academy Press, 2000). Available at <http://www.iom.edu/CMS/3800/5502.aspx>.

This report examines the effects of Medicaid managed care and the related issue of welfare reform on the viability and future integrity of safety net providers in primary care settings. The report recommends a new government initiative, in the form of competitive grants, to bolster the diverse set of health care institutions that provides care to tens of thousands of the nation's poor and uninsured. The report also calls for the creation of a new government oversight body to monitor and assess the condition of safety net providers and thoroughly review the impact of federal and state policies on the system.

Institute of Medicine, *Insuring America's Health: Principles and Recommendations* (Washington, DC: The National Academies Press, 2004). Available at <http://www.iom.edu/?id=19175>.

The sixth in a series of reports that examine the consequences of uninsurance on individuals, their families, communities and society, this report outlines principles that can be used to assess policy options. The committee recommends that by 2010 everyone in the United States should have health insurance and urges the president and Congress to act immediately by establishing a firm and explicit plan to reach this goal. The committee also offers a set of guiding principles for analyzing the pros and cons of different approaches to providing coverage.

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Grantmakers In Health, *More Coverage, Better Care: Improving Children's Access to Health Services* (Washington, DC: 2005). Available at [http://www.gih.org/usr\\_doc/More\\_CovBetter\\_Care\\_no25.pdf](http://www.gih.org/usr_doc/More_CovBetter_Care_no25.pdf).

This report reviews how the current health care system succeeds and fails for children, emerging policy developments, what grantmakers are currently doing to promote children's access to health services, and lessons learned to help guide future work.

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Grantmakers In Health, "Supporting Local Efforts to Improve Health Care Access," Issue Focus, *GIH Bulletin*, June 5, 2006. Available at [http://www.gih.org/usr\\_doc/Issue\\_Focus\\_6\\_5\\_2006.pdf](http://www.gih.org/usr_doc/Issue_Focus_6_5_2006.pdf).

This article discusses foundations' support of local initiatives to provide coverage and care for the uninsured, summarizing these program's strengths and limitations. The article concludes that though these initiatives are no substitute for a national solution, in the absence of broader reform they will probably continue to be a major strategy in covering the uninsured.

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Grantmakers In Health, *Improving Health Care Access: Grantmakers Share Their Experiences* (Washington, DC: 2006). Available at [http://www.gih.org/usr\\_doc/Access\\_2006\\_min\\_date.pdf](http://www.gih.org/usr_doc/Access_2006_min_date.pdf).

This collection of profiles tells the stories of how health funders across the country are working to improve access to health care. It includes interviews with grant-makers from Blue Cross Blue Shield of Massachusetts Foundation, The California Endowment, The Health Foundation of Greater Cincinnati, Robert Wood Johnson Foundation, The Henry J. Kaiser Family Foundation, W. K. Kellogg Foundation, Maine Health Access Foundation, Quantum Foundation, The Rhode Island Foundation, Rose Community Foundation, and Universal Health Care Foundation of Connecticut.

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Kaiser Commission on Medicaid and the Uninsured, *Health Insurance Coverage in America: 2004 Data Update* (Washington, DC: 2005). Available at <http://www.kff.org/uninsured/index.cfm>.

This is the latest in a series of annual chartbooks that provide data on health insurance coverage, with special attention to the uninsured. It includes trends and major shifts in coverage and a profile of the uninsured population.

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Kaiser Commission on Medicaid and the Uninsured, *Health Coverage for Low-Income Americans: An Evidence-Based Approach to Public Policy* (Washington, DC: 2006). Available at <http://www.kff.org/uninsured/7476a.cfm>.

This report provides an outline of an evidence-based framework for developing public policy approaches for health coverage of the low-income population. The authors summarize the research literature on issues related to the role for publicly sponsored health insurance, eligibility, participation, use of premiums, scope of benefits, use of cost-sharing, access, and financing.

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Meyer, Jack, and Sharon Silow-Carroll, *Increasing Access: Building Working Solutions* (Battle Creek, MI: W.K. Kellogg Foundation, June 2000). Available at [http://www.communityvoices.org/Uploads/1qzxc5fltm3ttrqh5sqmrl45\\_20020826091522.pdf](http://www.communityvoices.org/Uploads/1qzxc5fltm3ttrqh5sqmrl45_20020826091522.pdf).

This report delineates the forces driving barriers to access, and presents a comprehensive, multifaceted framework for addressing the problem. The authors

lay out a series of policy recommendations, along with a list of potential funding sources, and descriptions of promising community-based efforts geared to improving access to underserved populations.

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Rosenblatt, Robert, "The Robert Wood Johnson Foundation's Efforts to Cover the Uninsured," in Stephen L. Isaacs and James R. Knickman eds., *The Robert Wood Johnson Anthology: To Improve Health and Health Care, Volume IX* (San Francisco, CA: Jossey-Bass, 2006). Available at [http://rwjf.org/files/publications/books/2006/chapter\\_03.pdf](http://rwjf.org/files/publications/books/2006/chapter_03.pdf).

This article traces the foundation's 30-plus years of effort to increase Americans' access to health insurance. The author observes that the foundation has used three fundamentally distinct but not necessarily mutually exclusive strategies: supporting efforts to bring about fundamental overhaul of the system, working to expand insurance coverage incrementally, and funding research to provide a better understanding of the dynamics of the system and an empirical basis for policy decisions.

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Ryan, Jennifer, *Local Coverage Initiatives: Solution or Band-Aid for the Uninsured?* (Washington, DC: National Health Policy Forum, 2005). Available at [http://www.nhpf.org/pdfs\\_ib/IB803\\_LocalCoverageInitiatives\\_06-29-05.pdf](http://www.nhpf.org/pdfs_ib/IB803_LocalCoverageInitiatives_06-29-05.pdf).

This report surveys health coverage expansion initiatives that are operating on the county or local level, often without the benefit of federal funding. The paper explores the circumstances that have made these initiatives possible and considers the ongoing barriers that local policymakers face in sustaining the programs. Descriptions of four initiatives illustrate the range and variety of programs in operation today and offer both best practices and lessons learned for other communities. The paper also includes a brief analysis of the key elements that make up a successful coverage initiative. Finally, this issue brief considers the role of local and county-based initiatives in the context of overall health care delivery in the national policy framework, highlighting the prospects for sustainability and replication on a broader scale.

Schoen, Cathy, Michelle M. Doty, Sara R. Collins, and Alyssa L. Holmgren, "Insured But Not Protected: How Many Adults Are Underinsured?," *Health Affairs* Web Exclusive, June 14, 2005 W5-289–W5-302. Available at <http://content.healthaffairs.org/cgi/content/abstract/hlthaff.w5.289>.

This study estimates the number of people whose exposure to out-of-pocket costs was high relative to their incomes, placing them at financial risk and affecting their access to care. The authors estimate that nearly 16 million people ages 19-64 were underinsured in 2003. Underinsured adults were more likely to forgo needed care than those with more adequate coverage and had rates of financial stress similar to those of the uninsured. Including adults uninsured during the year, 35 percent (61 million) were under- or uninsured.

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Sheils, John, and Randall Haught, *Cost and Coverage Analysis of Ten Proposals to Expand Health Insurance Coverage* (Washington, DC: Economic and Social Research Institute, 2003). Available at <http://www.esresearch.org/publications/SheilsLewinall/Sheils%20Report%20Final.pdf>.

This report was part of the Covering America project, which was directed by the Economic and Social Research Institute and supported by a grant from Robert Wood Johnson Foundation. The purpose of the project was to generate serious thinking and debate about comprehensive policies to extend health coverage to uninsured Americans. A major part of the effort was the publication of a series of major proposals by leading health researchers and analysts that explore a variety of options for moving toward universal coverage. This report estimates the effects that 10 of the proposed reforms would have on the number of people who would be covered by public and private health insurance and the costs of extending coverage. All of these proposals would result in an increase in national health spending; increases range from \$23.0 billion to \$57.2 billion for 2002.

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State Coverage Initiatives, *State of the States* (Washington, DC: Academy Health, 2007). Available at <http://statecoverage.net/index.htm>.

This comprehensive review of coverage expansion efforts in all 50 states and Washington, D.C. is released annually.

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U.S. Census Bureau, *Income, Poverty, and Health Insurance Coverage in the United States: 2005* (Washington, DC: U.S. Government Printing Office, 2006). Available at <http://www.census.gov/prod/2006pubs/p60-231.pdf>.

This report presents data on income, poverty, and health insurance coverage in the United States based on information collected by the U.S. Census Bureau. Estimates are presented by characteristics such as race, Hispanic origin, nativity, and region. In 2005, 46.6 million people were without health insurance coverage, up from 45.3 million people in 2004. The percentage of people without health insurance coverage increased from 15.6 percent in 2004 to 15.9 percent in 2005. The percentage and the number of children (people under 18 years old) without health insurance increased between 2004 and 2005, from 10.8 percent to 11.2 percent and from 7.9 million to 8.3 million, respectively.





Aging

Americans are living longer and healthier lives than ever before. The U.S. Census Bureau has projected that the older population will double from 36 million in 2003 to 72 million in 2030, and will increase from 12 percent to 20 percent of the population in the same time frame. By 2050, the older population is projected to number 86.7 million. But, as the title of Robert Friedland and Laura Summer's groundbreaking 1999 report reminded us, demography is not destiny. How we experience this demographic change

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will depend on a variety of factors, including social and economic decisions that are ours to make. So while the growth of the population aged 65 and over presents a challenge for families, health care providers, policymakers, and others, forethought in policy planning and a willingness to invest resources where they are needed most can make the difference between this aging boom being a crisis or an opportunity (Mockenhaupt et al. 2006; U.S. Census Bureau 2005; Friedland and Summer 2006).

In the past century, average life expectancy at birth has risen from 47.3 years to 76.9 years. Two out of every five 65-74 year olds (41

percent) report their health as being excellent or very good (U.S. Census Bureau 2005). There is less disability among older people today than there was 30 years ago, and many chronic ailments such as heart disease, lung disease, and arthritis are occurring an average of 10 to 25 years later than they did in the past (Kolata 2006). This progress is a result of medical, public health, and technological advances, as well as major investments by the federal government in the health of older people. Medicare, the federal health insurance program created in 1965 for all people age 65 and older regardless of their income or medical history, now covers nearly 43 million Americans (The Henry J. Kaiser Family Foundation 2006). Also created in 1965, the Administration on Aging (AoA) provides home- and community-based care for older persons and their caregivers. Area agencies on aging, established in 1973 to respond to the needs of Americans aged 60 and over in every community, plan, coordinate, and offer information on community-based services, in-home services, and housing and elder rights programs. The National Institute on Aging, formed in 1974, provides leadership in aging research, training, and the dissemination of health information. And in 1987 the Nursing Home Reform Act established basic rights and services for residents of nursing homes, setting standards that form the basis for present efforts to improve the quality of care and the quality of life for nursing home residents (Klauber and Wright 2001).

Of course, a fit 65-year-old and a frail 85-year-old often have completely different health care and social support needs. The oldest old, those aged 85 years or older, are growing as a share of the older

population. In 1900, only 122,000 people were 85 years or older. By 2000, this group was 34 times as large at 4.2 million people (U.S. Census Bureau 2005).

The aging of the population is of concern to the health care and health policy communities primarily because older adults experience high rates of chronic diseases. Eighty percent of older Americans are currently living with at least one chronic condition, and 50 percent with at least two. In addition to causing pain, disability, and loss of

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function and independence, chronic diseases are a major contributor to health care costs (Merck Institute of Aging & Health and CDC 2004). Older people with chronic and disabling conditions are high users of medical resources, accounting for a disproportionate share of health care expenditures. They visit the doctor, use prescription drugs, and are hospitalized more often than younger people (Rice and Estes 1984). This has major implications for the elderly, especially at a time when the rising costs of health care are being shifted to the individual, and for health systems, particularly at a time when the long-term solvency of the Medicare program is being called into question (Novelli and Workman 2006).

Of course, many chronic diseases are preventable. The odds of chronic disease and disability clearly grow with age, but bad health is not an unavoidable effect of aging (Merck

Institute of Aging & Health and CDC 2004). A growing body of research—conducted by and inspired by the MacArthur Foundation’s Network on Successful Aging—suggests that behavioral change can ease health care costs for seniors and make a remarkable difference in their quality of life. In many cases, it seems that civic engagement, physical activity, and community design that supports independent living can delay or prevent disease and disability (Mockenhaupt et al. 2006; Farquhar 2006).

Because older Americans are high users of the health care system, they are especially vulnerable to its failings. Many U.S. residents struggle to get comprehensive, continuous care from our nation’s disjointed health care system. This process is particularly arduous for the elderly, due in great part to the fact that the acute and long-term care systems function separately. Acute care, designed to diagnose, treat, and prevent illness, is provided in doctors’ offices, clinics, and hospitals. Long-term care, designed to manage chronic conditions and assist the functions of daily life, is provided by a wide range of caregivers in many settings. The two types of care are also financed differently, with Medicare picking up most of the cost of acute care for those 65 and older, and Medicaid covering the cost of long-term care for low-income seniors (Alper and Gibson 2001). For those who do not qualify for Medicaid, long-term care presents a considerable financial burden, and few people have insurance policies that will pay for that care (Friedland and Summer 2006).

Promising efforts have been made to integrate acute and long-term care,

especially for the frail elderly. Some, which have used a small-scale team approach to create a seamless system of care, have been successful, while others, which have attempted large-scale system coordination, have had more mixed results (Alper and Gibson 2001; GIH 2001). Two of the most promising models have been the Program of All-Inclusive Care for the Elderly (PACE), which uses multidisciplinary teams to provide acute and long-term care in both inpatient and outpatient settings, and Social Health Maintenance Organizations (SHMOs), which combine managed care and expanded home- and community-based services. Both blend Medicare and Medicaid financing in order to integrate health and social services for frail older adults (Mockenhaupt et al. 2006).

Both our acute and long-term care systems are turning their attention to training and supporting the workforce of paid and unpaid caregivers (Mockenhaupt et al. 2006). Many health care providers do not have the training they need to appropriately treat older patients (Merck Institute of Aging & Health and CDC 2004). Geriatricians, valued for their skill at supervising treatment of multiple chronic conditions, weighing the pros and cons of numerous prescriptions, seeking answers outside medicine for persistent problems, coordinating with family members and other providers, and objecting to needless tests, are few. In 2005 there was one geriatrician for every 5,000 Americans 65 and older (Gross 2006). Some argue that more geriatricians need to be trained; others argue that more providers need to learn how best to respond to the needs of aging patients. And the shortage of

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geriatricians is not the only concern; the health care system is also experiencing shortages of nurses, geriatric social workers, and front-line workers in hospitals, nursing homes, and home health programs.

Most of the nation's long-term care services are provided by unpaid caregivers: the family, friends, neighbors, and other community members who help the elderly through their days. Although it saves the nation billions of dollars a year, this arrangement comes with a price. Many of these caregivers find themselves overwhelmed, isolated, emotionally drained, and in dire need of information, training and support (Mockenhaupt et al. 2006). And those who are members of the so-called sandwich generation find themselves simultaneously caring for their children and parents, making great sacrifices of time and money to do so.

Determining how the care provided to the elderly will be financed in the future is a major concern. Medicare's Part A Trust Fund, which pays for inpatient hospital, skilled nursing facility, home health, and hospice care, is funded mainly by a dedicated tax on earnings paid by employers and workers, and is projected to exhaust its reserves by 2018. And contrary to popular belief, Medicare pays only about half of older American's health care expenses, with the balance covered by private insurance, Medicaid, and

older people themselves. Out-of-pocket health care expenses and long-term care costs pose a significant financial burden for many elderly, and the financial security Medicare was designed to offer older people has eroded as these costs have continued to rise (The Henry J. Kaiser Family Foundation 2006; Friedland and Summer 2006).

All of these issues are made more complex by the growing diversity within the aging population. The gaps in access, quality, and health status that have long been documented between poor and nonpoor, well educated and less educated, and whites and people of color, will become even more pronounced as the population ages. Already, unmarried women and people of color are especially vulnerable to chronic health problems, poverty, and unmet health and social needs as they grow older. Research has also shown specific risks for other populations, such as older lesbian, gay, bisexual and transgender people, who are often more likely to live alone and less likely to have family support than the larger aging population. The diversity by age among those over 65 also means that while some older people will face age-related declines, others will continue to perform as well as the nonelderly and will crave opportunities to make meaningful contributions to their communities and to society (Mockenhaupt et al. 2006).

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Ever mindful of these challenges, funders are focused on a number of efforts related to aging and health, including training and supporting paid and unpaid caregivers, extending independent living, creating seamless systems of care, and helping seniors navigate Medicare.

### Training and Supporting Paid and Unpaid Caregivers

As the aging population grows, it becomes increasingly important to have in place paid and unpaid caregivers prepared to meet their health care needs.

**Centers of Excellence in Geriatric Medicine and Training:** In 1982, following a wide-ranging strategic planning process in which almost 50 areas of grantmaking were considered, The John A. Hartford Foundation's board of directors recognized that the increasing life expectancy and the decline of the infant mortality rate in the U.S. were shifting demographics in a way that would have profound implications for health care. The trustees set out on two new paths: aging and health and health care financing. In 1988, after an Institute of Medicine (IOM) study emphasized that it was necessary to develop the capacity to train academic leaders in geriatrics, the foundation established

the Academic Geriatrics Recruitment Initiative, which established 10 centers of geriatrics. In 1993, after a second IOM report emphasized that there were still inadequate numbers of faculty to meet the nation's training and research needs in geriatrics, the foundation transformed the initiative into the Hartford Centers of Excellence program (The John A. Hartford Foundation 2005). Then in 1995, in part because of the lack of national consensus for reform of the health care system, the foundation shifted its focus away from health care financing to focus solely on aging and health.

The foundation's Centers of Excellence in Geriatric Medicine and Training is now a \$36 million dollar initiative to help medical schools prepare faculty to ensure that future doctors are able to meet the needs of older patients. Currently, there are 24 active centers of excellence, 22 in geriatric medicine, and 2 in geriatric psychiatry. The strategy of the centers of excellence initiative is to identify medical schools with the necessary components for training academic geriatricians, such as research infrastructure, advanced training opportunities, and academic mentoring, then add resources to these institutions to train larger numbers of future faculty more rap-

idly than would otherwise be possible. Centers of excellence funds are used as salary support to allow for protected time to conduct research, train to become clinician educators, and pioneer new models of care (The John A. Hartford Foundation 2006).

In addition to carving out a niche and remaining committed to it over time, foundation staff emphasize the importance of evaluation, communications, and dissemination. The foundation's trustees believe that timely feedback and accurate information on the progress of grantees is so important that they created a freestanding board-appointed evaluation committee. The evaluation and monitoring process involves annual half-day site visits to up to 100 project sites a year, which is a time-intensive and costly process. But they help board and staff members quickly identify trends, gaps, and opportunities. Staff and trustees also noticed that the results of their initiatives were not always disseminated outside the grantees' immediate professional networks, to wider medical audiences, policymakers, or the public. To broaden the reach of its grants, the foundation created the Communication and Dissemination Initiative to help grantees and staff communicate the importance of, and innovations in, geriatric health care (The John A. Hartford Foundation 2005).

**Cash and Counseling:** Frail elderly people often face serious barriers when seeking personal assistance services. Home care agencies, the traditional providers of these services, frequently experience worker shortages and high staff turnover that make it difficult for them to



meet consumers' needs and cannot always tailor their services to meet an elderly person's specific needs. In 1995, Robert Wood Johnson Foundation (RWJF), the Office of the Assistant Secretary for Planning and Evaluation within the U.S. Department of Health and Human Services (ASPE), and AoA, launched the experimental Cash & Counseling program in Arkansas, New Jersey, and Florida to give Medicaid beneficiaries choice and control over their personal care needs. The program provides a self-directed, individualized budget to recipients of Medicaid personal care services. Participants use the money to hire their own caregivers, often friends or family members who had been providing unpaid care, or purchase items, such as chair lifts or touch lamps, which help them to live independently. Each person's budget is comparable to the value of services that he or she would have received from an agency. Consulting and bookkeeping services are available to help participants weigh their options and keep up with required paperwork (RWJF 2006).

An independent evaluation of the program by Mathematica Policy Research Inc. found that, in all three participating states, when Medicaid beneficiaries of various ages and disabilities were given the opportunity to direct their own supportive services and hire their own caregivers, their quality of life improved, satisfaction with services increased, unmet needs for care were reduced, and access to home care increased without compromising beneficiaries' health or safety (relative to randomly assigned control groups that received services from agencies). Moreover, by the second year of

enrollment, the consumer-directed option cost no more than agency care, due to lower spending for nursing home and other Medicaid services. Twelve additional states have now received funding from RWJF, ASPE and AoA to replicate or expand the Cash & Counseling model (Robert Wood Johnson Foundation 2006).

### Extending Independent Living

For most older people, institutionalization is a measure of last resort (Rice and Estes 1984). Preventing institutionalization requires redesigning communities to help people stay healthy, live independently, and lead fruitful and fulfilling lives (Mockenhaupt et al. 2006).

**Fall Prevention:** Falls are a common and often devastating problem among older adults. In California alone, over 1 million people age 65 and older fall each year. More than 100,000 of these falls result in a serious injury or fatality. In fact, almost 40 percent of those hospitalized for hip fractures never return home or live independently again, and 25 percent die within a year. Most falls are associated with

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one or more risk factors including weakness, unsteady gait, confusion, medications, and environmental hazards. Research has shown that attention to these risk factors can significantly reduce fall rates, and the most effective (and cost-effective) fall reduction programs are multifactorial. Optimal approaches involve a combination of medical management, physical activity, and

home modification. The high level of coordination needed to carry out these programs requires the support of strong community partnerships (Archstone Foundation 2006).

Since 1996, fall prevention has been an area of interest for the Archstone Foundation with more than 25 grants being awarded totaling over \$10 million. During the first 10 years of grantmaking, the Archstone Foundation focused on broad public health and health care delivery issues. In 1995, the foundation began a two-year evaluation process

fall outside of the three priority areas and will continue to conduct responsive grantmaking as a means to address emerging needs in the community (Archstone Foundation 2006).

In 2003, the foundation brought together key stakeholder groups throughout California to begin a strategic planning process to help prevent falls among older adults. This resulted in the foundation's establishment of the Fall Prevention Center of Excellence. The center is a public-private partnership responsible for coordinating a statewide effort to address falls among seniors and deliver integrated fall prevention services. Funding will be allocated to test programs, expand integrated programs and support broad-based community coalitions. In April 2006, the foundation announced the approval of 11 grants under the California Senior Fall Prevention Projects, totaling \$364,822 over eighteen months (Archstone Foundation 2006).

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examining the first 10 years of operation. Through this process, the board of directors decided to target its work exclusively on issues of aging. Since 1995, the foundation has taken a leadership role in the field of aging, funding a variety of aging projects that address keeping frail elders in their homes for as long as possible, the quality of nursing home care, and end-of-life issues. As the foundation's knowledge of the field grew, it began focusing grantmaking on preparing society for an aging population. Then with the economic challenges of 2002 and 2003, the foundation refocused its strategy on three priority areas for initiative-based grantmaking, committing a total of \$24 million over five years for fall prevention, elder abuse and neglect, and end-of-life issues. In addition, the foundation values the ability to be responsive to needs that

**Aging in Place:** The mission of The Horizon Foundation is to promote and enhance the health and wellness of the Howard County, Maryland community. Following extensive planning, in 1999, foundation's trustees determined that the health and wellness of older adults would be a major, continuing priority. Over a period of five years, The Horizon Foundation teamed with the county office on aging and other community practitioners and leaders to create a service model designed to start permitting the quality of life and quality of care that older residents both want and deserve—ideally, in their own homes, and at a cost that the community can afford.

The first step in this process was the multifaceted Aging-In-Place Initiative from 1999 to 2002. From the beginning, the foundation's approach was based on three overarching principles: forging a strong partnership between the public and private sectors, integrating service components into a seamless service delivery model that is supported by appropriate planning and evaluation, and developing benchmark information against which progress toward aging in place could be measured, and measuring that progress. Guided by these principles, the Aging-In-Place pilot program consisted of four service components: home repair, remodeling, and assessment; fall prevention; mental health; and affordable in-home care.

The first five years of the initiative provided foundation staff with valuable implementation experience, data, and community partnerships, which have informed the initiative's current work and future goals. Inspired by Denmark's highly regarded system of integrated care for older adults, the foundation and its partners decided to focus their joint efforts on increasing the period of functional health of older adults with chronic conditions, with the potential dual benefits of improving health care utilization systems and the quality of life of the county's seniors. Together, the program elements of this phase offer potential for linking adults with chronic conditions with the services they need to enable them to remain in their homes as long as they want to do so, as well as to reduce the costs of their care (The Horizon Foundation 2005).

**Naturally Occurring Retirement Communities:** The New York-based

United Hospital Fund established its Aging in Place Initiative in 1999 to foster the development of new models of care supporting the health and well-being of older people living in the community. These models bring together health care and community resources to address the needs of residents of naturally occurring retirement communities (NORCs), which are housing developments, neighborhoods, or geographic areas built or established for multiage populations but becoming home, over time, to large concentrations of seniors. The initiative is led by Freda Vladeck, who, with the residents of Manhattan's Penn South Houses, worked to create the first NORC supportive service program. Since then, the number of such programs across the country has grown to more than 80. These programs have proven to be invaluable in helping seniors stay in the homes where they have long resided, which, not surprisingly, many prefer (United Hospital Fund 2006).

The initiative's NORC Health Care Linkage Project, a collaborative effort made possible by grants from the United Hospital Fund and The New York Community Trust, is currently entering its third and final phase. Launched in June 2003, the project aims to strengthen effective linkages between supportive service programs in naturally occurring retirement communities and key health care providers serving the community. In 2006, funding was awarded to four programs that illustrate the various ways to address these issues:

- The Lincoln Square Neighborhood Center is creating an integrated medication information sharing

system between Lincoln-Amsterdam Senior Care and Roosevelt Hospital's emergency department to promote medication safety and adherence practices for seniors with multiple chronic health conditions.

- Montefiore Medical Center is linking its discharge planning process to the array of supportive nonmedical services available to seniors living in the Co-Op City Senior Services Program—thus creating a virtual care network.
- Samuel Field YM & YWHA is linking the Deepdale Cares NORC Program to community physicians through a falls prevention project that works with community physicians to reduce clients' risk factors for falls.
- Spring Creek Community Corporation is establishing a coordinated and systematic approach between Spring Creek Senior Partners and community physicians on the identification, assessment, and treatment of seniors suffering from depression (United Hospital Fund 2006).

To synthesize lessons from the Health Care Linkage Project with the best thinking from around the nation on developing supportive health and social service programs to help seniors living in naturally occurring retirement communities, United Hospital Fund has launched the NORC Action Blueprint Project with the Daniels Fund, The Fan Fox & Leslie R. Samuels Foundation, and the Harry and Jeanette Weinberg Foundation. The goal of the Blueprint Project is to provide community leaders with information on programs to help seniors live as

### OBESITY ON THE RISE AMONG THE ELDERLY

The increase in prevalence of obesity among older adults has been dramatic. Between 1960-1962 and 2003-2004, the percentage of people age 65-74 who were obese rose from 18 percent to 35 percent. This is of concern both because obesity is associated with increased risk of disease and disability, and because it has been estimated that Medicare spends about 34 percent more on an obese person than on someone of normal weight.

Source: Federal Interagency Forum on Aging-Related Statistics 2006; Lakdawalla et al. 2006.

independently as possible in their own homes and communities. The Blueprint Project will define guiding principles, identify elements of successful NORC supportive service programs, present helpful program development and management tools, and take a broad look at program financing. The end product will be a Web-based tool, the Blueprint, which will facilitate access to this information for existing and new audiences and will allow for the information to be modified as lessons are learned and needs evolve (United Hospital Fund 2006).

### Creating Seamless Systems of Care

This nation's fragmented health care systems leave many seniors and their families frustrated by poor communication between providers or lack of coordination between services, which can lead to duplicated tests, treatment errors, or other threats to quality care. Several communities have experimented with system integration and care coordination in an attempt to find more consistent strategies for caring for older patients (Alper and Gibson 2001).

**PROGRAM OF ALL-INCLUSIVE CARE FOR THE ELDERLY (PACE):** In the late 1970s On Lok Senior Health Services in San Francisco's Chinatown developed a fully integrated model

of acute and long-term care for very frail seniors. Nurtured by Robert Wood Johnson Foundation, On Lok now operates seven centers serving San Francisco's diverse senior population—including Chinese, Vietnamese, Filipino, Korean, Central and South American, Mexican, African-American, Italian, and Russian elders—with each patient's needs monitored by an interdisciplinary care team and adjusted as his or her health care needs change. The foundation's interest in On Lok grew out of the foundation's efforts to improve care and support for people with chronic health conditions (Alper and Gibson 2001). On Lok was quickly recognized as an innovative coordinated care and financing program. In 1986 it became the model for Medicare's Program of All-Inclusive Care for the Elderly (PACE) demonstration program. In 1997, PACE became a permanent program under Medicare. Several foundations, including Archstone Foundation, The California Endowment, The John A. Hartford Foundation, Inc., Robert Wood Johnson Foundation, and Retirement Research Foundation, have supported both On Lok and the PACE program by supporting policy analyses and program evaluation and helping to expand the program into new communities around the country.



PACE is centered on the belief that the well-being of seniors with chronic care needs and their families can best be met in the community whenever possible. PACE serves patients age 55 and older who are certified by their state to need nursing home care. These frail elders have an average of eight diagnosed medical conditions that affect their health and functioning and 45 percent have dementia diagnoses. To enroll, patients must also be able to live safely in the community and live in a PACE service area. Through PACE, patients receive all the medical and supportive services needed to maintain independence in their homes for as long as possible. The continuum of services includes adult day care; nursing and therapeutic services; medical care; home health and personal care; prescription drugs; social services; medical specialty services such as dentistry, optometry, podiatry, and speech therapy; respite care; and hospital and nursing home care when necessary. PACE is financed through both Medicare and Medicaid. In 2003, more than 10,000 individuals participated in PACE programs associated with 27 facilities in 17 states.

For Robert Wood Johnson Foundation, rationalizing fragmented and unresponsive health care delivery systems has been a worthy but difficult endeavor. What impressed foundation staff about the PACE model was the effectiveness of the team approach, in which dedicated professionals work together to create their own system of care. Advocates of the model argue that the team approach is likely to be a key factor in making integration of acute and long-term care work, because it can lead to better commu-

### AS THE NATION GOES, SO GOES MEDICARE

In many ways, developments related to Medicare over the past 25 years have closely tracked changes in our health care system overall. Initially designed to resemble the type of insurance typical in the 1960s, the Medicare program has evolved as the needs of the aging population have changed. When it was established, the program did not pay for preventive services, outpatient prescription drugs, hearing or vision care, catastrophic coverage, or long-term care. In the late 1980s and early 1990s, with researchers exploring the link between disease prevention and successful aging, Congress began to add coverage for preventive services, such as flu shots and cancer screenings, to the program. In 1982, with growing public support for specialized end-of-life care, a hospice benefit was added. In 1998, with health care costs on the rise, the short-lived Medicare Catastrophic Act attempted to cap out-of-pocket costs for beneficiaries. In 1997, as the country experimented with managed care as a way to control costs and improve quality, Congress created Medicare+Choice, to encourage delivery of care through private plans, sweetening the incentive by allowing these plans to offer additional benefits (like outpatient prescription drugs, foot care, eyeglasses, and hearing aids) not otherwise covered by Medicare. Most recently, the Medicare Modernization Act of 2003 added a long-awaited outpatient prescription drug benefit.

Source: Rovner 2000; Alliance for Health Reform 2006.

nication among multiple providers caring for the same person and to a more consistent strategy for caring for the patient. In contrast, the foundation has experienced less success with an alternative that simply tries to coordinate the care offered by the long-term and acute systems. Nevertheless, since health care delivery systems are unlikely to undergo a major reconfiguration any time soon, foundation staff believe that coordination may be the most viable strategy to improve care on a large scale within the existing fragmented system (Alper and Gibson 2001).

**Care Transitions:** When patients are ready to leave the hospital and return home—or move on to another care setting, like a rehabilitation facility—good communication and coordination are essential to a smooth transition. Many patients do not receive clear instruc-

tions regarding their new medications or symptoms to watch for, or even the name of a person to contact with questions. For older patients and patients with chronic or complex conditions, improperly handled care transitions frequently result in readmission to the hospital, medical errors, and duplication and inefficiency costs for the health care system (The Commonwealth Fund 2006).

With funding from The John A. Hartford Foundation and Robert Wood Johnson Foundation, the University of Colorado Health Sciences Center developed the Care Transitions Measure (CTM), a tool that assesses problems in care coordination from the patient's perspective so that hospital systems can develop targeted solutions. The model consists of the following components:



### THE MEDICARE PRESCRIPTION DRUG BENEFIT

In January 2006, Medicare prescription drug coverage became available to the program's 43 million beneficiaries. To receive the coverage, however, beneficiaries must actively opt in to Medicare Part D by selecting a prescription drug plan (PDP). Seven and a half million dual eligibles, Medicare beneficiaries receiving drug coverage through Medicaid, were assigned to Medicare PDPs. The new Medicare drug benefit also includes additional subsidies for beneficiaries with limited incomes, including dual eligibles; Medicare beneficiaries with Supplemental Security Income; and beneficiaries enrolled in the Medicare savings program, which provides assistance paying for Medicare Part B premiums. Other qualified low-income beneficiaries may also be eligible for this extra help, which includes premium and cost-sharing subsidies.

Source: GIH 2006.

- a personal health record that consists of the essential care elements for facilitating productive interdisciplinary communication during the care transition;
- a structured checklist of critical activities designed to empower patients before discharge from the hospital or nursing facility;
- a patient self-activation and management session with a transition coach (a geriatric nurse practitioner) in the hospital, designed to help patients and their caregivers understand and apply the first two elements and assert their role in managing transitions; and
- transition coach follow-up visits in the skilled nursing facility or in the home and accompanying phone calls designed to sustain the first three components and provide continuity across the transition.

The intervention focuses on making sure that each patient is knowledgeable about medications and has a medication management system, understands and utilizes the per-

sonal health record to facilitate communication and ensure continuity of care plan across providers and settings, schedules and completes follow-up visit with the primary care physician or specialist physician, and is empowered to be an active participant in these interactions and is knowledgeable about indications that their condition is worsening and how to respond (University of Colorado Health Sciences Center 2006).

A 2004 grant from The Commonwealth Fund supported refinement and testing of the measure, as well as promotion of the CTM's use by health care providers. The Community Health Foundation of Western and Central New York is using the CTM in a new quality improvement collaborative that aims to improve care transitions for the frail elderly population (Community Health Foundation of Western and Central New York 2006; The Commonwealth Fund 2006).

### Helping Seniors Navigate Medicare

New Medicare benefits and other changes to the program have placed

additional demands on seniors, requiring them to make more complex and consequential decisions about their health coverage.

**The Central Florida Medicare Rx Coalition:** The Winter Park Health Foundation (WPHF) in central Florida names older adults as one of its four priority areas, and focuses on optimizing physical and mental health and well-being and promoting social and civic engagement. Most of the foundation's aging-related grantmaking has been directed at transportation; promoting healthy behaviors; encouraging lifelong learning and enhancing well-being; fostering meaningful connections with family, neighbors, and friends; providing opportunities for meaningful paid and voluntary work; and making aging issues a community-wide priority.

When the Medicare Prescription Drug Improvement and Modernization Act (MMA) was signed into law, WPHF added beneficiary education to its work. Building on the foundation's role as a community convener, foundation staff worked with local partners to build a coalition dedicated to community outreach and education on Medicare Part D. Capitalizing on its reputation, the foundation was able to draw a variety of organizations into its Central Florida Medicare Rx Coalition, including local AARP chapters, the state's health insurance assistance program, county government, and area agencies on aging.

In addition to hosting six Medicare fairs drawing more than 1,200 people, the group also succeeded in mobilizing 2-1-1 hotline staff members to receive and field Medicare drug benefit inquiries. It

also oversaw the distribution of educational materials. Some 158,000 copies of a special edition of the Florida Hospital Premier Health newsletter on the Medicare drug benefit were distributed. The efforts drew a great deal of media attention, most notably in the *Orlando Sentinel* which ran a series of informative stories about the new prescription plan. NBC Nightly News also filmed a segment at the West Orange information session which was aired nationwide. The Medicare Rx Coalition now is developing a work plan for Phase II of its community education and advocacy project focused on enrollment of eligible older adults (Winter Park Health Foundation 2006).

#### Make Medicare Work Coalition:

The Michael Reese Health Trust is using its proactive grants program to develop a coordinated response to the challenges presented by Medicare Part D in Illinois. Through the Make Medicare Work Coalition, the foundation – along with The Chicago Community Trust and the Retirement Research Foundation – funded key advocacy groups representing seniors and persons with disabilities. These advocacy groups work jointly to enhance advocacy, outreach, education, and enrollment. For example, resources for consumers and advocates were developed, including a Web site and printed materials. A speakers bureau was also created to help local organizations hosting health fairs and other events. In addition, the Make Medicare Work Coalition communicates policy analysis and implementation efforts through e-newsletters, listservs, and teleconferences to policymakers and other stakeholders. It also provides technical assistance to state agencies and the

governor's staff on questions related to Medicare Part D and has hosted a legislator briefing on the impact of the new benefit on Illinois' medical programs, the state's budget, and its low-cost drug program.

A key goal of the coalition is to marry policy and education and outreach efforts, using individual experiences to inform wise policy decisions. In its first year, consumers' feedback led to the coalition's policy advocacy on several issues, including the state's implementation of emergency procedures when dual eligibles had trouble receiving their medication. In the coming year, the coalition plan to continue its core activities; adjust to elimination of the state pharmacy assistance program; focus on implementation issues including exceptions and appeals; enhance targeted outreach to vulnerable populations including those eligible for extra help deaf limited English and Medicare Savings Programs enrollees; and conduct policy advocacy for the retention of retiree health benefits (Lavin 2006).

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# Fast Facts

## Population

The population age 65 and older is projected to double from 36 million in 2003 to 72 million in 2030, increasing from 12 percent to 20 percent of the population (U.S. Census Bureau 2005).

The oldest-old population (those aged 85 and older) is also projected to double, growing from 4.7 million in 2003 to 9.6 million in 2030 (U.S. Census Bureau 2005).

In 2003, non-Latino whites accounted for nearly 83 percent of the U.S. older population, followed by African Americans (8 percent), Latinos of any race (6 percent) and Asians (3 percent). By 2030, the projected composition of the older population will be 72 percent non-Latino white, 11 percent Latino, 10 percent African American, and 5 percent Asian (U.S. Census Bureau 2005).

Since the 1960s, the proportion of the older population living in poverty has declined. Still, in 2003, 10.2 percent of the population 65 and older lived in poverty, and an additional 6.7 percent were near poor, with incomes between 100 percent and 125 percent of the federal poverty threshold (U.S. Census Bureau 2005).

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## Health Status

Average life expectancy increased from 47.3 years in 1900 to 76.9 years in 2000 (U.S. Census Bureau 2005).

There is less disability among older people today than there was 30 years ago, and many chronic ailments such as heart disease, lung disease, and arthritis are occurring an average of 10 to 25 years later than they did in the past (Kolata 2006).

About 80 percent of seniors have at least one chronic health condition and 50 percent have at least two. Between 1960-1962 and 2003-2004, the percentage of people age 65-74 who were obese rose from 18 percent to 35 percent (CDC 2003; Federal Interagency Forum on Aging-Related Statistics 2006).

## Health Care Costs

Almost 40 percent of health care spending, about \$735 billion annually, is incurred by people over age 65 (The Century Foundation 2006).

Among older Americans, almost 95 percent of health care expenditures are for chronic diseases (Merck and CDC 2004).

The aging of the population is only one factor contributing to rising health care costs. Projections for long-term Medicare spending through 2075 by the Congressional Budget Office indicate that “approximately 30 percent of that growth is due to society’s aging; the remaining 70 percent is attributable to general growth in health care costs in excess of the rate of gross domestic product growth” (The Century Foundation 2006).

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## Health Insurance Coverage

Retiree health benefits are on the decline. Thirty-five percent of large firms offered retiree coverage in 2006, down from 66 percent in 1988 (The Henry J. Kaiser Family Foundation and Health Research and Educational Trust 2006).

Medicare, the federal health insurance program created in 1965 for the disabled and people age 65 and older regardless of their income or medical history, now covers nearly 43 million Americans (The Henry J. Kaiser Family Foundation 2006a).

Medicare pays for just over half (55.2 percent) of older Americans’ health care costs. The Medicaid program pays 10 percent of older Americans’ expenditures, private insurers pay for 12 percent, and older people cover one fifth (20.4 percent) of the cost of services themselves (Friedland and Summer 2005).

The proportion of older persons’ income spent on health rose from 8.1 percent in 1997 to 9.9 percent in 2001. This proportion varies widely by socioeconomic and health status. Poor or near poor older people spend 21.5 percent of their income on health care costs (The Century Foundation 2006).

## Prescription Drugs

People age 65 and older account for 34 percent of all prescriptions for medications (Merck Institute of Aging & Health and CDC 2004).

As of June 2006, the U.S. Department of Health and Human Services (HHS) reported that 22.5 million beneficiaries were enrolled in Medicare prescription drug plans. Based on HHS estimates, 4.4 million beneficiaries, or more than 10 percent of the Medicare population, had no prescription drug coverage in 2006 (The Henry J. Kaiser Family Foundation 2006b).

The drug benefit offers substantial premium and cost-sharing assistance for beneficiaries with low incomes and modest assets. HHS estimates that 3.1 million beneficiaries who are eligible for this assistance are not currently receiving it (The Henry J. Kaiser Family Foundation 2006b).

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## Long-Term Care

Nearly 79 percent of people who need long-term care live at home or in community settings. Most long-term care is provided by informal caregivers (Merck Institute of Aging & Health and CDC 2004, The Century Foundation 2006).

The value of services that family caregivers provide at no cost is estimated to be \$257 billion a year (Merck Institute of Aging & Health and CDC 2004).

Excluding informal care, Medicaid is the largest source of funding for long-term care of the elderly. In 2004, Medicaid paid 35 percent of long-term care costs, while Medicare paid 25 percent, seniors paid 33 percent out of pocket, and private insurance paid 4 percent (The Century Foundation 2006).

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Kolata, Gina, "So Big and Healthy Grandpa Wouldn't Even Know You," *The New York Times*, July 30, 2006.

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## Recommended Reading

AARP Public Policy Institute, *The State of 50+ America* (Washington, DC: 2004). Available on-line at [www.aarp.org/research/reference/statistics/aresearch-import-480-D18051.html](http://www.aarp.org/research/reference/statistics/aresearch-import-480-D18051.html).

In this report AARP examines the well-being of Americans age 50 and older in terms of 20 indicators reflecting key dimensions of well-being, economics, health, lifestyle, independent living, and long-term care. Although the report shows favorable trends on almost all measures over the past decade, the 50 plus population has not fared as well in the near term, doing worse on all but 2 of the economic and health indicators analyzed, and declining on 10 of 15 indicators of well-being overall.

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Burke, Shelia P., Judith Feder, and Paul N. Van de Water, eds., *Developing a Better Long-Term Care Policy: A Vision and Strategy for America's Future* (Washington, DC: National Academy of Social Insurance, 2005). Available on-line at [www.pascenter.org/publications/publication\\_home.php?id=268](http://www.pascenter.org/publications/publication_home.php?id=268).

This report focuses on developing a vision of a better, more responsive long-term care system and the policies to promote it, as well as developing a strategy to put long-term care on the national policy agenda. The current long-term care system falls far short of meeting reasonable expectations for its performance. Achieving a long-term care system that meets individual needs and distributes costs equitably, the report concludes, will require greater federal involvement and financing. The report is the final product of the National Academy of Social Insurance's study panel on long-term care.

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Cohen, Gene D., *The Mature Mind* (New York, NY: Basic Books, 2005).

Drawing on the latest studies of the aging brain and mind, Gene Cohen debunks the myth of aging as an inevitable decline of body and mind. He introduces the concept of developmental intelligence, a maturing synergy of cognition, emotional intelligence, judgment, social skills, life experience, and consciousness. Drawing on the results of two groundbreaking studies, Cohen illustrates that the years after age 65 are anything

but retiring, and that creativity, intellectual growth, and more satisfying relationships can blossom at any age.

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Freedman, Marc, *Prime Time: How Baby Boomers Will Revolutionize Retirement and Transform America* (New York, NY: Perseus Books Group, 1999).

Marc Freedman predicts that a new kind of aging will bring new life to America. *Prime Time* highlights initiatives that tap retirees for such roles as foster grandparents and volunteers at free medical clinics. The book also profiles people who are now reaping the benefits of remaining socially productive. Freedman takes issue with the notion that old boomers will be a burden on the nation's health care and Social Security systems. Instead, they will be the largest, best-educated, and healthiest group of retirees ever.

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Friedland, Robert B. and Laura Summer, *Demography is Not Destiny, Revisited* (Washington, DC: Georgetown University Center on an Aging Society, 2005). Available on-line at [www.cmwf.org/usr\\_doc/789\\_friedland\\_demographynotdestinyII.pdf](http://www.cmwf.org/usr_doc/789_friedland_demographynotdestinyII.pdf).

This report provides a framework and basic data on the U.S. population and the challenges presented by an aging society. It also examines public policies that encourage and facilitate education, basic research, and how the application of promising technologies can enhance the well-being of current and future generations of older people.

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Grantmakers In Health, *Implementing the Medicare Prescription Drug Benefit*, Issue Focus, *GIH Bulletin*, April 3, 2006 (Washington DC: April 2006). Available on-line at [www.gih.org/usr\\_doc/Issue\\_Focus\\_4-03-06.pdf](http://www.gih.org/usr_doc/Issue_Focus_4-03-06.pdf).

On January 1, 2006, Medicare prescription drug coverage became available to the program's 43 million beneficiaries. To receive the coverage, however, beneficiaries must actively opt in to Medicare Part D by selecting a prescription drug plan (PDP). Seven and a half million dual eligibles, Medicare beneficiaries receiving drug coverage through Medicaid, were assigned to Medicare PDPs on January 1st.

Grantmakers In Health, *New Choices and Hard Decisions: Helping Seniors Navigate Medicare*, Issue Focus, *GIH Bulletin*, May 3, 2004. Available on-line at [www.gih.org/usr\\_doc/Helping\\_Seniors\\_Navigate\\_Medicare.pdf](http://www.gih.org/usr_doc/Helping_Seniors_Navigate_Medicare.pdf).

Educating seniors on the changes to the Medicare program has been a challenge for both the public and private sectors. Reaching the nation's 41 million Medicare beneficiaries — 35 million of whom are over the age of 65 — will require a mix of customized, one-on-one assistance and broad education campaigns. This Issue Focus proposes that providing information and referral services for seniors and their families is an area ripe for foundation work, and outlines a number of opportunities for grantmakers.

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Grantmakers In Health, *Long-Term Care Quality: Facing the Challenges of an Aging Population* (Washington, DC: 2001). Available on-line at [www.gih.org/usr\\_doc/53838.pdf](http://www.gih.org/usr_doc/53838.pdf).

For all the sophistication of our health care system, the U.S. does not have a highly developed and supportive long-term care network that takes good care of its elderly. This Issue Brief offers an overview of the primary factors influencing the quality of long-term care services, including demographics, service providers, financing, and policy and regulation. It also profiles innovative grantmaker programs.

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Iezzoni, Lisa I., *When Walking Fails: Mobility Problems of Adults with Chronic Conditions* (Berkeley, CA: University of California Press, 2003).

Roughly one in ten adult Americans find their walking slowed by progressive chronic conditions like arthritis, back problems, heart and lung diseases, and diabetes. In book, Lisa Iezzoni describes the personal experiences of and societal responses to adults whose mobility makes it difficult for them to live as they wish because of physical and emotional conditions, as well as persisting societal and environmental barriers. Iezzoni explains who has mobility problems and why; how mobility difficulties affect people's physical comfort, attitudes, daily activities, and relationships with family and friends throughout their communities; strategies for improv-

ing mobility; and how the health care system addresses mobility difficulties, providing and financing services and assistive technologies.

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The Henry J. Kaiser Family Foundation, *Medicare Chart Book 2005* (Menlo Park, CA: 2005). Available on-line at [www.kff.org/medicare/7284.cfm](http://www.kff.org/medicare/7284.cfm).

This resource features more than 80 charts and tables with detailed information about the Medicare program and the 42 million seniors and younger people with disabilities who rely on Medicare for health insurance coverage. It covers a wide range of relevant data, including state-by-state information when available, such as benefits and utilization, supplemental insurance coverage, out-of-pocket spending, and financing and future projections for the Medicare program.

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Mockenhaupt, Robin E., Jane Isaacs Lowe, and GERALYN Graf Magan, "Improving Health in an Aging Society," in Stephen L. Isaacs and James R. Knickman eds., *The Robert Wood Johnson Anthology: To Improve Health and Health Care, Volume IX* (San Francisco, CA: Jossey-Bass, 2006). Available on-line at [www.rwjf.org/files/publications/books/2006/chapter\\_02.pdf](http://www.rwjf.org/files/publications/books/2006/chapter_02.pdf).

In this chapter of *The Robert Wood Johnson Anthology: To Improve Health and Health Care, Volume IX*, the authors suggest the nation's aging population presents a unique opportunity. They set the foundation's work in aging into a context of what society needs to do to promote the health and well-being of older adults. The chapter presents five propositions about how people can age in a healthy way. For each proposition, the authors present the research supporting the proposition and then discuss the relevance of foundation-supported programs. The authors also review the successes and failures of a broad range of initiatives and suggest future paths that the foundation might take.

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Novelli, Bill and Boe Workman, *50+: Igniting a Revolution to Reinvent America* (New York, NY: St. Martin's Press, 2006). Available on-line at [www.aarpmagazine.org/books/fifty\\_plus.html](http://www.aarpmagazine.org/books/fifty_plus.html).

In this book AARP CEO Bill Novelli challenges the retirement-age generation to come together and grasp the unique opportunity that faces them to transform society. Novelli identifies several opportunities for this generation including transforming health care, reinventing retirement, revolutionizing the workplace, building livable communities, and leaving a lasting legacy.

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Prevratil, Joseph, "Taking Action in Aging Issues: Creating an Agenda, Finding Common Ground" Views from the Field, *GIH Bulletin*, June 2, 2000.. Available on-line at [www.gih.org/usr\\_doc/Aging\\_Issues.pdf](http://www.gih.org/usr_doc/Aging_Issues.pdf).

This Views from the Field article by Joseph Prevratil of the Archstone Foundation explores intersections between health and aging that could benefit from funder collaboration, including environment, disability, family caregiving, civic engagement, elder abuse, exercise and wellness, and workforce development.

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Schoenborn, Charlotte A., Jackline L Vickerie, and Eve Powell-Griner, "Health Characteristics of Adults 55 Years of Age and Older: United States, 2000-2003," *Advance Data from Vital and Health Statistics No. 370* (Hyattsville, MD: National Center for Health Statistics, 2006). Available on-line at [www.cdc.gov/nchs/data/ad/ad370.pdf](http://www.cdc.gov/nchs/data/ad/ad370.pdf).

The U.S. Centers for Disease Control and Prevention highlights the health characteristics of four age groups of older adults in this report: those 55 to 64 years, those 65 to 74 years, those 75 to 84 years, and those 85 years and over. The report provides estimates by sex, race and Hispanic origin, poverty status, health insurance status, and marital status.

Rowe, John W., and Robert L. Kahn, *Successful Aging* (New York, NY: Random House, 1998).

In this groundbreaking book John Rowe and Robert Kahn argue that aging does not have to be a painful process of debilitation. Their research shows that the influence of genetics shrinks proportionately as you get older, while social and physical habits become increasingly integral to your mental and physical health. The 10 years worth of research cited in *Successful Aging* reveal stunning facts about health in later life.



# Children & Youth

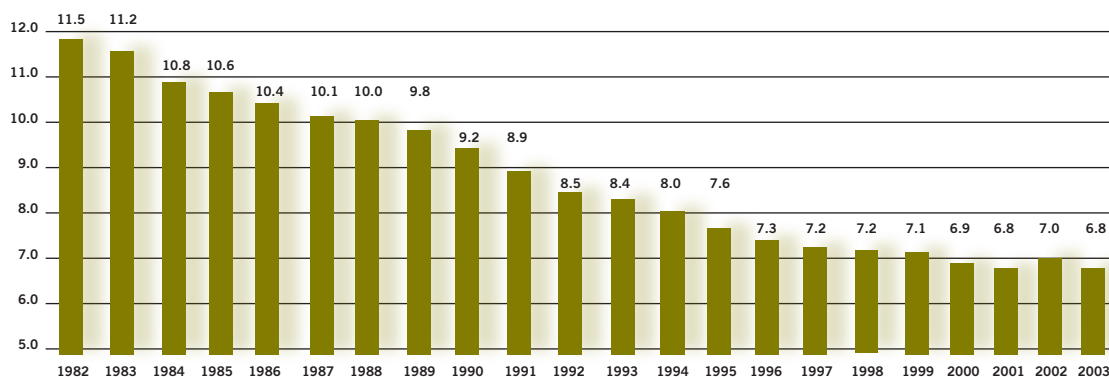


The United States has witnessed enormous improvements in children's health over the past several decades. Both childhood mortality and infectious disease rates have decreased. Rates of infant mortality, the most common indicator of child health, have dropped dramatically since 1982 (Figure 1).

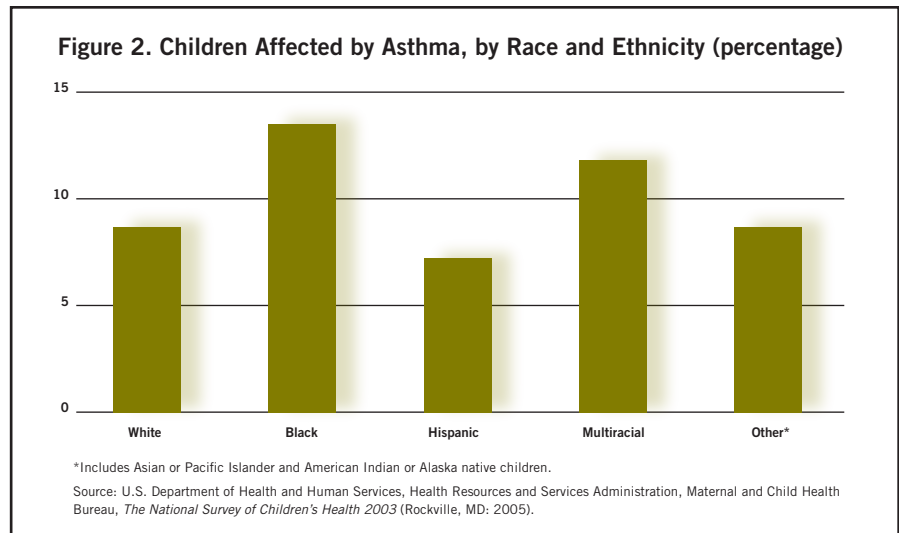
Despite these successes, the prevalence of chronic health problems such as obesity, mental illness, and asthma, is on the rise (Wise 2004). Over the past two decades, the rate of children with asthma has doubled, from 3 percent in 1981 to 6 percent in 2004 (Child Trends 2006). Over the past three decades, rates of obesity have doubled for preschool children and adolescents and have more than tripled for children aged 6 to 11 (IOM 2005). Despite the gains in infant mortality, the U.S. ranks behind many nations in this measure, including the European Union, Japan, New Zealand, the Czech Republic, and Cuba (CIA Worldbook 2006).

It is of great concern to many that these diseases and disorders are not equally distributed across the population, with some groups of children suffering more than others (Figure 2) (IOM 2004). For example, infant mortality among African Americans in 2000 occurred at a rate of 14.1 deaths per 1,000 live births, more than twice the national average of 6.9 deaths per 1,000 live births (Minino et al. 2002). African-American children are almost twice as likely to have asthma as white children (Child Trends 2006). While obesity is prevalent among all groups of children and youth, Hispanic, African-American, and Native American children are disproportionately affected (IOM 2005). Racial and ethnic minorities also experience lower rates of health insurance coverage and higher rates of poverty, making accessing appropriate health care even more difficult. Children have been the poorest age group in the U.S. since the 1980s (Wise 2004). In 2004, approximately 18 percent of all children in the

**Figure 1. Infant Mortality Rates in the U.S., 1982–2003 (per 100,000 live births)**



Mathews, T.J. and Marian F. MacDorman, "Infant Mortality Statistics from the 2003 Period Linked Birth/Infant Death Data Set" *National Vital Statistics Report* (54)16: 1-5, May 2006;  
Minino, Aialdi M., Elizabeth Arias, Kenneth D. Kochanek, Sherry L. Murphy, Betty L. Smith, "Deaths: Final Data for 2000" *National Vital Statistics Report* (50)15: 11-13, 2002.



United States lived in poverty. Over the last five years, child poverty has risen substantially, increasing by 12 percent (Koball and Douglas-Hall 2006).

Certain aspects of childhood make children's health needs different from those of adults. Illness, injury, or difficult family and social circumstances can seriously harm a child's physical and emotional development. Many complex challenges facing children—including family substance abuse, neighborhood violence, and learning problems—cannot be adequately addressed by traditional medical services and require more comprehensive care. And children are almost totally dependent on adults to identify and react to their health needs, to arrange and consent to care, and to follow treatment guidelines. For these reasons, health promotion, disease prevention, and coordinated care strategies are essential to children's health care (Halfon et al. 1996).

There are both short- and long-term consequences of poor childhood health. Healthy children are

more ready and able to learn, and are more likely to become healthy adults who can contribute to society. Children who are in poor health face disadvantages that often persist throughout their lives. Unhealthy children face higher rates of failure in school, often leading to additional societal expenditures for special education, mental health, and juvenile justice. Unhealthy children also often become unhealthy adults, with research showing that many adult health conditions and disparities have their roots in childhood. For this reason, poor childhood health is linked with lower rates of productivity later in life, with the result of increased rates of social dependency among individuals and diminished economic performance for the nation as a whole (Halfon 2005).

Over the past several decades, the federal government has implemented several popular and far-reaching programs to improve access to health services for the nation's low-income children and youth. For example, in 1981, the Maternal and Child Health Services Block Grant (Title V) recognized the critical issues

facing children with special health care needs (Children with Special Needs), facilitating the development of family-focused, community-based systems of care. A decade later, in 1991, the Health Resources and Services Administration (HRSA) began the Healthy Start initiative to reduce infant mortality. Introduced as a five-year demonstration program, community-based systems were tasked with reducing the infant mortality rate by 50 percent as well as improving the health and well-being of women, infants, children and their families. Originally, 15 demonstration programs were funded for a five-year period, including 13 urban and 2 rural programs. In 2002, HRSA funded 96 Healthy Start programs. Required elements of the program include a focus on reducing infant mortality, inclusion of the local community in planning, assessment of local needs, public education, a package of innovative health and social services for pregnant women and for infants, and an evaluation of the initiative.

Medicaid is the single largest health insurance program for children. In 2003, over 25 million children were enrolled in Medicaid. While children account for nearly half of all Medicaid enrollees, they account for only 19 percent of total program spending (Kaiser Commission on Medicaid and the Uninsured 2004). Medicaid has boosted the overall health of children through increased primary care utilization, decreased mortality and hospitalization rates, improved school readiness, and controlled health care costs.

The key component of Medicaid coverage for children is the manda-

tory Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. EPSDT includes a vast range of benefits, including screening; immunizations; health education; and vision, dental, and hearing services. States are required by law to provide EPSDT services to eligible children whether or not the state Medicaid plan provides the services to the rest of the Medicaid population. In 1989, EPSDT was expanded to benefit children with special health care needs.

The creation of the State Children's Health Insurance Program (SCHIP) in 1997 expanded children's public health insurance coverage. SCHIP provides health coverage to low-income children who live in families with income or assets above Medicaid eligibility levels, yet whose parents cannot afford to purchase private insurance. When SCHIP was established, the federal government committed \$48 billion over 10 years to support the state-administered program. Each state receives an annual allotment of this funding, at a match rate higher than that for the Medicaid program.

SCHIP has resulted in major improvements in children's access and coverage. Under SCHIP, states have worked to improve enrollment and retention processes and have used many different outreach strategies. Declines in the number of uninsured children have been associated with the growth in SCHIP enrollment, and the program has been shown to reach the low-income children it was designed to target. SCHIP coverage has been found to diminish unmet need, boost preventive care, raise the

probability of having a usual source of care, lessen parents' stress and financial barriers, and improve children's access to oral health care. Medicaid has also increased enrollment of children by adopting many of the novel enrollment and retention procedures used in SCHIP (GIH 2006). Some argue that this progress is at risk, however, since states have only a few ways of cutting Medicaid and SCHIP costs, most of which transfer the burden to patients and their families (GIH 2006).

Schools can play an important role in the provision of health care services. The concept of school-based health centers (SBHCs) began in the late 1960s with pediatrician-formed school clinics in cities such as Dallas, Minneapolis, and Cambridge, Massachusetts (Morone et al. 2001). The programs usually provide comprehensive services and employ a variety of health professionals, including nurse practitioners, mental health care providers, nutritionists, and part-time physicians. Some programs provide laboratory tests and dental care. Initially, these centers were a lightning rod for controversy, particularly because of concerns about the distribution of contraceptives, but eventually gained widespread support. In 1994, HRSA launched a grant program, Healthy Schools, Healthy Communities, to support the development and operation of school-based health centers that provide preventive and comprehensive primary health care services to children at risk for poor health outcomes and other medically underserved populations. In other communities, students are served by school-linked services involving collaboration between schools, health

care providers, and social service agencies. Typically, school personnel provide students with referrals to services that are provided on or near school grounds.

Neuroscience as a discipline exploded during the second half of the 20th century, creating new knowledge about how children develop and what they need to succeed. Contrary to earlier thinking, brain development is now known to continue throughout adolescence and is not completed until early adulthood. Assisted by new imaging technologies, researchers have found that early adolescents experience a second surge in brain growth and change (Giedd et al. 1999). Growth in gray matter—the thinking part of the brain—during early adolescence may present a second window of opportunity for the acquisition of skills and abilities. There is also emerging evidence that adolescent brains process information differently than adults, which may help explain some characteristics of adolescent behavior. For example, one study found that young teens process emotional information in an area of the brain that mediates fear and other gut reactions, whereas older teens and adults process the same information in the frontal lobe, which handles tasks like planning and reasoning (National Institute of Mental Health 2001). Adolescents may also be more likely to respond to interpersonal interactions in an impulsive and emotional way, rather than by thinking through an appropriate response. Finally, there is evidence that adolescent brains are more susceptible than those of adults to short-term impairment and long-term damage from alcohol and

tobacco, and potentially from other drugs as well (GIH 2002).

This new information is driving new approaches to adolescent health. Positive youth development is not a specific program, but rather an approach to structuring services, systems, and supports for youth so that young people develop the skills and competencies they need to thrive and enter adulthood ready to face the numerous challenges of adult life. Grounded in the concept of resiliency, positive youth development seeks to help youth overcome or deal with negative conditions in their environments. The Minneapolis-based Search Institute identified 40 developmental assets that young people need to grow up to be healthy, caring, and responsible, including family support, safety, positive peer influences, school engagement, honesty, and self-esteem (GIH 2002). Positive youth development approaches seek to take advantage of opportunities presented by the various stages of adolescent development to influence behaviors, attitudes, and self-esteem (GIH 2002). Successful approaches have been linked to improved health outcomes, such as decreased teen pregnancy rates, lower rates of substance use, and fewer psychosocial problems. Overall, the U.S. teen pregnancy rate dropped 30 percent from 1991 to 2002 (Guttmacher Institute 2006).

### Philanthropic Efforts

Grantmakers have devoted significant resources to children's health over the past 25 years. Total foundation giving for children and youth reached a record \$3.2 billion in 2004 (Foundation Center 2006).

## EARLY CHILDHOOD

Programs that promote early and continuous prenatal care have been helpful in reducing the rates of preterm births, leading to lower rates of infant mortality. Home visitation programs, for example, are designed to help provide families with the skills they need to care for a new child. These programs are also proven to contribute to the healthy development of young children.

Robert Wood Johnson Foundation (RWJF) began the Nurse Home Visiting Program, now called the Nurse-Family Partnership, to help improve health outcomes for children born into disadvantaged families. The program began in 1978, built on research by then graduate student David Olds (Alper 2002). His theory was that poor, first-time parents often lack the necessary skills and supports that are the foundation of good parenting. Through the program, Olds set out to help women understand the influence of their behavior on the behavior of their children. Nurses, who received thorough training on maternal and infant development, visit women at various stages of pregnancy and through the child's second birthday to assist and coach the new family. Long-term research proved the positive effects—fewer runaways, less frequent use of tobacco and alcohol—of the program on children through adolescence. Research has shown that these programs have other positive effects as well: decreases in maternal smoking, increased spacing between pregnancies, and increased birth-weight. The results were so convincing that RWJF continued funding the program, as did other funders,

including The Commonwealth Fund, The David and Lucile Packard Foundation, The Pew Charitable Trusts, and The Colorado Trust. Today, the Nurse Family Partnership serves over 20,000 families in 22 states, with the hope that the program will be replicated in other areas (Nurse-Family Partnership 2006).

Over the past three decades, the Nurse-Family Partnership has evolved based on theory and research. One of the challenges Olds identified was that some home visiting programs do not work well because of poor implementation. To be effective, programs must invest not only in developing curricula but also in training nurses and implementing the program in the community. In one state, Olds and his colleagues worked to assure appropriate implementation by developing an Internet-based information system to improve monitoring efforts of local programs.

The Commonwealth Fund has also devoted significant resources to early childhood development. In 1994, the fund supported the creation of Healthy Steps, a national initiative focused on improving the quality of preventive health care for children and toddlers with an emphasis on fostering a close relationship between parents and providers. In a pediatric or family practice, a Healthy Steps team includes a specialist, such as a social worker or nurse, with child development

## Total foundation giving for children and youth reached a record \$3.2 billion in 2004.

training. The whole-child, whole-family model is designed to provide comprehensive services to children as well as support the parents and caregivers in the process of child-rearing. In 1995, the program developed 24 original sites, with funding from local and national foundations such as The Boston Foundation, The Dorothy Rider Pool Health Care Trust, W.K. Kellogg Foundation, and the Kansas Health Foundation. In 2003, RWJF became the lead national funder, and by 2005, the number of Healthy Steps sites grew to 43.

In 1999, The Commonwealth Fund launched the Assuring Better Child Health and Development (ABCD) initiative to strengthen the capacity of the health care system to support the early development of children from low-income families. The focus of the program is to help states improve the delivery of early childhood development services to children through their Medicaid programs. The four participating Medicaid programs—North Carolina, Utah, Vermont, and Washington—learned lessons that can be replicated in other states, including the importance of interagency collaboration, strategies for reimbursement and financing, and the significance of improving referral services. In January 2004, the fund launched the second phase, ABCD II, to help states promote the healthy mental development of low-income children under age five.



School-based health centers are an important provider of health services to school-aged children. The Health Foundation of Greater Cincinnati has worked extensively in this area, funding planning and development, SBHC start-up projects in schools, evaluation of SBHCs in the greater Cincinnati area, collection of data about the effectiveness of SBHCs across the nation, and the dissemination of evaluation results to help generate and retain community support. As part of its ongoing commitment, the foundation established the Center for the Promotion of Lifelong Health, now known as the Child Policy Research Center. The original grant's intention was to conduct a three-year study of the impact of school-linked health

**School-based health centers are  
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to school-aged children.**

services provided in elementary schools. The outcomes evaluated in the project include school connectedness, school absences, emergency department utilization, and referrals to off-site services. The process evaluation examined characteristics of school-linked health service users, the number of student encounters, reasons for visits, chronic illnesses of students, and parental satisfaction with services. Data collected for children with asthma suggested that school-linked programs have significant effects on the quality of care a child receives.

The foundation also commissioned a study to determine the effectiveness of funded SBHCs. Part of the study

evaluated how SBHCs affect students' health status, use of healthcare services, and school attendance. Another component looked at how the health care costs for students enrolled in Medicaid before and after the centers opened. The studies revealed, by the end of the evaluation period, that SBHC users had higher health status ratings and achieved those levels without significant increase in health care costs. Specifically, the evaluation found that every dollar spent on operating costs generated about \$2 in social benefits.

**DISPARITIES**

The Blue Cross Blue Shield of Minnesota Foundation, through its Growing Up Healthy in Minnesota initiative, made grants to nine organizations around the state to improve access to and use of preventive medical and dental services for children and teens. Focused particularly on the needs of immigrant communities and communities of color, the \$1.4 million initiative aims ultimately to improve the health of Minnesotans at highest risk for lifelong health disparities. Grantees included organizations providing direct health and dental care, education and referral services, and curriculum development and training groups. In two years, the program reached an estimated 17,500 people, approximately 6,000 of whom were children of color. Through Growing Up Healthy, grantees formed collaborations with community agencies serving immigrant groups or communities of color. Health and dental care providers strengthened their cultural competence by working with bicultural or bilingual community health workers. Grantee organizations also helped change

dental policy through advocacy work, integrated a wellness and fitness approach into a local public school system, and worked with faith leaders to change cultural norms regarding preventive health (Decker, Gerrard and Owen 2005). Using lessons learned from the initiative, the foundation developed Growing Up Healthy: Kids and Communities, a program that focuses on supporting culturally appropriate and community-based partnerships to improve the social determinants of children's health.

#### TEENAGE YEARS

The preteen period, between the ages 9 and 13, is an important time of a child's development. The Lucile Packard Foundation for Children's Health has focused on promoting the behavioral and emotional health of this often overlooked group. The foundation has devoted significant resources to organizations in the San Mateo and Santa Clara counties in California for a variety of programs, including an after-school program for preteen girls to build social and behavioral skills, child abuse prevention programs, and other youth development activities. An evaluation of the foundation's grants in this area found that balancing school- and community-based programs makes sense for reaching the greatest number of preteens. Successful programs target specific subgroups of youth and provide supportive relationships for youth.

In 1997, The Colorado Trust launched Assets for Colorado Youth (ACY), a six-year, \$10 million statewide effort based on the positive youth development model. Built on the Search

### The preteen period, between the ages 9 and 13, is an important time of a child's development.

Institute's 40 developmental assets, ACY originally provided grants to youth-serving agencies and community groups across Colorado and eventually evolved into an independent 501(c)3 organization.

OMNI Institute's extensive evaluation of the program yielded several results. First, the evaluators identified that the asset-building approach is different from other youth development programs. By connecting social change to everyday actions, grantee staff were more aware of the opportunities they had to shape youth. Second, asset building promotes self-awareness, relationship building, and empowerment. Finally, while difficult to prove the effort was indeed effective, the evaluators indicated that asset building caused grantee staff to be more aware of the potential of young people, which helped shape future programming. Organizations, as a result, were forced to examine their networks and realign if necessary to improve services (OMNI Institute 2003).

In response to alarmingly high rates of teenage pregnancy statewide, The California Wellness Foundation launched its 10-year, \$60 million Teen Pregnancy Prevention initiative in 1995. The foundation's board was concerned with the consequences associated with teen pregnancy, such as low birthweight babies and lower educational attainment for teen mothers. Because of the complexity of the issue, the board recognized

the need for a long-term commitment of resources. After examining literature on the issue, it was decided that a key component of the program would be focusing on the role of adults to prevent teen pregnancy. Over 10 years, the foundation has supported a variety of organizations, such as research institutes, education and policy advocacy programs, and community-based direct service agencies. Through work with grantees, the initiative has succeeded in filling gaps in knowledge about teenage pregnancy, in informing policymakers of strategies to prevent teenage pregnancy, in building the capacity of the state's adolescent health service providers, and, as hoped, in helping to reduce the state's teenage pregnancy rate. Since the initiative's conclusion, the foundation has continued to support teen pregnancy prevention programs. For instance, in 2005, the foundation awarded a three-year, \$225,000 grant to a new rural health clinic to provide access to contraceptive and reproductive health services to teens. Funding was also provided to convene a youth advisory council to help direct teenage pregnancy prevention services and programming. Eventually, the clinic will expand its services to operate as a primary care facility, offering a broad range of preventive health services for teens.

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# Fast Facts

## Health Indicators

At least 24 countries, including Japan, Cuba, and the Czech Republic, rank better than the U.S. on infant mortality (Starfield 2004).

The rate of low birthweight babies has increased from 6.8 percent in 1980 to 8.1 percent in 2004 (Federal Interagency Forum on Child and Family Statistics 2006).

In 2004, 83 percent of children ages 19 to 35 months had received the recommended combined series of vaccines, compared with 76 percent in 1996 (Federal Interagency Forum on Child and Family Statistics 2006).

Dental caries (tooth decay) is the single most common chronic childhood disease (HHS 2003).

In 2004, 18 percent of children were overweight (Federal Interagency Forum on Child and Family Statistics 2006).

The rate of children with asthma doubled, from 3 percent in 1981 to 6 percent in 2004 (Child Trends 2006).

Overall, the U.S. teen pregnancy rate dropped 30 percent from 1991 to 2002 (Guttmacher Institute 2006).

The rate of teen smoking decreased from 36 percent in 1997 to 29 percent in 2001 (CDC 2002).

Injuries, including homicide, suicide, and accidents, account for three of four deaths among adolescents ages 15 to 19 (Federal Interagency Forum on Child and Family Statistics 2006).



## Demography

Children under age 18 represented 25 percent of the population in 2004, down from a peak of 36 percent at the end of the baby boom in 1964. The number of children is projected to increase to 80 million and represent 24 percent of the population in 2020 (Federal Interagency Forum on Child and Family Statistics 2006).

In the U.S., 13 percent of children have at least one special health care need (Association of Maternal and Child Health Programs 2005).

Thirteen million children live in poverty. This number has increased 10 percent to 12 percent over the past five years (Brookings Center on Children and Families 2006).

In 2004, 16.1 per 1,000 infants and toddlers were victims of abuse or neglect (Urban Institute 2006).



## Access to Health Care

Twelve percent of all children are uninsured; 20 percent of children in low-income families are uninsured (Kaiser Commission on Medicaid and the Uninsured 2005).

In 2004, 29 percent of uninsured children had no usual source of health care (Federal Interagency Forum on Child and Family Statistics 2006).



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## Recommended Reading

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This essay examines the wide range of approaches employed by the foundation to improve the health of all children. The authors demonstrate how the foundation shifted its strategies in response to social and political changes and offer suggestions about how to improve children's health based on over 25 years of experience.

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Brodeur, Paul, "School-Based Health Clinics," in Stephen L. Isaacs and James R. Knickman, eds., *To Improve Health and Health Care 2000: The Robert Wood Johnson Foundation Anthology* (San Francisco, CA: Jossey-Bass, 1999).

Robert Wood Johnson Foundation has been involved in school-based health for over 25 years. This essay describes the foundation's work in establishing some of the first school-based health clinics in the nation as well as examines how to sustain the projects in the long term.

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Federal Interagency Forum on Child and Family Statistics, *America's Children in Brief: Key National Indicators of Well-Being, 2006* (Washington, DC: U.S. Government Printing Office, 2006).

Since 1997, the Federal Interagency Forum on Child and Family Statistics has published this annual report that includes detailed information on the well-being of children and families. The forum updates all data on its Web site (<http://childstats.gov>), and the report provides indicators such as teen birth rates, percentage of children living in poverty, and percentage of overweight children.

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Grantmakers In Health, "Adolescence to Adulthood: Crossing the Threshold," Issue Focus, *GIH Bulletin*, November 6, 2006.

The period between adolescence and adulthood is a time of great transition. This article outlines major health-related issues for transition-age youth and highlights some important work that foundations have been pursuing.

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Grantmakers In Health, *In Harm's Way: Aiding Children Exposed to Trauma* (Washington, DC: 2005).

Every year, thousands of children nationwide experience trauma as a result of exposure to violence, abuse, natural disasters, severe illness or injury, loss of loved ones due to violence or accident, or forced relocation. This Issue Brief focuses on the needs of children exposed to trauma, strategies for early identification and intervention, and ensuring the provision of timely and appropriate services to them and their caregivers.

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Grantmakers In Health, *More Coverage, Better Care: Improving Children's Access to Health Services* (Washington, DC: 2006).

This Issue Brief covers how the current health care system succeeds and fails for children, emerging policy developments, what grantmakers are currently doing to promote children's access to health services, and lessons learned to help guide future work.

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Institute of Medicine, *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Washington, DC: National Academy Press, 2000).

This report reviews the science of early childhood brain development. The report recommends that new investments in children's health take advantage of the research on early childhood development to improve existing policies aimed at raising and educating young children.

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Lawrence, Steven, Lauren LeRoy, and Anne L. Schwartz, *Foundation Funding for Children's Health: An Overview of Recent Trends* (New York, NY: Foundation Center, 2005).



This detailed examination of U.S. foundation health giving that specifically benefits children and youth studies funding trends from 1999 through 2003. The report breaks out giving by priority area, geographic region, and type of support.



Wise, Paul H., “The Transformation of Child Health in the United States,” *Health Affairs* 23(5): 9-25, 2004.

This *Health Affairs* article outlines trends in children’s health, with a specific look at the social disparities that persist. The author provides a thorough examination of the child health system—what works, what is broken and explains the implications for both practice and policy.



# Health Promotion

Health promotion is “the combination of educational and environmental supports for actions and conditions of living conducive to health” (Green and Krueter 1999). Moving beyond the traditional medical treatment of illness and injury, health promotion focuses on the social, physical, economic, and political factors affecting health, and includes activities such as tobacco control, injury prevention, immunization campaigns, and promoting active living and healthy eating.

**Moving beyond the traditional medical treatment of illness and injury, health promotion focuses on the social, physical, economic, and political factors affecting health.**

A groundbreaking study published in the *Journal of the American Medical Association* in 1993 showed that approximately half of all causes of premature death in America are linked to social and behavioral factors (McGinnis and Foege 1993). This study challenged the conventional wisdom that limited access to medical care was responsible for poor health outcomes by demonstrating that the most prominent contributors to mortality in the United States in 1990 were actually lifestyle or behavior-related, and included tobacco use (an estimated 400,000 deaths), diet and activity patterns (300,000), alcohol (100,000), firearms (35,000), sexual behavior (30,000), motor vehicles (25,000), and illicit use of drugs (20,000) (McGinnis and Foege 1993). Pointing out that less than 5 percent of the money spent annually on health care in America is devoted to

reducing these risks, the authors questioned the rationality of current national health policy and resource allocations.

A recurring theme in the field of health promotion is the question of who is responsible for assuring healthy behavior. Larry Green and Marshall Krueter (1999), two leading scholars in the field, note that “its evolution swings like a pendulum from one era, with heavy reliance on centralized government and institutions for environmental and policy change, to the next era, with heavy reliance on individuals and families or local government to change behavior, and back.” Recent experience with tobacco control and the obesity epidemic suggest that individuals, communities, and policymakers in both the public and private sectors all must be engaged.

Although much work remains, the recent reduction of tobacco use among Americans represents one of the greatest health success stories of the past 25 years. Left unabated, the growing obesity epidemic, however, threatens the progress made in improving Americans’ health. Moreover, the continued focus on funding treatment over prevention, along with questions about the efficacy of prevention strategies, limits the potential of health promotion strategies.

## Looking Back—Roots in Health Planning

An evolution in thinking about health promotion strategies grew out of the health planning experience of the post-World War II era. At that time, most formal health planning activities were focused on supporting the distribution and use of increasingly technological and

hospital-based medical services. With escalating health care costs, a shift began in the 1970s to find ways to reduce the use of health services. This spurred efforts to develop educational strategies and incentives that would help the public become more self-sufficient in health, to prevent diseases and injuries, to promote health, and to become better informed consumers of health care services (Green and Krueter 1999).

About the same time, new health promotion models emerged that provided alternatives to the models of addressing needs by building facilities. One of the most widely used models, Precede/Proceed, guided practitioners through a series of steps designed to help make social, epidemiological, behavioral, and environmental assessments and identify behavioral interventions. This model formed the basis for national community health promotion programs by The Henry J. Kaiser Family Foundation and the Centers for Disease Control and Prevention. (Green and Krueter 1999).

1974 marked a turning point in health promotion with the Government of Canada publishing a landmark policy statement entitled *A New Perspective on the Health of Canadians* calling for giving “human biology, the environment, and lifestyle as much attention as it has to the financing of the health care organization so that all four avenues to improved health are pursued with equal vigour” (LaLonde 1974).

### The Healthy People Agenda

Also in 1974, the U.S. Congress passed the Health Information and Health Promotion Act, creating an

office within the U.S. Department of Health and Human Services known today as the Office of Disease Prevention and Health Promotion. This office led the development of Healthy People 2000 and the subsequent Healthy People 2010 which reflect an objective process for setting national goals for health promotion and disease prevention.

Like its predecessor, Healthy People 2010 was developed through a broad consultation process, built on the best scientific knowledge and designed to measure programs over time. The national health objectives galvanized thinking about how to use community health measurement to drive accountability in health improvement programs, and served as the basis for the development of state and community plans. They also helped spur the development of tools by the Centers for Disease Control and Prevention (CDC) and partners such as the National Association of County and City Health Officials (NACCHO) that are used primarily by local public health agencies to assess, plan, and mobilize community health promotion efforts.

### Social Capital & Healthy Communities

Additional work in the 1990s promoted new ways to measure health and advanced the idea of building social capital to improve community health. Challenging the traditional approach to solving urban problems, which focuses service providers and funding agencies on the needs and deficiencies of neighborhoods, John Kretzmann and John McKnight argued that community assets are the key building blocks in sustainable urban and rural community

revitalization efforts. These community assets include the skills of local residents, the power of local associations, the resources of public, private, and nonprofit institutions, and the physical and economic resources of local places. While not designed specifically as a health promotion strategy, McKnight and Kretzmann provided a new framework known as asset-based community development (Kretzmann and McKnight 1993).

The healthy cities and communities movement also emerged in the 1990s. The movement promoted broad community engagement to resolve systemic challenges to community health, and advanced the idea of using community health indicators to both measure and drive progress (Association for Community Health Improvement 2006). Led by a number of groups including the Community Care Network Demonstration Program, ACT National Outcomes Network, and the Coalition for Healthier Cities and Communities, these efforts expanded the technical assistance available to communities and helped foster a network of community health advocates.

### Workplace Wellness

Growth in health care costs in the 1970s also created interest among employers in health promotion. The goals of worksite wellness programs are to improve employee health, reduce absenteeism, improve productivity, and reduce costs. Programs typically include health education, screening, and behavioral interventions on issues such as smoking cessation, weight loss, and stress management. The number of employers providing such programs has increased over time; over 80



percent of worksites with 50 or more employees, and almost all large employers with more than 750 employees, now sponsor at least one health promotion activity (Riedel 2001). A review of the evidence on health promotion programs reported impressive results: 18 of 18 intervention studies found that absenteeism dropped after the introduction of the health promotion program, and the six studies that reported cost benefit ratios averaged savings of \$5.07 for every dollar invested. Nearly all studies also found that medical care costs declined after the introduction of a health promotion program (Aldana 2001). Today, the consequences of obesity are increasingly gaining the attention of employers.

### Preventive Health Guidelines

In the 1990s, the CDC convened the Task Force on Community Preventive Services. This expert body was tasked with developing recommendations for practitioners and decisionmakers on community preventive services such as laws, education campaigns, health care system changes, and policies and programs aimed at improving health among populations of people. Out of this effort came *The Guide to Community Preventive Services*, which filters the scientific literature to summarize what is known about the effectiveness, economic efficiency, and feasibility of various interventions. To date, the task force has published over 100 findings across 16 topic areas, disseminating them through peer-reviewed journals and the Internet.

*The Guide to Clinical Preventive Services* is a companion guide to evidence-based prevention services for individuals. The primary audience

*The Guide to Community Preventive Services* filters the scientific literature to summarize what is known about the effectiveness, economic efficiency, and feasibility of various interventions.

for this guide is primary care clinicians, although the recommendations are also used to inform insurance benefit design. Information on the effectiveness of such interventions is changing health insurance, albeit slowly. Medicare introduced pneumococcal vaccine as a benefit in 1981, and screening for certain cancers was added later. Most recently, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 created a new benefit enabling Medicare beneficiaries who enroll in Medicare Part B to receive a one-time Welcome to Medicare visit within six months of their enrollment. This visit covers vaccinations, screening, and counseling, and is expected to expand the use of clinical preventive services.

### Building on What We've Learned About Changing Behaviors

As funders consider what is next in health promotion, it is important to reflect on what has been learned about the components of effective behavioral change interventions. Behavior that presents a risk to health is influenced not only by individual choices, but also by human biology, environment, social norms, culture, and access to social support, information, and health care services (IOM 2001). As a result, interventions that involve only the individual (for example, approaches that rely solely on personal self-control or willpower) are unlikely to change long-term

**A comprehensive strategy to promote healthy behaviors must include interventions at six levels to ensure that individuals are empowered to make healthy choices and have access to the support and services needed to sustain those choices.**

behavior unless other factors in a person's environment, such as family relationships, work situations, and social norms, happen to be aligned to support a change. The opportunities lie in a systems-oriented approach that addresses both individual and environmental factors. A combination of approaches that address individual, family, community, and societal factors has the greatest likelihood of being effective in helping people to change their behavior and to sustain behavior changes over time (IOM 2001).

A 2003 study by the Institute of Medicine that examined interventions to modify unhealthy behaviors found that effective strategies share three common elements (IOM 2003):

- They help people develop the skills needed to change behavior. In addition to knowing what they need to do to be healthier, people need to know how to change their behaviors. That is, they need information about strategies to maintain motivation and deal with barriers to behavior change.
- They provide comprehensive and sustained interventions. Multi-component, sustained interventions are more effective than single-component approaches of short duration. This is particularly true for sustaining behavior change, which is a greater chal-

lenge than achieving short-term behavior change.

- They ensure access to social and other supports that help people maintain changes in behavior. Interventions that focus only on individual self-control or willpower leave many factors to chance and are unlikely to succeed over the long term. Social support from family, friends, and others engaged in similar behavior change efforts can help people maintain their motivation. Other supports, such as environmental changes or campaigns that seek to change social norms, can help remove some barriers to behavior change.

A framework developed by the Prevention Institute, the Spectrum of Prevention, includes six complementary levels of intervention: strengthening individual knowledge and skills, promoting community education, educating providers, fostering coalitions and networks, changing organizational practices, and influencing policy and legislation (Prevention Institute 2006). When implemented together, these interventions are more likely to produce successful results than any single activity. A comprehensive strategy to promote healthy behaviors must include interventions at all six levels to ensure that individuals are empowered to make healthy choices and have access to the

support and services needed to sustain those choices.

The Spectrum of Prevention framework can be a useful template to create a health promotion plan. The Carlisle Area Health and Wellness Foundation, for example, adopted the Spectrum of Prevention in development of its plan for prevention and health promotion in 2004. Building on a health assessment that identified chronic diseases and unhealthy behaviors as top challenges, the foundation created a prevention and education task force to recommend ways to intervene at an early stage to stop or minimize diseases. The task force also used the Healthy People 2010 objectives to shape its thinking on the top issues identified in the assessment, including asthma, cancer, cardiovascular disease, diabetes, and substance abuse. They found that the Spectrum of Prevention framework was useful in thinking about addressing root causes, and helped lead to practical recommendations for preventing disease. The task force's work helped inform foundation activities including support for a workplace wellness program involving over 10,000 employees in 10 companies working collaboratively. The foundation is also supporting a new coalition, Carlisle Regional Advocates for Nutrition & Activity, involving over 20 organizations focused on youth, schools, community, and the workplace. Because of their networking, healthier choices in school lunches and vending machines have been instituted, school health councils are advocating for additional changes, and a new guide was developed to promote free physical activity opportunities in the region's public parks and trails. Finally, the foundation reports that its advocacy is

## THE TOBACCO REDUCTION SUCCESS STORY

One of the great health success stories of the last 25 years is reduction in tobacco use among Americans. Between 1982 and 2005, overall smoking rates dropped from 30 percent to 22 percent among high school seniors, and from 32 percent to 16 percent among adults (CDC 2007). Building on the 1964 Surgeon General's report on smoking and health, health promotion professionals advocated for a series of smoking bans, tobacco tax increases, and advertising restrictions that were implemented in the 1980s and 1990s. These efforts dramatically changed the environment and social norms from one that previously tolerated—if not outright encouraged—smoking, to one in which smoking is increasingly seen as socially unacceptable. This movement built upon increasing evidence of tobacco company malfeasance and the relentless toll smoking imposed on Americans' health. This culminated in November 1998, when the tobacco industry agreed to a Master Settlement Agreement with 46 states, paying \$206 billion in recognition of the health care costs previously incurred by states to treat tobacco-related illness.

The national decline in youth smoking that began in the late 1990s may have stalled, however. Factors that might have contributed to this stall include: smaller annual increases in the retail price of cigarettes; potentially less exposure or availability among youths to mass media smoking-prevention campaigns; less funding for comprehensive statewide tobacco-use prevention programs; substantial increases in tobacco industry expenditures on tobacco advertising and promotion in the United States from \$5.7 billion in 1997 to \$15.2 billion in 2003; and, smoking in movies, which has been linked to youth smoking, increased rapidly beginning in the early 1990s and by 2002 was at levels observed in 1950 (CDC 2006). These factors illustrate the challenges in sustaining and adapting health promotion strategies to ensure that they stay relevant.

There are signs that provide hope that tobacco control strategies can adapt to changing circumstances. The Surgeon General's 2006 report, *The Health Consequences of Involuntary Exposure to Tobacco Smoke*, concluded that there is no risk-free level of exposure to secondhand smoke and calls for complete indoor smoking bans. This report may provide new motivation for many states and localities to build on the lead of California, which became the first state in the nation to ban smoking in bars in 1998.

helping move Pennsylvania closer to becoming a smoke-free state (Carlisle Area Health and Wellness Foundation 2004).

### Taking on Tobacco

Because tobacco use represents the leading cause of preventable death in the U.S., this issue has attracted significant philanthropic resources. Since the early 1990s, Robert Wood Johnson Foundation has made over

500 tobacco control grants, encompassing research, policy interventions, prevention and cessation programs, education and advocacy, coalition building, leadership training, convening, and communications activities.

**SmokeLess States:** National Tobacco Policy Initiative was one of the largest investments made by the foundation with \$99 million autho-

rized in grants since 1992. Through this program, grants were awarded to nongovernmental organizations with the intention that they would educate the public and policymakers about the tobacco problem. Two features about the program are significant: the foundation encouraged its grantees to be activists, and advocacy was emphasized to bring about policy change. The program relied heavily on three major health voluntary organizations, the American Cancer Society, the American Heart Association, and the American Lung Association, to provide financial support and funds to help lobbying efforts which the foundation would not support directly.

At its height, SmokeLess States supported statewide coalitions in 42 states that worked to change policies such as increasing excise taxes on tobacco, promoting clean indoor air, and financing costs of cessation and treatment programs. The program concluded in 2004, and a review published in 2005 included the following reflections:

- When considering what will be needed to maintain the gains made over the project's life, the foundation realized it should have acted sooner and more aggressively to sustain efforts in the states and should have encouraged the coalitions to diversify their funding sources earlier in the program.
- Efforts to diversify the coalition membership were not as successful as hoped. The foundation should have made more clear its belief that the tobacco control movement will not survive if it does not grow to represent the population of the states.

- Clear benchmarks and the ability to measure progress were critical. While they encountered resistance, program officials believe that utilizing benchmarks and offering technical support to help coalitions meet them was well worth the effort.
- The program demonstrated that advocacy, though not a strategy employed frequently by foundations, can be an effective way to improve the health of the public.
- It is vital to recognize the contribution of grantees and staff, and in hindsight, the foundation wished it had celebrated the state coalitions' achievements more than just annually.
- Overall, the program was considered a success, and in addition to insight on the effects of advocacy, this program demonstrates the role of coalitions in bringing about social change (Gerlach and Larkin 2005).

The American Legacy Foundation focuses exclusively on tackling the nation's leading killer. Established in March 1999 as a result of the Master Settlement Agreement between the states and the tobacco industry, the foundation develops national programs that address the health effects of tobacco use through several strategies. These include grants; technical training and assistance; youth activism; strategic partnerships; countermarketing and grassroots marketing campaigns; public relations; research; and community outreach to populations disproportionately affected by the toll of tobacco.

The American Legacy Foundation's work to reduce tobacco use among young people has demonstrated the potential of a multidimensional media campaign. The truth<sup>®</sup> campaign is a hard-hitting media campaign that uses edgy television, radio, and print ads featuring youth-led activism against tobacco companies and exposing the industry's deceptive marketing techniques. Advertising, grassroots and promotional events, and an interactive Web site give teens the facts about the health effects, social costs, and addictiveness of tobacco so they can make informed decisions about tobacco use. The effects of this campaign have been stunning: in 2002, there were 300,000 fewer youth smokers because of truth<sup>®</sup> (Farrelly et al. 2005). The foundation has also committed nearly \$35 million over four years in grant awards to 17 states to foster statewide youth-led efforts against tobacco use. The foundation, however, received what is likely the last guaranteed payment in 2003. As a result, the foundation and the truth campaign are now facing a serious funding challenge. Efforts are being made to raise funds to continue the truth<sup>®</sup> campaign and the foundation's other programs.

### The Obesity Challenge

The dramatic rise of obesity in America in recent decades also illustrates a dire need for effective health promotion strategies that facilitate better nutrition and physical activity. The U.S. Surgeon General, Institute of Medicine (IOM), and director of the Centers for Disease Control and Prevention (CDC) have all declared that the U.S. is facing an obesity epidemic. During the 1960s and 1970s, 13 percent to 14 percent of Americans were classi-

fied as obese. That number began rising during the 1980s and increased at a rapid pace throughout the 1990s (Hedley, et al. 2004). Today, two-thirds of U.S. adults (over 97 million people) are overweight or obese. Close to 31 percent of U.S. children (over 9 million) are overweight or at a risk of becoming overweight, and childhood obesity has more than doubled in the past 25 years (Hedley, et al. 2004; Ogden et al. 2006).

The Institute of Medicine's (IOM) 2005 report, *Health in the Balance: Preventing Childhood Obesity*, found that many of the factors driving obesity rates stem from widespread cultural changes that have significantly altered the environment in which food and physical activity choices are made. Historically, however, strategies to reduce obesity have focused on individual behavior modification and treatment without addressing the context in which these behavioral choices are made (Joint Center of Political and Economic Studies and PolicyLink 2004).

While personal responsibility regarding good nutrition and physical activity is critical, a consensus is emerging that reversing the obesity epidemic demands more than traditional exhortations that tell people to eat less and move more. Individuals need supportive environments that facilitate healthy choices. Efforts to change individual behaviors are likely to be more effective if pursued along with health promotion activities that change policies and address the environmental factors influencing eating and physical activity patterns.

The California Endowment's Healthy Eating, Active Communities

## Strategies to reduce obesity have focused on individual behavior modification and treatment without addressing the context in which these behavioral choices are made.

Initiative (HEAC) is one example of a philanthropic effort focused on reducing disparities in obesity and diabetes by improving the food and physical activity environments for children. HEAC is designed to demonstrate how collaborative approaches can change environmental risk factors for children and families. The foundation's experience with asthma, tobacco prevention, and other community-based public health programs led to the conclusion that creating healthy eating and physical activity environments in low-income and resource poor communities will require a shift from policies, practices, and norms that foster unhealthy foods and inactivity, to policies and practices that position healthy foods and physical activity as the best options. The goal of HEAC, therefore, is to engage youth, families, community leaders, health professionals, and others in creating healthy environments in order to facilitate healthy choices, particularly in low-income communities.

Grantees consist of collaboratives that include a school district, a broadly representative community organization, and the local public health department. They are asked to work in five different areas: schools, after school, neighborhood, health care, and media and marketing. The initiative's hallmark is its collaborative nature working to influence change at the community, and ultimately individual level; however, the initiative includes



other components beyond the community grants, including program support to other local agencies for technical assistance, statewide policy advocacy, communications, and public affairs and evaluation.

To share lessons and resources, and to build momentum for policy and advocacy work addressing these issues, the HEAC initiative is supporting the formation of a network of programs, including the community demonstration project grantees. These grantees will implement and evaluate strategies to improve environments for healthy eating and physical activity and create momentum for widespread changes in policy and practice that will ultimately lead to preventing obesity.

Officials in Arkansas are also sharing some of the preliminary lessons learned from implementation of legislation creating a comprehensive program to combat childhood obesity. The major provisions of the law required the following:

- annual body mass index (BMI) screenings for all public school students, with the results reported confidentially to parents;
- restricted access to vending machines in public elementary schools;
- disclosure of schools' contracts with food and beverage companies;
- creation of district advisory committees made up of parents, teachers, and local community leaders; and
- creation of a child health advisory committee to recommend additional physical activity and nutrition standards for public schools (Ryan et al. 2006).

The Robert Wood Johnson Foundation provided support to the Arkansas Center for Health Improvement for the creation of a BMI database and for data analysis to support evaluation efforts. In a July 2006 report in *Health Affairs*, Arkansas officials announced new statewide data showing that while childhood obesity is still a major threat, the state has halted the progression of the epidemic among its public school students. The lessons they report from this experience include:

- Policy development and implementation can be achieved in a rapid cycle (two to four years) at the state level by identifying and coordinating existing related activities, using both national and local resources, and employing trusted relationships among interested stakeholders and advocates.
- A proposed policy (such as legislation) should be clear in its intent and mechanism with which to achieve the desired change, yet not attempt to prescribe in detail what the changes must be.
- Complex issues require the involvement of multiple stakeholders; however, each stakeholder's primary concerns must be recognized and acknowledged to obtain and retain long-term support. For example, schools support child health and disease prevention; however, their primary responsibility is scholastic achievement.

- State versus local control issues can create tension and resistance to activities regardless of potential benefits.
- Addressing privacy concerns when dealing with sensitive health information is essential in garnering acceptance of activities such as BMI assessments.
- Tailoring local empirical data to provide school- and district-specific information that documents the scope of the problem is critically important to maintaining the program's viability through the first years of implementation.
- Long-term support and programmatic sustainability can be encouraged by incorporating activities into existing state agency work plans and budgets (Ryan et al. 2006).

### Putting Prevention Into Practice

Having evidence-based recommendations on preventive services does little good if they are not supported by appropriate strategies and infrastructure to assure implementation. Despite widespread insurance coverage for adult vaccinations, cancer screening, and cardiovascular disease prevention measures, most Americans are not up to date with these routine services.

In 1995, the Donaghue Foundation, Berkshire Taconic Community Foundation, and Robert Wood Johnson Foundation supported the creation of Sickness Prevention Achieved through Regional Collaboration (SPARC), a New England-based organization that set out to broaden delivery of preventive services throughout its communities. SPARC put together a plan to create,

coordinate, and monitor countywide strategies to increase the use of immunizations and disease screening. The model regards the physician practice as only one element of a network of coordinated prevention activities, and encompasses other partners including local health departments and visiting nurse associations (Shenson 2006).

Working with these partners, SPARC developed an initiative in 1997 to assure the delivery of pneumococcal vaccinations (PPV) at all community flu shot clinics. Using Medicare reimbursement data, they were able to demonstrate a doubling of the annual PPV rates in two counties. SPARC also developed a mechanism to provide mammography appointments at flu shot clinics for women who were behind schedule for breast cancer screenings, which also resulted in a doubling of mammography rates among women attending these flu shot clinics. The approach is being replicated with additional funding from RWJF, CDC, and others. Other SPARC efforts include providing access to preventive services near polling places, delivering hepatitis B vaccinations at public high schools, and creating prevention links with senior centers and Meals-on-Wheels programs.

### Promoting and Evaluating a Population Health Approach

Demonstrating results from community-based health promotion programs is challenging. The Henry

## Having evidence-based recommendations on preventive services does little good if they are not supported by appropriate strategies and infrastructure to assure implementation.

J. Kaiser Family Foundation's Community Health Promotion Grants Program (CHPGP), for example, was a "community-based initiative designed to promote improved health by changing community norms, environmental conditions, and individual behavior" in 11 communities between 1987 and 1992 (Wagner et al. 2000). CHPGP provided grants and technical assistance to local coalitions for the development of programs to reduce several health problems including substance abuse, adolescent pregnancy, cardiovascular disease, cancer, and injury. Program development and design was largely under local control, with technical support from the Health Promotion Resource Center at Stanford University. The foundation gave grantees substantial flexibility to develop program targets and activities tailored to meet local priorities, and gave emphasis to empowering communities by developing coalitions to find consensus and coordinate action among key organizations (Wagner et al. 2000).

An evaluation of this program published in 2000 found little evidence of positive changes in the outcomes targeted by the intervention communities, with the exception of two grantees that achieved positive outcomes targeting dietary behavior and adolescent substance abuse. The evaluators noted, however, several design factors that may have affected their findings. First, four years may not be long enough

to achieve changes in population behavior. Second, the program relied exclusively on self-reported measures of behavior, and there was a low response rate to a telephone survey component. They further noted that producing even small changes in population behavior requires powerful interventions, reaching large proportions of the target population and that “with few exceptions, the less successful CHPGP programs implemented interventions that were too weak to have much effect on individual behavior, too limited to reach broad segments of the target population, or both” (Wagner et al. 2000). The evaluators recommended that the field should focus on developing theories and methods that can improve the design and evaluation of community-based interventions.

Subsequently, one of the largest philanthropic efforts to test new health promotion interventions was the California Wellness Foundation’s (TCWF) Health Improvement Initiative (HII). In January 1995, the TCWF board of directors approved this five-year \$20 million program. It began with an exploration of some fundamental questions, including: “What creates good health? Why are some Californians healthy and others not? If the personal health care model is necessary but insufficient to improve health, then what? How do we shift investments from treatment to prevention? What is the point of entry for improving population health? In terms of morbidity, mortality, and disability, where are we making progress and why? Do outcomes matter?” (Isaacs 2002).

Reflection on these questions and further diagnosis informed the

development of HII. Specific goals of the initiative included: promoting awareness of the broad determinants of health; shifting the current focus and investment in health toward prevention; establishing comprehensive, integrated systems of preventive services; and demonstrating that population health improvements can occur in real-world settings.

The HII consisted of three integrated components: the Public Education and Policy Program, the Health Partnership Program and the Initiative Support Program. Grantmaking in the Public Education and Policy Program focused on public opinion polling; nonpartisan policy analysis; and policymaker and public education about population health. The Health Partnership Program, the centerpiece of HII, enabled 15 geographically diverse California community or county-based health partnerships to design and implement local health improvement plans. The Initiative Support Program was responsible for building a learning community in support of population health improvement. This was accomplished through the provision of technical support services. Finally, the initiative evaluator was charged with enhancing the efforts of the health partnerships and supporting grantees through a continuous quality improvement evaluation and assessing HII implementation and impact.

According to TCWF, the Health Improvement Initiative was an important undertaking to change the emphasis from a personal health care orientation to a population perspective among service providers and other sectors of the community. While acknowledging the difficulties in evaluating such a complex

initiative, some of the key accomplishments cited by the foundation include: the establishment of a statewide policy center, the Center for Health Improvement, which has made significant contributions to improving policymakers' awareness of population health issues; shifting attention of policymakers and community members to prevention; and creating new sources of information on prevention. The Health Partnership Program succeeded in establishing or energizing 15 collaboratives which improved or expanded access to direct preventive services, prompted service integration, facilitated local population health measurement and policy development, and developed and recognized local leadership. The Initiative Support Program also created a sustainable learning community that facilitates problem solving in a supportive environment and created a responsive technical support delivery system (Isaacs 2002).

Overall, TCWF learned that, despite the difficulties of changing systems and fostering authentic community involvement, important changes can occur in communities' capacity to improve population health. They reported that grant resources are necessary but insufficient to bring about change, and that technical support, partnerships, and a learning community greatly improve the prospects for healthy and sustainable communities. TCWF notes the HII's lessons have been extended to both state and national forums, and that the population health debate, both in California and nationwide, will continue to be influenced by HII publications, grantees, and those who contributed to its population health improvement efforts.

A report by the IOM in 2000 concluded that despite breakthroughs in efforts to map the human genome, the outlook for improving the nation's health will not improve unless greater resources are devoted to addressing the behavioral and social factors that account for the majority of disease, disability, and death in the United States. The report demonstrates that the key to helping enjoy healthier, longer lives is to understand how to promote behavioral change and create healthier environments (IOM 2000). Health philanthropy can continue to provide the needed resources to improve this understanding.

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# Fast Facts

## Actual Causes of Death

A 2004 CDC study shows that the ten leading causes of death in 2000 were tobacco, poor diet and physical inactivity, alcohol consumption, microbial agents, toxic agents, motor vehicle crashes, incidents involving firearms, sexual behaviors, and illicit use of drugs. The study confirms earlier findings that many causes of premature death in America are linked to social and behavioral factors (Mokdad et al. 2004).

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## The Burden of Chronic Disease

More than 90 million Americans live with chronic illnesses, many of which are largely preventable (CDC 2005a).

Chronic diseases account for 70 percent of all deaths in the United States; one-third of the years of potential life lost before age 65; and more than 75 percent of the nation's medical care costs (CDC 2005a).

The estimated direct and indirect costs associated with smoking exceed \$75 billion annually. Approximately \$300 billion was spent on all cardiovascular diseases in 2001, and over \$129 in lost productivity was due to cardiovascular disease. The direct medical costs associated with physical inactivity was nearly \$76.6 billion in 2000 (CDC 2005a).

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## Tobacco Use

In 2004, 23 percent of men and 19 percent of women 18 years of age and over were current smokers. This is a sharp decline from 1965, when more than one-half of adult men and one-third of adult women smoked, although declines have slowed since 1990 (CDC 2006a).

Between 2003 and 2005, the percentage of high school students who reported smoking cigarettes in the past month remained stable at 22 percent after declining from 36 percent in 1997 (CDC 2006a).

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## Alcohol Use

In 2004, the estimated prevalence of binge drinking (having five or more drinks on at least one occasion during the preceding month) among adults was 14.9 percent (Hughes et al. 2006).

In 2004, the estimated prevalence of heavy drinking among adults was 4.8 percent. Heavy drinking is defined as having an average of two or more drinks per day for men or one or more drinks per day for women during the preceding month (Hughes et al. 2006).

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## Obesity

During the 1960s and 1970s, 14 percent of Americans were obese. That number began rising during the 1980s and increased at a rapid pace throughout the 1990s. Today, two-thirds of U.S. adults (over 97 million people) are overweight or obese (Hedley et al. 2004).

Close to 31 percent of U.S. children (over 9 million) are overweight, and childhood obesity has more than doubled in the past 25 years (Hedley et al. 2004; Ogden et al. 2006).

The obesity epidemic is occurring in people across all socioeconomic and ethnic groups, although African Americans, Hispanics, and American Indians are disproportionately affected (IOM 2005).

In 1991, four states had obesity prevalence rates of 15 percent to 19 percent and no states had rates at or above 20 percent. In 2005, only four states had obesity prevalence rates less than 20 percent, while 17 states had prevalence rates equal to or greater than 25 percent, with three of those having prevalence equal to or greater than 30 percent (CDC 2006c).

The most recent data on obesity suggest that the increases in body weight are continuing in men, children, and adolescents, but may be leveling off in women (Ogden et al. 2006).

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## Use of Preventive Services

Americans are increasingly using many types of preventive or early-detection health services. In 2004, 83 percent of children 19–35 months of age had received a combined vaccination series protecting them against several childhood infectious diseases, and the percentage of children receiving varicella (chickenpox) vaccine has increased sharply since it was first recommended in 1996 (CDC 2006b).

In 2004, about two thirds of adults age 65 years or older received an influenza vaccination during the preceding 12 months, and about 65 percent of older adults had ever had a pneumococcal vaccination (Hughes et al. 2006).

Slightly more than half (53 percent) of adults over 50 years old have ever had a sigmoidoscopy or colonoscopy to screen for colorectal cancer (Hughes et al. 2006).

In 2004, the estimated prevalence of men over 40 years old who had a PSA test to screen for prostate cancer during the preceding two years was 52 percent (Hughes et al. 2006).

In 2004, six out of every seven women over 18 years old (85 percent) had a Pap test within the preceding three years. Three out of four women over 40 years old had received a mammogram within the preceding two years (Hughes et al. 2006). The percentage of women receiving Pap smears and mammograms has increased since 1987 but has leveled off in recent years (CDC 2006a).



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Ogden Cynthia L., Margaret Carroll, Lester Curtin, et al., "Prevalence of Overweight and Obesity in the United States, 1999-2004," *Journal of the American Medical Association* 295:1549-1555, April 2006.

## Recommended Reading

Grantmakers In Health, *Selling Healthy Lifestyles: Using Social Marketing to Promote Change and Prevent Disease* (Washington, DC: 2004). Available on-line at [http://www.gih.org/usr\\_doc/Selling\\_Healthy\\_Lifestyles\\_Issue\\_Brief.pdf](http://www.gih.org/usr_doc/Selling_Healthy_Lifestyles_Issue_Brief.pdf).

As a behavior change technique, social marketing has proven effective in motivating people to make the complex and difficult behavior changes that can improve health and reduce the risk of chronic diseases such as cardiovascular disease, cancer, and diabetes. This Issue Brief uses the lens of tobacco prevention and cessation, physical activity, and healthy eating to examine how health grantmakers can use social marketing principles and techniques to encourage and support the adoption of healthier behaviors across the lifespan.

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Grantmakers In Health, *Healthy Behaviors: Addressing Chronic Disease at Its Roots* (Washington, DC: 2004). Available on-line at [http://www.gih.org/usr\\_doc/Healthy\\_Behaviors\\_Issue\\_Brief.pdf](http://www.gih.org/usr_doc/Healthy_Behaviors_Issue_Brief.pdf).

Chronic diseases such as heart disease, cancer, lung disease, stroke, and diabetes are among the most serious threats to the nation's health. This Issue Brief explores the contribution of specific behaviors to the development of chronic diseases and discusses how research on tobacco control can guide grantmakers interested in designing comprehensive strategies that help people adopt healthy behaviors and create environments that help people be successful in their efforts to live healthier lives.

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Grantmakers In Health, *The Nation's Leading Health Indicators: Measuring Progress, Taking Action* (Washington, DC: 2003). Available on-line at [http://www.gih.org/usr\\_doc/Health\\_Indicators.pdf](http://www.gih.org/usr_doc/Health_Indicators.pdf).

This resource portfolio provides profiles on each of the nation's leading health indicators created as part of Healthy People 2010. Focusing on ten leading indicators such as physical activity, tobacco use, immunization, and access to care, the portfolio provides key data and examples of activities health funders are supporting in each area.

Frumkin, Howard, Lawrence Frank, and Richard Jackson, *Urban Sprawl and Public Health: Designing, Planning, and Building for Healthy Communities* (Washington, DC: Island Press, 2004).

This book addresses the central question: "How does the physical environment in which we live affect our health?" The authors examine the direct and indirect impacts of sprawl on human health and well-being, and discuss the prospects for improving public health through alternative approaches to design, land use, and transportation. The book summarizes the evidence linking adverse health outcomes with sprawling development, and outlines the complex challenges of developing policy that promotes and protects public health.

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Green, Lawrence and Marshall Krueter, *Health Promotion Planning: An Educational and Ecological Approach* (Mountain View, CA: Mayfield Publishing Company, 1999).

This standard public health text provides a comprehensive overview of the principles and processes of health promotion planning. The book includes an overview of health promotion and the author's PRECEDE/PROCEED model framework; a chapter on each of five assessment planning phases; a chapter on evaluation basics; a chapter on specific applications of the planning framework in each of four settings: community, workplace, school, and health care; and a final chapter on computer applications of the framework.

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Institute of Medicine, *Health and Behavior: The Interplay of Biological, Behavioral, and Societal Influences* (Washington, DC: National Academy Press, 2001).

This report reviews recent advances in understanding the complex interplay among biological, psychological, and social influences on health. Special attention is given to new research on behaviors that influence health, the role of social networks, and socioeconomic status. The book highlights what can we learn from applied research on interventions to improve the health of individuals, families, and communities, and how to expeditiously translate research findings into applications.

Institute of Medicine, *Preventing Childhood Obesity: Health in the Balance* (Washington, DC: The National Academies Press, 2005).

This landmark IOM study presents a comprehensive national strategy on childhood obesity, with specific recommended actions for families, schools, industry, communities, and government. The report provides an examination of the extent and consequences of obesity in U.S. children and youth, including the social, environmental, and dietary factors responsible for increased prevalence. It explores the actions needed to initiate, support, and sustain the societal and lifestyle changes that can reverse the trends. A 2006 follow-up report from the IOM Committee on Progress in Preventing Childhood Obesity, *Progress in Preventing Childhood Obesity: How Do We Measure Up?*, examines the efforts made by obesity prevention initiatives since publication of *Health in the Balance*.

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Institute of Medicine, *Promoting Health: Intervention Strategies from Social and Behavioral Research* (Washington, DC: National Academy Press, 2000).

This report identifies promising areas of social science and behavioral research affecting health. It includes 12 papers commissioned from some of the nation's leading experts that review current research and evidence in detail, and assess whether the knowledge base of social and behavioral interventions has been useful in the development of broader public health interventions. The report asserts that behavioral and social interventions offer great promise to reduce disease morbidity and mortality, but that their potential to improve the public's health has been relatively poorly tapped.

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Isaacs, Stephen L., ed., *Improving Population Health: The California Wellness Foundation's Health Improvement Initiative* (San Francisco, CA: Social Policy Press, 2002).

This book presents the story of The California Wellness Foundation's Health Improvement Initiative, a five-year \$20 million grantmaking program to improve the health of Californians through population-based approaches. The program focused on increasing public

recognition of the importance of factors other than health care in determining the health of residents, and supported building new collaborative approaches to improve health. Including the perspectives of both the foundation officials who led the initiative and its evaluators, this report shares lessons for others engaging in similar programs.

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McGinnis, J. Michael and William H. Foege, "Actual Causes of Death in the United States," *Journal of the American Medical Association* 270:2207-2212, November 1993.

This seminal article showed that approximately half of all causes of premature death in America are linked to social and behavioral factors, most importantly tobacco use, poor diet and exercise, and excessive alcohol consumption. The article argues for reshaping public policy priorities away from paying for the treatment of disease toward addressing the behavioral and social conditions that lead to preventable disease and premature death.

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Nestle, Marion, *Food Politics: How the Food Industry Influences Nutrition and Health* (Berkeley, CA: University of California Press, September 2003).

Written by Marion Nestle, editor of the 1988 *Surgeon General's Report on Nutrition and Health* and currently a professor of nutrition at New York University, this book focuses on the food industry's influence on Americans' diet. The book explores how food interests use their influence to seek changes in governmental dietary advice, push soft drinks in schools, and evade regulation.

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Task Force on Community Preventive Services, *Guide to Community Preventive Services* (New York, NY: Oxford University Press, 2005). Available on-line at <http://www.thecommunityguide.org/library/book/>.

The Task Force on Community Preventive Services developed this guide to recommend evidence-based community or populationwide interventions based on reviews of their effectiveness, economic efficiency, and

feasibility. The main topic areas include vaccine-preventable diseases, tobacco use prevention and control, reducing motor vehicle occupant injury, diabetes, physical activity, oral health, social environment, prevention of injuries due to violence, and cancer screening. The product is a companion to the *Guide to Clinical Preventive Services* (available at <http://www.ahrq.gov/clinic/prevnew.htm>), which similarly provides evidence-based recommendations on clinical screening, counseling, and preventive medication topics. Both guides help help policymakers, clinicians, and insurers “distinguish necessary from unnecessary services and have identified those services that are harmful or about which there is uncertainty.”



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*Healthy People 2010: Understanding and Improving Health* (Washington, DC: U.S. Government Printing Office, 2000.) Available on-line at <http://www.healthypeople.gov/document/tableofcontents.htm#under>.

*Healthy People 2010* presents a comprehensive, national health promotion and disease prevention agenda. Designed to serve as a roadmap for improving the health of all people in the United States, *Healthy People* has two overarching goals: to increase quality and years of healthy life and to eliminate health disparities. These two goals are supported by specific objectives in 28 focus areas, such as access to health care, cancer, diabetes, immunizations, and violence prevention, with each objective including targets to be achieved by the year 2010.





HIV/AIDS

More than 25 years after the virus first emerged, HIV/AIDS has caused more than 25 million deaths. An estimated 40.3 million people are now living with the virus, and 4 million people are newly infected each year (UNAIDS 2005, 2006). Despite improved access to antiretroviral treatment and care, HIV/AIDS remains the leading cause of death among those ages 15 to 59 worldwide (The Henry J. Kaiser Family Foundation 2006a). Developing nations experience increasing and staggering prevalence. Sub-Saharan Africa, home to nearly two-thirds of people living with HIV/AIDS, has been the hardest hit region, but other areas such as Latin America and the Caribbean experience high prevalence rates among adults (The Henry J. Kaiser Family Foundation 2006a). Over the past 25 years, the epidemic has exposed weaknesses in the financing and delivery systems, disparities in treatment and prevalence, the effects of stigma, and the need for evidence-based prevention efforts

## The Early Years

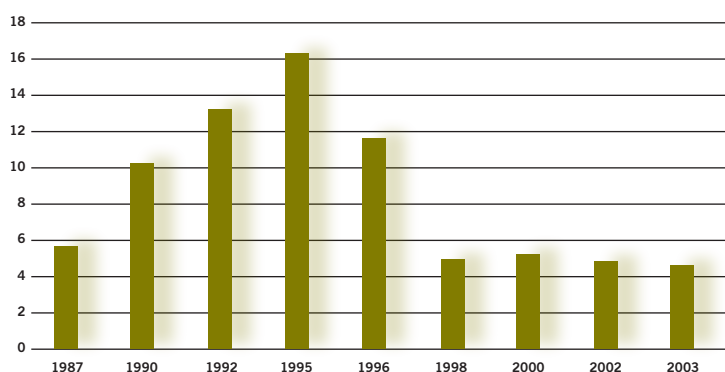
The emergence of HIV in the early 1980s brought fear and uncertainty.

The Centers for Disease Control and Prevention (CDC) first reported the virus in 1981, and it was not until 1983 that the U.S. Public Health Service issued recommendations of preventing transmission through sexual contact and blood transfusions. By this point, the virus was increasing rapidly but had not been isolated. In 1984, scientists Robert Gallo and Luc Montagnier identified Human Immunodeficiency Virus (HIV) as the causative agent of AIDS.

Because of wide misperception of how the virus spread, many individuals with HIV/AIDS faced serious discrimination: eviction, unemployment, and social humiliation. There was considerable confusion and fear as to how the virus could be transmitted; many people believed that the virus could be spread through casual contact, such as shaking hands or sharing a telephone. A public icon of the era, Ryan White, was noted for his struggle after he was banned from school when school officials discovered he had contracted HIV through blood products used to treat his hemophilia. With the help of AIDS advocates, he won the case against his school, but his family was forced to move to a new town because of threats of violence.

By the middle of the decade, years of inaction had caught up, and the government's slow response had cost thousands of lives. The peak of new HIV infections occurred around 1985, at an estimated 160,000 (The Henry J. Kaiser Family Foundation 2006b). President Reagan finally publicly addressed HIV/AIDS in 1986, the same year Dr. C. Everett Koop released the

**Figure 1. Mortality from HIV, 1987–2003, (deaths per 100,000)**



Source: The Henry J. Kaiser Family Foundation, *AIDS at 25: An Overview of Major Trends in the U.S. Epidemic*, Chartpack, Menlo Park, CA 2006)

*Surgeon General's Report on HIV/AIDS*, calling for condom use and improved AIDS education.

After it became clear that the virus was not an isolated event and thanks to increasing advocacy, monitoring and treatment efforts improved. In 1985, the U.S. Food and Drug Administration (FDA) approved the first test to detect antibodies to HIV

compelled to pass the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act to provide funding for primary care and support services for individuals living with HIV disease who lack health insurance and financial resources for their care. Congress also enacted the Housing Opportunities for People with AIDS (HOPWA) Act of 1991 to provide housing assistance to people living with AIDS. In 1993, President Clinton established the White House Office of National AIDS Policy to focus on coordinating domestic efforts to reduce the number of new infections in the U.S., particularly in segments of the population that experiencing new or renewed increases in the rate of infection.

As more well-known individuals made their HIV status public, the public perception of the illness shifted. In 1991, Magic Johnson shocked sports fans by retiring from professional basketball because of his HIV status. Johnson's announcement changed the perception that AIDS was a disease affecting only gay men and started a national discussion about how privilege can buy access to expensive, lifesaving therapy.

By the mid-1990s, AIDS was no longer considered a death sentence. In 1995, the new age of highly active antiretroviral therapy (HAART) emerged with the FDA approval of the first protease inhibitors, saquinavir. In part because of HAART, by 1997, AIDS-related deaths in the U.S. declined by more than 40 percent (Figure 1) (CDC 2001).

With the introduction of HAART, the 1996 reauthorization of the CARE Act specifically earmarked

## The emergence of HIV in the early 1980s brought fear and uncertainty.

in the bloodstream. One year later, azidothymidine (AZT), the first antiretroviral drug for HIV/AIDS, began clinical trials and was FDA-approved in 1987. The AIDS Coalition to Unleash Power, or ACT UP, was established in 1987 to oppose the high price of AZT and the slow pace of FDA approval. The drug price was subsequently lowered. Despite incredible medical and scientific gains, access to treatment is still limited to those without significant financial resources or public assistance.

A tumultuous decade left a nation afraid, bereaved, and inspired to act. Activists throughout the country voiced opinions about discrimination of people with HIV/AIDS, prices of lifesaving drug treatment, and the search for a cure.

### The Nineties

The 1990s saw several developments in policy and treatment. By 1990, there were 150,000 reported AIDS cases in the U.S. (The Henry J. Kaiser Family Foundation 2006c). In response to the enormity of this statistic, the U.S. Congress was

funding for AIDS Drug Assistance Programs (ADAPs) to provide HIV-related treatment medications to low-income people with HIV/AIDS who have limited or no prescription drug coverage. Amendments to the CARE Act in the 2000 reauthorization allow states to use ADAP funds to pay for services that enhance access, adherence, and monitoring of drug treatments.

As individuals with HIV/AIDS lived longer because of new therapies, there was growing recognition of comorbidities faced by vulnerable populations. Mental health and drug abuse disorders and infectious diseases such as Hepatitis C and tuberculosis disproportionately affect people with HIV/AIDS. Other conditions, referred to as social comorbidities, such as homelessness and poverty, present challenges to finding appropriate housing, medical care, and adequate food (IOM 2005).

As the virus increasingly ravaged developing countries, researchers and policymakers began to turn their focus abroad. In 2000, the CDC formed the Global AIDS Program, which has collaborated with governments, the World Health Organization, universities, and nongovernmental organizations to help combat the spread of HIV/AIDS. It adheres to a three-pronged strategy: prevention, treatment, and information and capacity building.

### 2000 and Beyond

Recent years have seen an increased commitment to global funding. In 2003, the Bush Administration asked Congress to commit \$15 billion over five years to combat AIDS in Africa and the Caribbean.

## Just as with other health conditions such as diabetes and cardiovascular disease, HIV reflects a set of racial, ethnic, and class inequalities.

The President's Emergency Plan for AIDS Relief (PEPFAR) nearly tripled the U.S. commitment to international AIDS assistance, aiming to prevent 7 million new infections, provide antiretroviral treatment for 2 million people living with AIDS, and support 10 million people living with AIDS, including AIDS orphans (Office of the Press Secretary 2003). While PEPFAR is on track to fulfill its \$15 billion plan to fight HIV/AIDS, some critics point out that the funding lacks adequate focus on prevention and has unrealistic strings, such as a requirement for recipients to promote abstinence-only programs.

In 2003, UNAIDS and the World Health Organization announced the 3 by 5 initiative, aimed at treating 3 million people with antiretroviral treatment by 2005. The initiative was a step towards the goal of making universal HIV/AIDS prevention and treatment accessible for all who need them. The initiative fell short of its target by about 700,000 people, but it was instrumental in creating support for the expansion of universal HIV treatment.

During this decade, attention has been paid to the shifting demographics of the disease. Just as with other health conditions such as diabetes and cardiovascular disease, HIV reflects a set of racial, ethnic, and class inequalities. Racial and ethnic minorities, the poor, and the uninsured are more likely to con-

tract HIV (Parada 2000). Although African Americans and Hispanics accounted for nearly 70 percent of all new U.S. HIV/AIDS cases in 2004, these groups made up only 27 percent of the total U.S. population (The Henry J. Kaiser Family Foundation 2005). African Americans have not seen equal benefits from treatment and prevention initiatives. The CDC has set a goal to eliminate disparities in HIV by 2010. Strategies to reduce rates of infection among minority populations include early diagnosis, more effective services, increased access to treatment, and medical provider education.

HIV also increasingly affects women. From 1981 to 1987, men accounted for 92 percent of the cases, compared with 74 percent from 1996 to 2000 (CDC 2001). The disease once believed to be exclusive to gay men is now affecting women at an alarming pace. Between 1999 and 2003, the number of AIDS diagnoses increased 15 percent among women and 1 percent among men (CDC 2004). In 2000, the number of women dying from AIDS exceeded the number of men.

Future programs must consider the implications of an aging HIV-infected population. Most individuals face the typical ailments that increase with age – higher rates of heart disease and diabetes, for instance – but for those living with HIV, the challenge of treating more than one chronic disease can be overwhelming. Medication management



becomes more important than ever, as patients are more likely to be taking a wide variety of drugs to treat their conditions.

The statistics are still shocking. While the overall rate of new HIV cases has decreased since the 1980s, HIV/AIDS prevalence is at its highest rate ever and continues to increase each year. In 2005, 4.1 million people were newly infected with HIV worldwide, including 540,000 children (The Henry J. Kaiser Family Foundation 2006a). The epidemic is considered a threat not only to individuals and their families but also to the stability of entire nations.

### Challenges

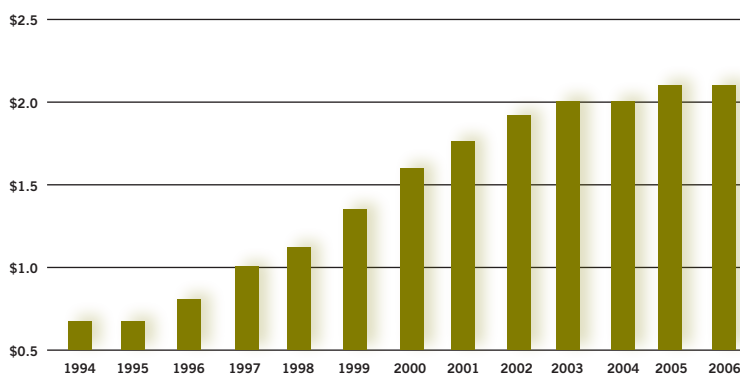
Treatment presents challenges, even among those who opt to follow a regimen. While the impact of HAART has been significant, its use is complicated. Treatment regimens can require several pills taken throughout the day, and high rates of adherence are necessary to avoid the development of drug-resistant strains of the virus. Treatment should not be confused with a cure.

HAART may reduce the perceived seriousness of the epidemic; in the U.S. and elsewhere, new therapies can lead some to reengage in risky behaviors. While treatment has reduced the number of deaths, the rate of new infections has not decreased.

Flaws in the financing and delivery system persist. The existing delivery system has not accounted for the shift from treating HIV as an acute condition to a chronic illness (IOM 2005). As a result of HAART, more people are living with HIV/AIDS than ever before, over 1.1 million in the U.S. alone (The Henry J. Kaiser Family Foundation 2006b). The system of care has shifted as well. In the past, most care was provided on an inpatient or hospice basis; now, two-thirds of HIV care occurs in physician offices, community health centers, and clinics. Lessons from managing chronic conditions such as diabetes may apply to HIV as well; effective treatment relies on provider coordination and training.

As with any discretionary federal grant program, the futures of PEPFAR and CARE are uncertain. Funding for PEPFAR is scheduled to run out in 2008, and it will be up to the next president to sustain the commitment. After over a year of debate in Congress, the Ryan White CARE ACT was reauthorized in 2006. The new law, The Ryan White HIV/AIDS Treatment Modernization Act, is authorized for 3 years. Funding for CARE has been relatively stable for the past several years (Figure 2), even though demand for HIV/AIDS therapy has increased. To assure ample funding for metropolitan areas and newly emerging affected rural areas, overall funding has been increased.

**Figure 2. Funding for the Ryan White CARE Act, FY 1994–2006 (in billions)**



Source: The Henry J. Kaier Family Foundation, Chartpack, *AIDS at 25: An Overview of Major Trends in the U.S. Epidemic*, 2006

It is imperative to devote more attention and funding to prevention efforts. In 2006, just 4 percent of federal funding for HIV/AIDS was devoted to domestic prevention efforts. The current focus on testing and treatment fails to address the most significant means of stopping the spread of the virus; without a vaccine, the only way to slow the spread of HIV is to prevent new cases. Prevention is more important than ever and requires a multi-dimensional approach that could encompass needle exchange, male circumcision, condom distribution, mircobicides, and improved education.

In the absence of a vaccine, testing has emerged as a means to controlling the spread of the virus. In 2006, the CDC issued recommendations for mandatory testing, including:

- screening for patients in all health-care settings after the patient is notified that testing will be performed unless the patient declines (opt-out screening);
- annual screening for persons at high risk for HIV; and
- routine screening for all pregnant women.

Controversy swirls around these recommendations. Many advocates fear that providers will not offer the education and counseling that should come with HIV testing. Instead, testing should be seen as an opportunity to educate the public about risk prevention and healthy behaviors.

Globally, the epidemic has yet to peak. Estimates of new infections still exceed deaths by millions per

year. In many regions, most individuals with HIV do not know their status and have little or no access to treatment (Curran 2006).

After 25 years, there is still no cure. Even with treatment and increased funding, the only way to fight the epidemic is to reduce the incidence.

### Grantmaker Activity

Philanthropy has played a critical role in addressing the AIDS crisis. Very early on, the lack of government recognition or funding diminished any sense of urgency by other funders. In 1983, however, two years after the first identified case of HIV, several foundations, including The New York Community Trust, and The San Francisco Foundation, acted by funding existing social services organizations that were responding to the epidemic (Funders Concerned About AIDS 2003). Funding declined in the mid-1990s, a result of what some observers call AIDS fatigue. In recent years, U.S. funders have funneled more money to the global epidemic. In 2004, U.S. philanthropy provided nearly \$346 million to HIV/AIDS-related causes (Funders Concerned About AIDS 2006). Despite this level of commitment, many funders remain reluctant to get involved in HIV/AIDS philanthropy, perhaps because it involves dealing with uncomfortable issues of sex, drugs, politics, and other charged issues.

**While the overall rate of new HIV cases has decreased since the 1980s, HIV/AIDS prevalence is at its highest rate ever and continues to increase each year.**

Overall, as the epidemic has changed, funding strategies have evolved as well. As people live longer, funders are directing more money toward services for individuals living with HIV/AIDS, such as food programs, housing assistance, and needle exchange. Instead of helping people die comfortably, services are now geared toward enhancing quality of life. Illustrative examples of grantmaking practices follow.

### EARLY FUNDING

Robert Wood Johnson Foundation (RWJF) was one of the first philanthropies to take on HIV/AIDS. In 1986, in response to the growing urgency of the situation, RWJF announced its first program focused on HIV/AIDS. This move marked a striking departure from the foundation's typical resistance to fund a single disease. In particular, foundation staff stirred up controversy among its conservative board of directors. But by the mid-1980s, the foundation felt the growing public urgency and decided to act. Identifying a promising service delivery model from San Francisco, foundation staff tested it in communities throughout the country. The AIDS Health Services Program adopted a community-based case management approach to caring for patients as opposed to providing inpatient treatment. The federal government stepped forward to provide matching emergency funding for the

program, and eventually enacted the Ryan White CARE Act, based on the RWJF model. With the introduction of support from the federal government, the foundation decided to end the program in 1991.

#### COLLABORATIVE EFFORTS

Because AIDS involves a combination of conditions, the most effective grantmaking initiatives involve case management, nutrition support, housing and transportation support, emergency financial assistance, emotional support, and emergency medical expenses.

The National AIDS Fund (NAF) is one of the largest philanthropic organizations focused on HIV/AIDS. Developed in 1988 by the Ford Foundation, NAF's purpose is to direct critical resources to community-based organizations to fight HIV/AIDS at the local level. Through 29 state and local funding collaboratives, or community partners, the fund provides grants and other support to over 400 community-based organizations annually, principally for prevention efforts. With its community partners, NAF has committed over \$134 million for AIDS funding.

The San Diego HIV Funding Collaborative, a NAF community partner, was formed in 1990 by several local funders, including Alliance Healthcare Foundation, and concerned community members. Since its inception, the collaborative has raised nearly \$4 million (\$1.3 million from Alliance Healthcare Foundation) for a wide array of HIV/AIDS services, including medical services, prevention and education services for homeless and runaway youth,

culturally and ethnically appropriate education services, hospice care, and harm reduction services and materials. The collaborative makes the majority of its grants through a request for proposals process and sets aside funds for special projects, discretionary grants, and emergencies.

One challenge the collaborative faces, which is common to many AIDS organizations, is donor fatigue. As the public increasingly considers HIV a chronic disease, some of the urgency of previous years has disappeared. The collaborative hopes to shift the perception that HIV is no longer a serious public health threat and inform people that young people and people of color are infected at higher rates.

Through its involvement with the collaborative, Alliance Healthcare Foundation has learned the power of leveraging. The foundation provides approximately \$100,000 per year to the collaborative: a \$15,000 grant as well as approximately \$85,000 in in-kind services. The foundation's strong support allows the collaborative to exist and raise money from other donors.

#### SUPPORTING ADVOCACY

Many foundations understand that advocacy can be a powerful tool in combating the challenges of the HIV/AIDS epidemic. The New York Community Trust, for example, has been a pioneer in supporting HIV/AIDS advocacy. As one of the first foundations to enter HIV/AIDS philanthropy, the trust continues to support the cause by administering the New York City AIDS Fund, a community partner of NAF, founded in 1988. Despite gains in

knowledge about HIV prevention, with the advent of HAART, young people are frequently not protecting themselves against infection. After studies revealed a shocking percentage of young people of color in the New York City area were infected, the trust provided a grant to the Legal Action Center of the City of New York to support prevention programs for at-risk populations. The center educates the public by organizing community forums about HIV infection; helps agencies that serve poor women to start HIV-prevention programs; performs media outreach; and works with the State AIDS Institute, community groups, government, foundations, and businesses to fund creative HIV prevention approaches for women of color.

The San Francisco AIDS Foundation was instrumental in the passage of the CARE Act as well as the enactment of HOPWA. To continue its commitment to influencing HIV/AIDS policy, the foundation organized its HIV Advocacy Network (HAN) to engage members to work with decisionmakers. To assist advocates in their work, HAN holds periodic briefings on the latest issues in HIV/AIDS, circulates an e-newsletter, provides training on advocacy skills, and organizes members to make lobbying trips to Washington, DC and Sacramento. Similarly, The New York AIDS Coalition, with funding from The New York Community Trust, has advocated to increase overall funding for the CARE Act rather than changing how the money is distributed, and to stop proposed cuts in Medicaid. The coalition also will offer workshops to teach New Yorkers with AIDS about

the CARE and Medicaid proposals and encourage them to meet with their elected officials to protest the cuts.

#### REACHING OUT

One of the New York Community Trust's top priorities is supporting the development of HIV prevention programs, and it has funded programs such as the Street-based Employment Empowerment Team (STREET) Project that provides outreach to street-based sex workers in the Bronx. STREET works with individuals to encourage HIV prevention education, counseling, and testing. In 2003, in response to the rising rates of HIV infection in communities of color, the trust worked to increase awareness of AIDS and to encourage testing among African Americans and Latinos. The trust worked with the Federation of Protestant Welfare Agencies to launch a bilingual media campaign that will provide information on services.

Many foundations are supporting evidence-based prevention efforts that the government may be reluctant to fund. Needle exchange programs, which provide sterile needles to injection drug users who turn in their used syringes, have been shown to help prevent the transmission of HIV. Such programs are controversial, however, because many believe they promote drug use. Public Welfare Foundation has funded needle exchange programs since 1996 when it received a funding proposal from Prevention Point Philadelphia, a comprehensive harm reduction program that provides needle exchange, street outreach, and basic medical care. From the foundation's point of view, harm

reduction programs are a way of sustaining life. Harm reduction programs can reach a marginalized population that traditional social services may not have reached. Because of the success of Prevention Point and despite the continued controversy, the foundation has gone on to provide over \$2 million in grants to support this life-saving work.

**AIDS is likely to be with us for a very long time, but how far it spreads and how much damage it does is entirely up to us.**

—PETER PIOT

#### FUNDING THE SCIENCE

The International AIDS Vaccine Initiative (IAVI) is a public-private partnership started by the Rockefeller Foundation in 1996 to fund clinical research. IAVI advocates for a vaccine to be a global priority and works to assure that a future vaccine will be accessible to all who need it. Operational in 23 countries, IAVI has invested more than \$100 million in vaccine research and development. Other funders of the IAVI include The New York Community Trust, the Bill and Melinda Gates Foundation, the Starr Foundation, and Broadway Cares/Equity Fights AIDS. Despite the number of unanswered questions surrounding the development of a vaccine, IAVI has helped double the number of vaccine candidates between 2000 and 2005.

GlaxoSmithKline (GSK) supports a variety of scientific initiatives, including improving the convenience of delivering HAART, addressing drug-resistant strains of HIV, and researching a vaccine against HIV



infection. To augment this work, GSK has recognized the importance of community-based responses to HIV/AIDS. In 1992, GSK launched the Positive Action program to provide community organizations across the world with prevention education, fundraising assistance, direct counseling and medical services, and outreach strategies. Positive Action has provided training for health care workers in East Africa, assisted community clinics in Kenya with improving antiretroviral provision, and helped disseminate prevention messages to women and families in rural India.

#### A GLOBAL EFFORT

The Henry J. Kaiser Family Foundation launched loveLife in 1999 to reduce HIV infection among South African adolescents. Half of South Africa's new HIV infections occur in people before reaching the age of 25. The foundation found that modest changes in adolescent sexual behavior could substantially curtail the HIV epidemic. loveLife's target group is 12- to 17-year-olds, but special programs focusing on children 6 to 12 years of age are also part of the campaign. The initiative was developed through a two-year process of investigation, consultation, and planning, including a review of international HIV prevention programs, an evaluation of existing HIV education efforts, and extensive focus group research among young South Africans. The initiative uses popular culture to promote sexual responsibility and healthy living, while at the same time developing frontline services that are more responsive to the sexual health concerns and needs of adolescents. Beyond HIV prevention, loveLife

aims to prevent other concerns related to sexual health, such as teenage pregnancy and sexually transmitted infections, and to address gender disparities that have impeded progress in the fight against AIDS. Kaiser has also designed several other media campaigns abroad, including India's Heroes Project, in conjunction with the Gates Foundation, and Russia's STOP SPID, which uses PSAs, television and radio programming, and print editorial content.

In the 1998, the Bill and Melinda Gates Foundation entered the field of HIV/AIDS philanthropy, awarding substantial grants to the Population Council to develop microbicides and to IAVI. The Gates' presence has boosted the overall level of giving to HIV/AIDS efforts as well as international media attention. The foundation's focus is to help significantly slow the global spread of HIV. The foundation seeks to fund in areas that maximize use of existing prevention tools or develop effective preventive technologies. Among the foundation's most notable initiatives are its work to prevent HIV in African youth, its support of the Global Fund for AIDS and Health, and its funding for a third-phase trial of a microbicide.

While we have come a long way since the birth of HIV/AIDS, there is still a long road ahead. As Peter Piot, the executive director of UNAIDS, said in the 2004 Report on the Global AIDS Epidemic, "AIDS is likely to be with us for a very long time, but how far it spreads and how much damage it does is entirely up to us" (UNAIDS 2004). With over 40 million individuals infected and

countless lives affected, there is no time to spare.

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# Fast Facts

## The Worldwide Effects of HIV/AIDS

Since the beginning of the epidemic, HIV/AIDS has claimed more than 25 million lives (The Henry J. Kaiser Family Foundation 2006).

Worldwide, 39 million people are currently living with HIV/AIDS (The Henry J. Kaiser Family Foundation 2006).

During 2005, 4.1 million people were newly infected with HIV, including 540,000 children (The Henry J. Kaiser Family Foundation 2006).

In West Africa, only 1 percent of children and pregnant women with HIV receive antiretroviral treatment (UNICEF 2006).

Without increased action to prevent the spread of the pandemic, more than 18 million children in Africa will have lost one or both parents to AIDS-related illness by 2010 (UNICEF 2006).

Young people, ages 15 to 24, account for over 40 percent of new adult HIV infections (The Henry J. Kaiser Family Foundation 2006).

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## The Effects of HIV/AIDS on the United States

Over 500,000 people have died from HIV/AIDS since the beginning of the epidemic (The Henry J. Kaiser Family Foundation 2005).

In 2003, an estimated 1.1 million people were living with HIV/AIDS (The Henry J. Kaiser Family Foundation 2005).

Approximately 24 percent to 27 percent of those infected with HIV do not know it (The Henry J. Kaiser Family Foundation 2005).

The Centers for Disease Control and Prevention (CDC) estimates that between 40 percent and 60 percent of the infected population does not receive regular treatment (Taylor 2005).

Racial and ethnic minorities account for over 70 percent of new AIDS cases (The Henry J. Kaiser Family Foundation 2005).

In 2002, HIV was the leading cause of death for African-American women ages 25 to 34 (The Henry J. Kaiser Family Foundation 2005).

In 2004, 27 percent of new HIV/AIDS cases were among women (CDC 2005).

Approximately half of individuals in treatment for HIV have a comorbid mental illness (IOM 2004).

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## Building the Case for Improved Prevention Efforts

Circumcised men are 60 percent less likely than uncircumcised men to become infected with HIV from female partners (Global HIV Prevention Working Group 2006).

Antiretroviral therapy can cut the risk that an HIV-infected pregnant woman will transmit HIV to her child by nearly 50 percent (Global HIV Prevention Working Group 2006).

Fewer than one in five individuals at high risk for HIV infection have access to effective prevention (Global HIV Prevention Working Group 2006).

By 2008, \$11.4 billion will be needed annually for HIV prevention—two-and-a-half times current spending (Global HIV Prevention Working Group 2006).

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## Recommended Reading

Bronner, Ethan, "The Foundation and AIDS: Behind the Curve but Learning the Way," in Stephen L. Isaacs, and James R. Knickman, eds., *To Improve Health and Health Care: Volume V: The Robert Wood Johnson Foundation Anthology* (San Francisco, CA: Jossey-Bass, 2002).

In this essay, Ethan Bronner chronicles how the Robert Wood Johnson Foundation addressed the AIDS crisis in the United States. The story recollects the high level of sensitivity surrounding the topic and how the foundation overcame stigma to make an important contribution to a deadly epidemic.

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Funders Concerned About AIDS, *U.S. Philanthropic Commitments for HIV/AIDS 2004* (New York, NY: 2006).

This annual resource tracking report compiles information about the activity of U.S.-based grantmakers in the field of HIV/AIDS. The report separates domestic and international grantmaking, and provides a list of the top HIV/AIDS grantmakers in the U.S.

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The Henry J. Kaiser Family Foundation  
<http://kff.org/hivaids/index.cfm>

The Henry J. Kaiser Family Foundation is a source of independent and current information on HIV/AIDS. The Web site provides policy reports, fact sheets, and survey data, as well as information on the foundation's media partnerships, journalist training programs, and HIV/AIDS initiatives in South Africa.

Institute of Medicine, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White* (Washington, DC: National Academies Press, 2004).

This IOM report examines the current standard of care for HIV patients and assesses the system currently used for financing and delivering care. The book recommends expanded federal funding for the treatment of individuals with HIV through a program that would provide timely access and consistent benefits with a strong focus on comprehensive and continuous care and access to antiretroviral therapy.

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Shilts, Randy and William Greider, *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Press, 1987).

In the first major book on AIDS, *San Francisco Chronicle* reporter Randy Shilts examines the making of an epidemic. Shilts researched and reported the book exhaustively, chronicling almost day-by-day the first five years of AIDS. The author challenges all aspects of society: the medical and scientific communities; the massmedia; the gay community; and the Reagan Administration who he claims cut funding, ignored calls for action, and deliberately misled Congress.

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UNAIDS, *Report on the Global AIDS Epidemic* (Geneva, Switzerland: 2006).

This report includes country, regional and global estimates for the HIV/AIDS epidemic at the end of 2005 and 2003. It also describes the evidence, the success stories, and the challenges that confront countries and the international community in responding to the epidemic.



# Mental Health



Mental illness is one of the most prevalent conditions affecting the U.S. population, yet the system is marked by fragmentation and dysfunction. Mental health is the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity. The term mental illness refers collectively to all diagnosable mental disorders. A mental disorder is a health condition marked by alterations in mood, thinking, or behavior associated with distress and impaired functioning (HHS 1999).

**Mental disorders are the leading cause of disability in the U.S. and Canada for people ages 15 to 44.**

Mental disorders are among the most common of chronic diseases. Approximately one in four U.S. adults (57.7 million people) suffers from a diagnosable mental disorder in a given year (National Institute of Mental Health 2006). About 6 percent of the population has a serious mental illness, such as schizophrenia, bipolar disorder, or major depression, that limits their ability to function in many areas of life such as employment, self-care, and interpersonal relationships (National Institute of Mental Health 2006; HHS 1999). Mental disorders are the leading cause of disability in the U.S. and Canada for people ages 15 to 44 (National Institute of Mental Health 2006). In the U.S., mental disorders collectively account for more than 15 percent of the overall burden of disease from all

causes and slightly more than the burden associated with all forms of cancer (HHS 1999). Approximately 45 percent of individuals with any mental disorder meet the criteria for at least one other mental health disorder (National Institute of Mental Health 2006).

While mental health is crucial to overall health, its importance has not always been recognized. Stigma surrounding mental illness persists with serious consequences. According to the Surgeon General's report on mental health, stigma is a product of fear and misinformation and can lead to isolation, discrimination, and outright abuse of affected individuals. Individuals with mental illness often avoid seeking treatment because they fear the stigma associated with their condition.

The evolution of the U.S. mental health care system over the past two decades can be characterized by several defining trends: an increased science and research base, increased advocacy, and the transformation of the financing and delivery system (HHS 1999).

## Science and Research

As researchers have gathered new information about the brain, the treatment of mental disorders has evolved. Over the past few decades, scientists have gained the ability to study the activity of the brain through technologies such as positron emission tomography and functional magnetic resonance imaging. As the ability to learn how the brain functions increases, researchers will be able to see the effects of psychotherapy and medication.

Mental health services research has demonstrated the positive effects of a psychosocial approach to treating mental disorders. While specific effects vary depending on population, overall studies demonstrate that treatment is more effective than placebo (HHS 1999). Psychotherapy is often referred to as “talk therapy,” because treatment is largely accomplished through verbal communication with a therapist. Different approaches include psychodynamic therapy, based on the theories of Freud, and behavior therapy, which focuses on changing current behavior patterns. Recent approaches combine behavior therapy with a cognitive approach, helping to promote adaptive behavior.

In the late 1980s, pharmaceutical companies focused on the development of medications to treat mental disorders. The result was a new wave of antidepressants—selective serotonin reuptake inhibitors—and antipsychotic medications that are as effective as the older medications, but with significantly fewer and less severe side effects. While many older pharmacotherapies were used primarily for serious mental illnesses, new drugs are also effective in treating those with relatively mild conditions (GIH 2003).

The adoption of evidence-based practices will help improve the quality of mental health services. For some conditions, such as depression, psychotherapy may be as effective as antidepressant medication. For others, such as schizophrenia or bipolar disorder, medication may be necessary for the individual to function, but psychosocial interventions can help improve outcomes.

The infrastructure for assuring the delivery of these interventions, however, is weak. While medication is government regulated, its availability ample, and its administration generally straightforward, there are no training, licensure, or certification requirements obligating providers to have competency in evidence-based psychosocial treatments such as cognitive-behavioral therapy. In addition, it is difficult for consumers to identify which providers deliver such treatments (Patel et al. 2006).

### Advocacy and the Consumer Movement

Over the past few decades, consumer groups have played a critical role in influencing changes within the mental health system.<sup>1</sup> Specific organizations representing patients and families have developed important goals of overcoming stigma and promoting recovery from mental illness (HHS 1999). Their work has drawn attention to the limitations of the mental health system with respect to financing, quality of care, and access to services. For example, Mental Health America (formerly the National Mental Health Association) has made significant progress in strengthening the child mental health movement and through its affiliate network, educates the public about mental health. The National Alliance on Mental Illness (NAMI), founded in 1979, is the nation’s largest grassroots mental health organization and places a priority serving families of adults with chronic mental illness. NAMI has also been a strong force behind mental health parity legislation, which aims to provide coverage for mental health services that is equal to that of physical health services.

The work of these groups and others legitimized the empowerment model for individuals with mental illness, influenced legislation that created mental health planning councils in each state, and worked to expand the role of consumers as an integral part of the mental health care system. Because of their work, individuals with mental illness are more fully involved in the planning, delivery, and evaluation of their care.

### Financing and Delivery System

Mental health policy over the past two decades has been a story of both progress and retreat. Fragmentation is a defining characteristic of the mental health service delivery system. With little coordination or information sharing, health care providers, schools, social service programs, prisons, and government agencies make critical decisions about the services people with mental health disorders receive (LeRoy et al. 2006).

The passage of the Mental Health Systems Act in 1980 called for a community-based system of treating mental illness and recommended that a substantial portion of the new resources be provided to support community mental health centers. The Reagan Administration, however, reversed the act a year later as part of its efforts to reduce taxes, federal spending, and the role of the federal government in addressing social issues. The new legislation, the Omnibus Budget Reconciliation Act of 1981, provided a block grant for states to provide mental health and substance abuse services, reversing the commitment of several decades of federal leadership

<sup>1</sup> Some users of mental health services refer to themselves as consumers. The term is not uniformly accepted, however, as some contend that users of the mental health system do not have the same power of choice and advantage as consumers in other markets (HHS 1999).

in mental health policy (Grob 2001). Under fiscal pressures themselves, states looked to federal entitlement programs, such as Medicaid and Social Security Disability Insurance, to support individuals with mental health disorders.

The integration of people with mental illness into the community was supported by the American with Disabilities Act (ADA), signed into law in 1990. The act made it illegal to discriminate against an individual with a disability, defined as a physical or mental impairment that substantially limits one or more major life activities. Individuals with mental illness are using the ADA to challenge arrangements and programs that impede full community participation. In 1999, in *Olmstead v. L.C. ex. rel. Zimring*, the U.S. Supreme Court found that the provisions of the ADA prohibiting discrimination in the administration of public programs prohibits states from unnecessarily institutionalizing people with disabilities if their needs can be met in a community setting. In 2001, an executive order required states to swiftly implement the decision (GIH 2003).

In 2002, the Bush Administration established the New Freedom Commission on Mental Health and tasked the group with conducting a comprehensive study of the gaps in the mental health care system and providing actionable recommendations to governments and mental health care providers (SAMHSA 2005). The commission concluded that “wholesale and fundamental transformation of the mental health service delivery system is required” (SAMHSA 2005). The commission

also articulated an agenda for federal action in 2005, which includes specific steps towards public awareness and action, community-level treatment, cost effective treatment, improved research and its application, and funding for state-level transformation (SAMHSA 2005). Such profound recommendations will likely take years to implement.

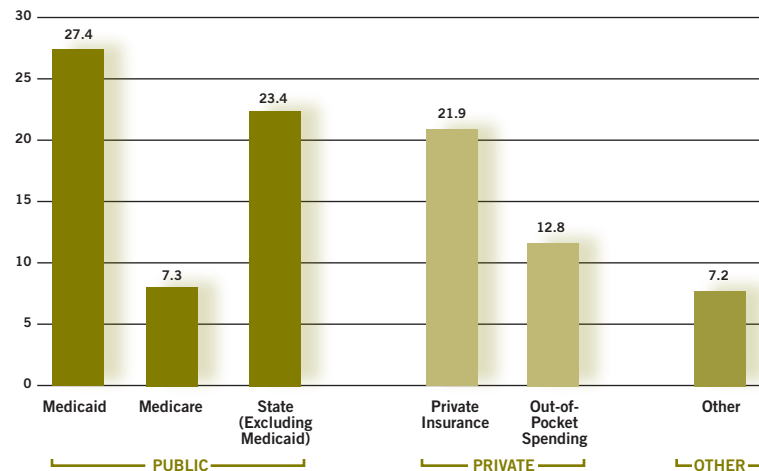
### Spending

During the 1990s, nominal spending on mental health services provided by both public and private providers grew dramatically, from \$48.9 billion in 1991 to \$85.4 billion in 2001 (Frank and Glied 2006). The rate of growth in mental health spending, however, was slightly lower than the increase in overall health spending over the same period. As a result, spending for mental health care has declined as a percentage of overall health spending, from 8.4 percent in 1991 to 5.9 percent in 2001 (Frank and Glied 2006).

## Mental health policy over the past two decades has been a story of both progress and retreat.

In 2001, mental health spending represented just under 6 percent of all health care spending, and the aggregate share that total mental health spending claims of national income has been stable over the past 35 years. Various payers contribute to mental health spending (Figure 1). Of the amount spent in 2001, approximately 58 percent came from federal, state, or local governments. The remainder of mental health spending in 2001 was supplied by private sector sources, including private insurance and out-of-pocket

**Figure 1. Total Mental Health Expenditures by Funding Source, 2001 (percentage)**



Source: Frank, Richard G. and Sherry Glied, "Changes in Mental Health Financing Since 1971," *Health Affairs* (25)3: 601-613, 2006.

spending. The share of mental health spending coming from all public sources has increased in recent years, rising from approximately 47 percent in 1971 to approximately 58 percent in 2001 (Frank and Glied 2006).

The early 1990s saw a push toward managed mental health care and behavioral health carveouts, which are separate contracts for managed mental health services. This trend has resulted in lower payments for services provided by both individual mental health providers and institutions (HHS 1999). In the private insurance market, the move to managed mental health care reduced spending on specialty mental health services, with observed reductions ranging from 20 percent to 50 percent depending on the study. In the public sector, a study of state Medicaid managed care programs showed that managed mental health care significantly reduced Medicaid payments to providers of inpatient mental health treatment. In states

that use adequate capitation rates in their Medicaid managed care programs, managed behavioral health care can be implemented successfully, from the perspective of both Medicaid beneficiaries and mental health providers. A desire to achieve cost reductions, however, has led some states to set capitation rates that are too low. In turn, provider payments are decreased, making practice impossible for providers in some areas (GIH 2003).

### Workforce Issues

Workforce shortages plague the mental health care system. Specific underserved populations include children and adolescents with serious mental disorders and older people. Geographically remote areas face critical workforce shortages as well. In certain areas in the east south central region of the U.S., there are 8.2 psychiatrists per 100,000 population, compared with 22.1 per 100,000 in the mid-Atlantic region (SAMHSA 2005). Moreover,

the mental health workforce does not reflect the growing diversity of the nation, nor of the population it treats (IOM 2005).

The mental health workforce shortage presents a barrier to access. Some providers have increasingly focused on those with the most severe mental illnesses, leaving those with less severe conditions without access to care. Those who can access care often find that services are limited; providers in the public mental health system often lack sufficient resources to provide evidence-based treatment such as assertive community treatment, psychiatric rehabilitation, and intensive case management. Individuals experiencing an acute mental health condition may languish in emergency rooms because psychiatric hospital beds are not available. Similarly, those ready for discharge from inpatient care may find that there are no appropriate residential or community services available.

Tracking the supply and distribution of mental health professionals and documenting workforce shortages is difficult. First, the mental health workforce is composed of many different types of providers offering a wide array of mental health and related services. For some mental health services, a shortage of one type of provider can be addressed if other appropriate providers are available. (For example, areas with shortages of mental health social workers may be able to rely on mental health nurses and psychiatric technicians to provide some of the services typically provided by social workers.) There are limits to substitution, however. For example, a

**In 2004, foundation giving for behavioral health was \$204 million—approximately 6 percent of total health giving.**

shortage of psychiatrists, common in rural areas, may prevent individuals with mental disorders from receiving needed prescription medications. Second, licensing and certification requirements vary across states. Because each state makes its own decisions about which types of providers need to be licensed or certified, the cadre of licensed mental health professionals varies considerably. Third, not only are training requirements inconsistent among schools and professions, most often physicians with little or no mental health training, such as emergency room doctors or general practitioners, are expected to detect mental disorders and provide treatment. Despite the lack of consistent national data on the mental health workforce, there is consensus among experts that workforce shortages are reaching crisis proportions in many states and localities (GIH 2003).

In general, the workforce is not sufficiently equipped to supply service to all individuals who are in need. Reasons for the shortage include a smaller number of workers entering the field, a lack of sufficient training opportunities, and state variation in licensure requirements that limit the ability to practice across state lines. In addition, certain populations, such as residents of rural areas, have even less access to trained professionals.

### **Philanthropic Opportunities**

Over the past few decades, funders have supported a variety of pro-

grams to improve the mental health care system. Between 1991 and 2000, foundation funding for behavioral health increased significantly from \$108 million to \$218 million (Brousseau et al. 2003). Since 2000, this amount has decreased, however, despite the continued need for mental health services and system transformation. In 2004, foundation giving for behavioral health was \$204 million—approximately 6 percent of total health giving (Foundation Center 2006). Efforts described below include providing services for children and youth, integrating mental health services, encouraging advocacy, improving the workforce, and increasing cultural competence. These examples are illustrative and only highlight a fraction of philanthropy's contribution to the field of mental health.

#### **SERVICES FOR CHILDREN**

Robert Wood Johnson Foundation's (RWJF) Mental Health Services Program for Youth (MHSPY) began in 1988 with the intention of promoting coordinated community-based services, rather than institutional care, for children with mental health care needs. Roughly based on a federal initiative called Child and Adolescent Service System Program (CASSP) that sought to ensure coordination among child-serving agencies, MHSPY adopted the theory that community-based services would require fewer financial resources than institutionalization. Eight communities, geographi-



cally and demographically diverse, received funding to serve children with the most serious mental disorders, such as major depression, bipolar disorder, and conduct disorder. Further complicating the plan of care, many children had more than one diagnosis, and some were involved in the child welfare or juvenile justice systems. The grantees focused on a number of strategies to avoid institutionalization: providing comprehensive case management, changing the financing system, and promoting interagency coordination.

The evaluation of the program found that the grantee sites did expand services to children and that case management became universal practice. Low hospitalization rates were noted in each of the sites—mostly 5 percent or less—despite previous histories of high hospital or residential treatment (Saxe and Cross 1998). The evaluation could not, however, objectively measure the effectiveness of the treatments. Anecdotal evidence suggested that sites were successful in providing holistic treatment services for the children and their families and that this method of patient-focused care was critical to the success of coordinated care. Respite services were another factor in easing the burden on families.

MHSPY was replicated in 12 states, building on the lessons learned from the original program. The goal for the new program was to assist states with local initiatives that provide child-centered care with a focus on the family. Despite the challenges of integrating funding streams, a lack of involvement of education officials, and changes in the political envi-

ronment, the replication program achieved measurable outcomes, such as a reduction of 1,000 children in residential treatment centers in Illinois, yielding taxpayer savings of \$36 million; a 95 percent reduction in institutional placements in Mississippi; and a decrease in hospital utilization in San Francisco by about one third (RWJF 2000).

#### SYSTEMS INTEGRATION

In 2003, a group of eight Colorado foundations—Caring for Colorado Foundation, The Colorado Health Foundation, The Colorado Trust, Daniels Fund, The Denver Foundation, First Data Western Union Foundation, Rose Community Foundation, and Rose Women’s Organization—formed a collaborative to study the mental health needs of the state. The study revealed a crisis within the state’s fragmented mental health care system. Specifically, it found that, of the 900,000 Coloradans who need mental health services each year, fewer than one-third receive them. It also exposed a statewide shortage of mental health providers, particularly for children, older adults, and residents of rural areas (TriWest Group 2003). Evaluators offered several recommendations: improve awareness among decisionmakers, promote integrated funding and service provision, implement evidence-based treatment, and examine strategies to boost access for underserved groups.

In response to the study’s findings, several members of the collaborative, including Caring for Colorado Foundation, The Colorado Health Foundation, The Colorado Trust, and the Denver Foundation launched Advancing Colorado’s Mental

Health Care in 2005. The goal of the project is to improve the coordination of mental health services across agencies and facilitate patient navigation of the system. The grantees include:

- Denver Public Schools, which is using school-based resource teams to coordinate services with community agencies;
- Prowers County Behavioral Health Integration Project, which is taking a proactive approach to addressing mental health by supporting new mothers and developing a jail diversion program;
- El Paso County Co-Occurring Disorders Collaboration and Health District of Northern Larimer County, which are both developing new services for individuals with co-occurring mental and substance abuse disorders;
- Mesa County Consortium on Health, which is working with other agencies to reduce cultural and language barriers to care; and
- Summit County Collaborative, which focuses on children with severe emotional disturbances.

#### ADVOCACY

Since its conception in 1978, The John D. and Catherine T. MacArthur Foundation has been a strong champion of mental health advocacy. Through its research networks, the foundation has brought knowledge to practice and helped shape the mental health policy landscape (MacArthur Foundation 2005). In particular, through the MacArthur Research Network on Mental Health



Policy Research, the foundation has worked to encourage evidence-based practice, improve mental health financing, and ensure fairness and equity in the management of mental health benefits. The foundation has also supported the Judge David L. Bazelon Center for Mental Health Law in Washington, DC. Founded in 1972 by a group of committed lawyers and professionals in mental health, the center has succeeded in securing legal rights for individuals with mental disabilities. Such landmarks include outlawing abuse of patients in an institutionalized setting and guaranteeing the rights of individuals with mental disabilities to education, to live in the community, and to receive federal entitlements.

In 2001, The California Endowment launched its Special Mental Health Initiative with \$24 million to identify effective mental health practices and programs in the state. A group of 46 grant recipients created projects to work independently or collaboratively over four years in underserved communities to provide direct services, training, community education, or other services. A learning community of these grantees convened periodically to share information and lessons learned. Specific projects related to improving the workforce include developing and implementing a promotores model of mental health support; offering cultural competence training to mental health providers; recruiting and training community health workers to facilitate peer support groups; and supporting an infant mental health specialist training program.

Through the learning community, grantees shared ideas about addressing the workforce shortages in the state. With limited resources, nonprofits must find innovative ways to recruit and retain qualified providers. One program was able to recruit a master's level, bilingual therapist only after raising the salary by 30 percent. Other programs have worked to develop the paraprofessional workforce, including promotores, teachers, and child care providers, but have met resistance in terms of scheduling, funding, and unexpected demands. Some program directors have worked tirelessly to overcome resistance on the part of counties to hire paraprofessionals.

**The foundation explored the evidence base for treating mental illness and determined that many evidence-based practices, once adapted for cultural differences, would indeed be appropriate for many minority groups.**

Grantees found that these workforce strategies led to better outcomes in their programs. Many of the training programs resulted in more integrated service delivery models, and dissemination of mental health knowledge throughout agencies helped agency staff be better prepared to detect mental disorders. Other grantees were able to achieve the ultimate goal of increasing the workforce capacity. One program reported an overall increase of 186 percent over 17 months in Latino lay mental health workers employed in key agencies (The California Endowment 2006).

## Cultural Competence

During a 2005 strategic planning process, The Hogg Foundation for Mental Health in Texas created new funding priority areas, one of which is cultural competence. According to population estimates, just over half of the Texas population consists of racial and ethnic minorities. To serve this growing group, the foundation seeks to address not only disparities within the health care system but also care that is incongruent with certain cultures. The foundation explored the evidence base for treating mental illness and determined that many evidence-based practices, once adapted for cultural differences, would indeed be appropriate for many minority groups. With goals of increasing the availability of mental health services for people of color and generating knowledge about the cultural adaptations of evidence-based practice, the foundation released a request for proposals. In July 2006, the foundation announced awards of more than \$2.9 million over three years to five organizations to adapt the delivery of evidence-based practices to be compatible with the cultures of their populations of color. Grantees are working on a variety of cultural adaptation projects, including therapy for Latino adolescents with depressive disorders and treatment for African-American children with attention-deficit hyperactivity disorder. During the first year, the grantees will develop proficiency in a specific evidence-based practice. By the second year of the initiative, grantees will have implemented a cultural adaptation of the evidence-based practice by modifying the provision of services, changing provider relationships with clients, or altering

the evidence-based practice itself. Finally, an independent evaluator will use program evaluation results throughout the process to provide feedback to the foundation and grantees on the impact of their efforts.

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# Fast Facts

## Prevalence

Approximately one in four adults suffers from a mental disorder in a given year (National Institute for Mental Health 2006).

Approximately one in five children and adolescents experiences a mental disorder in a given year (HHS 1999).

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## The Costs of Mental Illness

In the U.S., mental disorders account for more than 15 percent of the overall disease burden and slightly more than the burden associated with all forms of cancer (HHS 1999).

In 1996, direct treatment of mental disorders cost the U.S. \$69 billion (HHS 1999).

The direct and indirect costs of untreated mental disorders exceed \$300 billion annually (GIH 2003).

In 2004, 31,647 people committed suicide (Minino et al. 2006).

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## The Mental Health Care System

More than 33 million Americans seek mental health services each year (IOM 2005).

Nearly two-thirds of all people with diagnosable mental disorders do not seek treatment (HHS 1999).

Close to two thirds (62 percent) of mental health expenditures are government-funded (Frank and Glied 2006).

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## Vulnerable Populations

An estimated 40 percent of homeless individuals have substance use disorders; 20 percent have serious mental illnesses (SAMHSA 2003).

Roughly two-thirds of children with major depression also exhibit symptoms of another mental disorder (HHS 1999).

Older adults have the highest rates of suicide (HHS 1999).

The prevalence rate of suicide for American Indians and Alaskan Natives is 1.5 times the national rate (HHS 2001).

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## Recommended Reading

Frank, Richard G. and Sherry A. Glied, *Better But Not Well: Mental Health Policy in the United States Since 1950* (Baltimore, MD: The Johns Hopkins University Press, 2006).

This book provides insight into the past half-century of mental health care in the U.S., covering important advances in understanding mental illnesses, increases in spending on mental health care and support of people with mental illnesses, and the availability of new medications that are easier for the patient to tolerate. The authors argue that although these changes have made things better for those who have mental illness, they are not quite enough.

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Garduque, Laurie, “Putting Knowledge to Work for Mental Health,” Views from the Field, *GIH Bulletin*, October 22, 2001.

In this article, Laurie Garduque of The John D. and Catherine T. MacArthur Foundation challenges the philanthropic community to do better when it comes to funding for mental health. She describes how grantmakers can—and should—play a key role in charting new territory, challenging service systems to do better, and promoting the adoption of evidence-based practices.

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Grantmakers In Health, “Addressing Maternal Depression,” Issue Focus, *GIH Bulletin*, October 18, 2004.

This article outlines the prevalence of and treatment opportunities for maternal depression. It also discusses the effects of maternal depression on children and families and provides examples of philanthropic activity.

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Grantmakers In Health, *In Harm’s Way: Aiding Children Exposed to Trauma* (Washington, DC: 2005).

Exposure to violence, abuse, or natural disasters can have both immediate and long-term effects on children’s health and their ability to function fully in their families, schools, and communities. This Issue Brief focuses on the needs of children exposed to trauma, strategies for early identification and intervention, and ensuring the provision of timely and appropriate services.

Grantmakers In Health, *Turning the Tide: Preserving Community Mental Health Services* (Washington, DC: 2003).

This Issue Brief highlights the crisis in community mental health programs, citing inadequate financing and a shortage of appropriately trained providers as two major problems. The authors explore how health grantmakers can support community programs that provide critical mental health intervention and treatment services to children and adults.

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Institute of Medicine, *Improving the Quality of Health Care for Mental and Substance-Use Conditions* (Washington, DC: The National Academies Press, 2005).

This report, part of the IOM’s Quality Chasm Series, examines the mental health care delivery system and addresses issues pertaining to health care for both mental and substance-use conditions. It provides system improvement strategies for clinicians, health insurance providers, policymakers, and other stakeholders.

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Jamison, Kay Redfield, *An Unquiet Mind: A Memoir of Moods and Madness* (New York: Alfred A. Knopf, Inc., 1995).

This memoir examines bipolar disorder from the perspectives of both the healer and the healed. Dr. Jamison, a psychologist and professor of psychiatry at Johns Hopkins University, tells the story of her struggle with bipolar disorder.

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Saxe, Leonard and Theodore P. Cross, “The Mental Health Services Program for Youth” in Stephen L. Isaacs and James R. Knickman, eds., *To Improve Health and Health Care: 1998—1999* (San Francisco, CA: Jossey-Bass, 1998).

This essay chronicles Robert Wood Johnson Foundation’s involvement in providing community-based services for children and youth with mental illness. The authors describe the challenges encountered in implementing, financing, and coordinating services in the Mental Health Services Program for Youth.

U.S. Department of Health and Human Services,  
*Mental Health: A Report of the Surgeon General*  
(Rockville, MD: 1999).

This seminal report enforced the message that mental health is fundamental to overall health. Calling for increased understanding of mental disorders, the report explains the neuroscience of mental health, calls for the use of evidence-based practice, and outlines the disparities in access to mental health services.



U.S. Department of Health and Human Services,  
*Mental Health: Culture Race, and Ethnicity—A  
Supplement to Mental Health: A Report of the  
Surgeon General* (Rockville, MD: 2001).

This supplement to *Mental Health: A Report of the Surgeon General* outlines the extent to which racial and ethnic disparities exist in the prevalence of mental disorders and in mental health treatment. The report pays special attention to vulnerable, high-need populations, such as the homeless and the incarcerated, in which minorities are overrepresented.





# Public Health

The nation's public health system is the first line of defense against numerous threats. It ensures the public's health and safety by identifying and tracking disease, protecting food and water supplies, educating the public about health issues, and responding to disasters. Public health, however, remains largely invisible to most Americans—until something goes wrong. An outbreak of food poisoning or the start of the annual flu season heightens awareness of our vulnerability. These episodes also bring attention to an overburdened public health system challenged by fragmented funding streams, inadequate staffing and training, outdated information technology and communications systems, and an aging laboratory system.

**Public health remains largely invisible to most Americans—until something goes wrong.**

Public health stakeholders, including health philanthropy, can incite and sustain change to ensure that these systems are working. Health funders are uniquely positioned to strengthen the public health infrastructure. They can act as neutral conveners, provide grants for startup funding, coordinate collaborators, and encourage community engagement.

Foundations can also educate and inform the public about a wealth of public health issues, as well as impress upon policymakers the value and benefits of public health.

## What is Public Health?

The vision of public health in the United States is one of healthy people living in healthy communities (American Public Health Association 2004). This ideal rests on the Institute of Medicine's (IOM) definition of public health as "organized community efforts aimed at the prevention of disease and promotion of health" and its mission as the "fulfillment of society's interest in assuring the conditions in which people can be healthy" (IOM 1988).

The network of people, systems, and organizations making it possible to carry out essential public services is considered the system's infrastructure. Essential public health services can reduce the burden of preventable illness and injury and avoid costly medical services needed to treat preventable illness. Basic infrastructure is also essential to respond effectively to bioterrorism, emerging infectious diseases, and other health threats.

## The Evolution of Public Health and Its Expanding Role

Public health has evolved over time to reflect the changing health burdens on society. The discipline began in the 19th century as a response to local disease threats such as scarlet fever, measles, typhoid fever, smallpox, and yellow fever (Fee and Brown 2002). The majority of deaths early on were attributable to infectious diseases, as well as poor hygiene, deficient nutrition, and unsafe working conditions (CDC 1999). Successful public health interventions decreased the incidence of certain infectious diseases, and in most

### TEN ESSENTIAL PUBLIC HEALTH SERVICES

- 1) *Monitor* health status to identify community health problems.
- 2) *Diagnose* and investigate health problems and health hazards in the community.
- 3) *Inform*, educate, and empower people about health issues.
- 4) *Mobilize* community partnerships to identify and solve health problems.
- 5) *Develop* policies and plans that support individual and community health efforts.
- 6) *Enforce* laws and regulations that protect health and ensure safety.
- 7) *Link* people to needed personal health services and assure the provision of health care when otherwise unavailable.
- 8) *Assure* a competent public health and personal health care workforce.
- 9) *Evaluate* the effectiveness, accessibility, and quality of person and population-based health services.
- 10) *Research* for new insights and innovative solutions to health problems.

Source: American Public Health Association, *The Essential Services of Public Health* (Washington, DC: 2004).

cases eradicated the threat. Public health then began to expand its role and increase its activities.

While the first half of the 20th century brought great advances in the public's health and longevity, public health as a discipline ebbed and flowed. In the 1940s it gained attention with the development and broad use of penicillin and improved vaccines. This period also saw establishment of the Center for Controlling Malaria, the precursor to the Centers for Disease Control and Prevention (CDC). Interest in public health waned in the 1950s but reemerged in the 1960s along with an increasing interest in addressing social inequities and the growth of the modern environmental health movement (Fee and Brown 2002).

The 1980s saw public health again retreat, largely due to the Reagan Administration's market-oriented policies and reductions in social programs and regulatory agencies (Fee and Brown 2002). The effects of cutbacks to state funding and the

use of block grants led to decreased funding for public health infrastructure. New infectious diseases such as HIV/AIDS began emerging at the same time; and diseases once thought to be under control, such as tuberculosis and cholera, were re-emerging.

In recent decades, chronic diseases, such as cancer and heart disease, have become the leading causes of death. In response, public health activities have broadened to include health education and promotion. To accommodate this shift toward personal health promotion, public health has been drawn away from some of its population-based core functions. Public health agencies have also taken on the added responsibility of providing health care services, most often to at-risk populations.

The importance of public health and experts' concerns about the weakness of our public health infrastructure resonated with the broader population in 2001. The terrorist attacks of

September 11th and subsequent anthrax attacks revealed the system's vulnerabilities, specifically in the area of emergency preparedness and response. As a result, vast amounts of public and private funds poured into the system to prepare for and respond to future disasters, whether manmade or natural. For example, funds were used to buy equipment, such as biohazard suits for first responders and to develop plans for mass vaccinations in case of a deliberately introduced smallpox outbreak. At the same time, new infectious diseases were emerging, including West Nile virus and SARS. The public health system's ability to monitor, detect, and respond to outbreaks on a global level was clearly challenged.

Hurricane Katrina tested the system again in 2005, revealing continued flaws in the public health system's infrastructure. Communication and coordination among federal, state, and local agencies, as well as non-profit entities such as the Red Cross and United Way, appeared to be almost nonexistent. Questions of who was leading recovery efforts, providing shelter and medical services, monitoring the immediate and long-term environmental impact, and clearing debris plagued the system in the weeks and months following the storm.

### Challenge: System Overburdened Infrastructure

Today's public health system is overburdened. And its responsibilities continue to expand. One major shift has been the movement from focusing on discrete interventions, such as water supply management and sewage disposal, to broader social

and cultural reforms to address the root causes of illness. For example, public health agencies have taken on overweight and obesity and are working to educate the public about the benefits of healthy eating and exercise. With this shift, public health has been drawn away from some of its core functions, such as epidemiology and surveillance.

In many communities, the public health system has also become a provider of health care services to the uninsured or in areas where services are unavailable. As suggested by the IOM in 2003, this default status of many public health agencies is "consuming resources and impairing the ability of governmental public health agencies to perform other essential tasks." Furthermore, the health care and public health systems often do not interact effectively. As a result of this poor communication and coordination, some public health services, such as disease detection, may be more difficult to carry out.

For too long, infrastructure has been neglected. As a result, public health does not have the capacity required to respond quickly and effectively to threats such as an influenza epidemic or a devastating hurricane. The three critical and interrelated elements of infrastruc-

ture are organizational capacity, workforce capacity and competency, and information and data systems. Each has its own unique set of hurdles to overcome in order for the public health system to function effectively. Health funders are well positioned to strengthen the public health infrastructure. Successful strategies include partnerships with public health agencies, academia, and community-based groups; support for workforce development and leadership training, including scholarships and training programs; and funding improvements in information technology and communication systems.

### Organizational Capacity

The organizational capacity of the public health system is comprised of federal, state, and local health departments and laboratories. Effective functioning of public health agencies requires, among other things, a responsive organizational structure and modern facilities. Also included are partnerships with private entities to ensure that services are provided (CDC 2002).

One of the largest initiatives to strengthen state and local public health systems was Turning Point: Collaborating for a New Century in Public Health. The initiative, developed and funded by Robert Wood

**For too long, infrastructure has been neglected. As a result, public health does not have the capacity required to respond quickly and effectively to threats such as an influenza epidemic or a devastating hurricane.**

Johnson Foundation (RWJF) and the W.K. Kellogg Foundation, started in 1997. Its mission was to transform and strengthen the U.S. public health system by making it more community-based and collaborative. RWJF's participation in Turning Point stems in part from the IOM's seminal 1988 report, *The Future of Public Health*, which described a public health system in disarray and identified weaknesses such as funding, leadership, and data collection and analysis. Foundation staff also engaged in ongoing dialogue

**With combined commitments of more than \$24 million dollars from the two foundations, Turning Point provided support for state and local communities to improve the performance of their public health systems through strategic development and implementation processes.**

with experts in the field of public health. In exploring strategies to improve the public health system, the foundation took advantage of key strategic opportunities, signaling that this was the right time to invest in public health. As RWJF senior program officer Susan Hassmiller (2002) put it, "states faced increased responsibilities at the same time that resources for public health were diminishing...[and] there were new public health leaders coming to the forefront at the state and community level, providing the impetus for change with a vision for a more integrated health system."

At the same time RWJF was exploring how to strengthen public health

at the state level, the W.K. Kellogg Foundation was seeking strategies to build local public health capacity. At a joint meeting in 1996, the foundations decided that they could have the greatest impact on the public health system by forging a funding partnership. With combined commitments of more than \$24 million dollars from the two foundations, Turning Point provided support for state and local communities to improve the performance of their public health systems through strategic development and implementation processes. Its efforts drew upon the strength of collaborations and involved key public and private sector partners. RWJF ultimately funded projects in 21 states. The W.K. Kellogg Foundation funded 14 communities within these states.

Foundations at the state and local level have also contributed to the success of Turning Point programs. They have provided matching grants; supported conferences and other convenings; and awarded grants for scholarships, training, and other educational opportunities for individuals involved in Turning Point programs. States and communities were able to leverage these funds, some of which were only a few thousand dollars, to support the broader goals of Turning Point.

Several states participating in Turning Point took on the challenge of building public health organizational capacity. In New Hampshire, stakeholders, including the Community Health Institute and the New Hampshire Public Health Association, developed a grant program to create regional public health structures in areas where there were no

local health departments. At the time, only two of the state's 234 towns and cities had formal public health departments and there were no county health departments. By pooling resources from towns, the state health department, and the CDC, New Hampshire's Turning Point program was able to fund four community collaborations covering 37 towns and cities. State and local funders also contributed to this effort, including the Endowment for Health, the Foundation for Healthy Communities, and the New Hampshire Charitable Foundation.

The terrorist attacks of September 11th occurred just as New Hampshire's coalitions were beginning their work and attracted the attention of state leaders. Working with the state public health department, the coalitions were able to use new bioterrorism funds to develop systems and services that effectively respond to disasters and assist communities in recovery (Kassler and Goldsberry 2005). The new resources also allowed additional towns and cities to be brought into the program. By 2004, the New Hampshire Public Health Network, as the program became known, covered 67 percent of the state's population and included almost half of its cities and towns. Evaluation results show that the network helped increase coordination between state and local agencies, formalized the role of nongovernmental organizations in providing public health services, and strengthened the capacity of local governments to partner more effectively with nongovernmental agencies (Turning Point 2004). The success of the state's work became evident in early 2004 with an out-

break of hepatitis A. Communities were able to quickly make decisions about informing the public of the outbreak and disease symptoms, and to provide more than 2,500 area residents with antibody treatments (Turning Point 2004).

A second component of Turning Point was the development of National Collaboratives of Excellence. During the initiative's planning phase, several areas were identified as requiring additional work to effectively improve the public health system, including information technology, public health law, performance management, leadership, and social marketing. Grantees were not only requesting additional information on these topics, but they began to exchange ideas and information with each other. As a result, RWJF decided to create a formal infrastructure for discussion of these topics, as well as development of models and solutions (Hassmiller 2002).

While the two foundations' funding of Turning Point has ended, the important work begun through the initiative continues. For example, a major accomplishment of the initiative was the development of new structures to expand the capacity of states to respond effectively to public health issues. These structures include offices dedicated to public health improvements in state health departments; public health insti-

## A major accomplishment of the initiative was the development of new structures to expand the capacity of states to respond effectively to public health issues.

tutes; and the expansion of local public health systems through governmental agencies and partnerships (Brodeur 2005). In addition, several participating states developed new or enhanced existing leadership programs and training opportunities to build a more competent public health workforce (Brodeur 2005). Bobbi Berkowitz (2005), director of the Turning Point National Program Office at the University of Washington, suggests that the initiative's legacy will include "the institutionalization of the collaborative partnership approach, permanent broad-based citizen involvement in public health,...steady and predictable funding for public health,...and informed and engaged policymakers."

Using lessons learned from Turning Point, RWJF has begun to focus on public health performance management. The foundation is supporting efforts to establish performance baselines and benchmarks that will help improve public health agencies' performance and accountability. It has awarded grants to the National Association of City and County Health Officials and the Association of State and Territorial Health Officials to develop a framework for a voluntary accreditation system for state and local public health agencies. Foundation staff are also working to build the field of public health systems research to determine the



optimal application of resources that public health agencies need to do their jobs effectively.

### Workforce Capacity and Competency

The second core infrastructure element is workforce capacity and competency. This includes the more than 500,000 professionals working in federal, state, and local public health departments. These frontline workers are responsible for such tasks as tracking disease trends, inspecting restaurants and childcare centers, implementing community-wide immunization campaigns, and responding to emerging threats and outbreaks. Unlike other health profession fields, there is little uniformity and standardization in public health training. Only 44 percent of public health workers have received formal academic training in public health, and 78 percent of public health administrators lack such training (Baker and Koplan 2002). Admission into the public health workforce may be accomplished through many routes, from formal training in an accredited school of public health to a high school diploma with a willingness and aptitude for learning. Moreover, the public health field lacks continuing education and certification opportunities.

Foundations can build public health workforce capacity by providing grants to schools of public health, funding education and leadership training opportunities at the state and local levels, supporting research, and sponsoring national conferences. From the start, the Kansas Health Foundation has worked to strengthen its state's public health system. One of its first areas of

focus was workforce development. With the realization that the state's department of public health only had two epidemiologists, the foundation decided it could have a significant impact by supporting additional staff epidemiologists. This initial work led the foundation to look more closely at the needs of local public health agencies in educating and training staff. In the mid-1990s the foundation began to provide continuing education scholarships for local public health department employees. The scholarships were favorably received, with a program officer at the foundation noting that many local employees "tell us that they would not otherwise have the opportunity for continuing education because their small health departments just don't have the funding" (Williams 2002).

As the Kansas Health Foundation's work in this area evolved, staff also began to tackle the issue of leadership development. In 2003, the foundation awarded a six-month planning grant and a four-year implementation grant to support development of the Kansas Public Health Leadership Institute. The institute provides leadership training for workers in public health and allied fields. Its curriculum includes specific modules based on competencies developed by the National Public Health Leadership Development Network. It also provides an opportunity for participants to develop their leadership knowledge, skills, and competencies in order to strengthen organizational effectiveness and positively affect the state's public health system. In 2006, the leadership institute entered its fourth training cycle.

### Information and Data Systems

The third infrastructure element is information and data systems. A 2001 study revealed that only 68 percent of county health agencies had Internet connectivity (Baker and Koplan 2002). Such shortfalls make it difficult for public health agencies to conduct day-to-day business, and can be deadly in emergency situations such as disease outbreaks or natural disasters. The delivery of effective public health services depends on timely and reliable information and data. This infrastructure element also includes alert systems, such as the CDC's Health Alert Network. This nationwide integrated information and communications system can distribute health alerts, prevention guidelines, and other information to public health professionals, health care providers, and the public in an efficient and timely manner.

Foundations can provide the resources necessary for public health departments to purchase, update, and utilize information and communication technology. They can also fund initiatives to support private organizations to collect information relevant to their communities. The Kansas Health Foundation supported the development and installation of the Kansas Integrated Public Health System (KIPHS). This comprehensive health information system is designed to enhance the quality, effectiveness, and efficiency of public health practice. It assists state and local health departments in obtaining accurate data on health issues and integrating data from multiple sources. For example, the system is connected to the CDC's national surveillance system. In

October 1998, the Kansas Health Foundation awarded a \$1.8 million grant to implement the KIPHS software throughout the state, and it has been installed in several county health departments. A central data clearinghouse was established, as well as an office within the Kansas Department of Health and the Environment. The Kansas Health Institute administers the grant, and the CDC provides additional support.

In the past, public health agencies typically developed information systems without taking advantage of the experiences of other agencies, or sharing information and collaborating across states and other jurisdictions. To foster collaborative work, RWJF awarded more than \$3 million to the Public Health Informatics Institute in 2004. The program, InformationLinks, is working to spur the development of collaboratives among state and local public health agencies to exchange health information and foster the rapid and timely sharing of information between public health and health care systems, between public health systems and local communities, and among public health agencies within and across jurisdictions. The institute also evaluated strategies aimed at advancing state and local public health agencies' informatics capacity. This evaluation revealed that collaboration was in fact a powerful lever to improve information infrastructure. A partnership between the Association for Public Health Laboratories and state and local public health laboratories, for example, was able to successfully define comprehensive technology requirements and design laboratory

information management systems (RWJF 2006).

RWJF is also supporting professional training in public health informatics. With demands on public health agencies increasing and resources growing ever scarcer, there is an urgent need for experts trained in the application of informatics to public health practice. The

**Spending for public health today is a small fraction of the nation's total health spending. In fact, as much as 95 percent of health care-related spending is allocated to medical care and biomedical research**

foundation is interested in promoting increased academic attention to training and research in public health informatics as a means to strengthen the bridges between universities and public health practitioners. Specifically, the foundation is supporting the National Institutes of Health's National Library of Medicine to provide in-depth training in basic information science and public health principles at four universities.

### **Challenge: Financing Public Health**

Current financing of public health programs reflects the nation's health priorities. Historical investments in public health services and infrastructure have paid off. In the last century, support for immunization programs drastically reduced deaths due to infectious disease. Spending for public health today, however, is a small fraction of the nation's total health spending. In fact, as much

as 95 percent of health care-related spending is allocated to medical care and biomedical research (IOM 2003).

Funding for public health decreased throughout the 1990s and this had a direct impact on the quality, provision, and organization of public health services. The majority of public health funding is categorical, meaning it is designated for specific services or programs, making it difficult for state and local public health departments to respond to unexpected events, such as outbreaks of food-borne illness or West Nile virus. Tight state budgets have also reduced public health spending. The Trust for America's Health estimates that more than two-thirds of states cut public health funding during the 1990s (Trust for America's Health 2003).

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Public health received a huge influx of federal funds after September 11, 2001. Designed to improve the response to future emergencies, the funds went to states and localities, either directly or through grants from the CDC and other federal agencies. There are concerns, however, that while investments in emergency preparedness are critical to the nation's safety, this type of categorical spending may compromise public health's mission (Akhter 2002). For example, some local

health departments reported cutting back on public health services, such as screenings for heart disease and cancer, children's dental services, and prenatal care, to meet requirements in the federal government's new smallpox vaccination program (Trust for America's Health 2003).

While the funds helped address some problems, most states are now only modestly more prepared to respond to public health emergencies (2003). Funding aimed at preparing for crises, however, does have a dual utility. It can be used to build and repair the infrastructure required to sustain the public health system's day-to-day responsibilities. Much of the federal funding from 9/11 was used by states and localities to purchase or upgrade equipment, supplies, and pharmaceuticals to enhance preparedness and response; conduct exercises to test emergency response capabilities and timeliness; and improve surveillance and detection.

Working with public and private stakeholders, health grantmakers can educate legislators and other decisionmakers about the value of allocating integrated funds based on community need. State Turning Point programs, for example, learned early on that they must find new and creative approaches to using funds. In Nebraska, Turning Point participants developed a strategic plan to strengthen the state's fragmented and underfunded public health system. As a result, a portion of the state's tobacco settlement funds were dedicated to building the public health system. Keys to gaining and sustaining this funding include creating a diverse network

of partners to support collaborative decisionmaking, seeking input from the community, and demonstrating accountability by documenting results and communicating them to policymakers and the general public (Palm 2005).

### Challenge: Emergency Preparedness and Response

In order for the public health system to respond in a timely and effective manner to natural disasters, chemical or biological events, or disease outbreaks, a stable infrastructure must be in place. Public health agencies must have the capacity to prepare for, detect, and respond to health threats. Most state and local public health departments, however, are not fully prepared. As evidenced by both the September 11th attacks and Hurricane Katrina, the public health system lacks key elements needed to respond adequately.

Public health preparedness efforts at all levels needs to be accelerated. In a study of preparedness for major emergencies, Trust for America's Health found that five years after the September 11th and anthrax tragedies, emergency preparedness is still inadequate, stating that the U.S. is "nowhere near as prepared as we should be for bioterrorism, bird flu, and other health disasters" (2006).

There is also wide variance in preparedness at the state level. In its *Ready or Not? Protecting the Public's Health from Diseases, Disasters, and Bioterrorism*, Trust for America's Health evaluated the emergency preparedness of all 50 states and the District of Columbia. States received one point for achiev-

ing each indicator, with zero as the lowest possible overall score and 10 the highest. The indicators focus on key areas of preparedness such as data systems that are compatible with the CDC National Electronic Disease Surveillance System, increased or maintained levels of funding for public health services, sufficient laboratory capacity, having two weeks of hospital bed surge capacity, and not having a nursing workforce shortage. Half of states scored six or less on the scale of 10 indicators. Oklahoma scored the highest with 10 out of 10; California, Iowa, Maryland, and New Jersey scored the lowest with four out of 10. As in past reports, Trust for America's Health continues to call for an all-hazards preparedness approach to protect against a range of possible threats (2006).

Trust for America's Health's *Ready or Not?* also makes specific recommendations to improve the nation's preparedness. It suggests developing federal standards that states should be accountable for reaching, the results of which should be made publicly available; establishing temporary health benefits for the uninsured or underinsured during times of emergency; designating a single senior official within the U.S. Department of Health and Human Services to be in charge of and accountable for all public health programs; improving emergency surge capacity capabilities; modernizing technology and equipment; and including the public in emergency planning (Trust for America's Health 2005)

A critical challenge to state and local health departments is that public

health crises, whether an outbreak of West Nile virus or a natural disaster, do not have borders. The nationwide E. coli bacteria outbreak in September 2006 is an excellent example. Contaminated spinach grown in California and shipped across the country resulted in E. coli-related illnesses in 26 states. Public health departments commonly look to geopolitical borders and focus on state and county lines. Communication and cooperation across boundaries are critical, but often do not exist.

In an emergency situation, an effective public health response requires partnerships between public health departments (including the CDC) and the health care providers, nonprofit organizations, and other agencies within a community. Developing new or enhancing existing emergency preparedness plans can contribute to strengthening the overall public health infrastructure. The tools needed to identify and respond to disease outbreaks are the same as those needed for a bioterrorist event. Health care providers are often the first to see patients with disease symptoms, whether the result of West Nile virus or anthrax. Communicating information about such patients to public health departments and coordinating efforts to track and contain disease are critical, but cannot take place unless the necessary relationships and tools—the infrastructure—are in place.

In the aftermath of the September 11th attacks, the CDC Foundation established the Emergency Preparedness and Response Fund to help the CDC and others prepare for

and respond to a variety of emergencies. The fund was created to address needs recognized on that day; CDC workers in New York City relying on cell phones to communicate and import data, could not get through because of the unusually high call volume following the disaster. These first responders lacked the means to purchase satellite phones that would have helped them perform their jobs more effectively, instead of relying on cell phones that could not transmit.

The Emergency Preparedness and Response Fund helps to remove barriers for public health workers responding to future emergencies. They are able to purchase time-sensitive, specialized equipment or services needed to get their jobs done when responding to an emergency event. At the request of CDC director, Dr. Julie Gerberding, the fund was activated in the aftermath of Hurricane Katrina. The fund allowed the CDC Foundation to respond immediately to requests for help from the Gulf Coast region. It supported CDC teams deployed to flooded communities and evac-

Dr. Gerberding also requested that the scope of the Emergency Preparedness and Response Fund be broadened to provide resources directly to state and local public health agencies in the Gulf Coast region. To do this, the CDC Foundation issued a call for support. Kaiser Permanente gave a gift of \$2 million to the fund and RWJF awarded a \$1 million grant. Many other foundations gave grants as well, enabling the CDC Foundation to respond to requests from public health agencies. Initial grants focused on meeting immediate needs of hurricane evacuees and health professionals. The foundation provided grants to purchase medications for evacuees with chronic conditions, such as high blood pressure and diabetes; to provide emergency dental, hearing, and vision screenings for evacuees, as well as replacing eye glasses and hearing aids; and to evaluate the mental health needs of evacuees and health workers and provide counseling and assistance when needed.

Like many other communities, the September 11th attacks were a wakeup call for Howard County, Maryland. In order to meet the health consequences of natural or manmade disasters, the Horizon Foundation partnered with the county government to develop the Community Emergency Response Network (CERN). CERN is composed of approximately 40 members including frontline responders and representatives of numerous community organizations and is chaired by the foundation's president. Since its inception in 2001, CERN has developed a communitywide disaster response plan to ensure optimum preparedness in

**In order to meet the health consequences  
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uee shelters, allowing them to use special emergency credit cards to purchase needed tools, from laptop computers to wireless Internet cards to banners promoting hand washing in shelters.



the event of a terrorist attack. It has also supported government disaster planning through coordination of the emergency plans and resources of participating members. Specific CERN functions include planning, a high level of interagency coordination, the development of tabletop exercises, disaster plan review, shelter planning, and communications enhancement. Special attention has been paid to the provision of information on disaster response, the needs of public schools, and the roles of nonprofit providers. CERN activities fall under and are functionally integrated with the county's Emergency Operations Center. One of the network's many achievements was to develop new safeguards to support the county's first responders. They include upgraded planning capabilities by local institutions, enhanced communications, tabletop exercises to test local readiness, volunteer training and deployment, and expanded shelter capacity.

In May 2006, The Horizon Foundation used the success of CERN to convene stakeholders, including government, health care providers, businesses, and civics groups, to plan how the county would respond in the case of an avian flu pandemic. This day-long conference introduced the foundation to new community partners and spotlighted areas where the foundation could apply its resources. For example, the meeting spurred the foundation to work more closely with neighborhood-based groups. This led to the foundation's support of Neighbor-to-Neighbor, a program to encourage communication within families and neighborhoods before a disaster occurs so that individual homes and

## Many foundations are committed to improving the public health infrastructure by fostering partnerships among public and private stakeholders.

neighborhoods will be prepared and self-reliant for up to three days following a local or regional disaster or emergency.

### Challenge: Effective Partnership

Public health stakeholders are becoming increasingly aware of the benefits of partnerships. They are sharing information, leveraging resources, and engaging community members to generate positive results for population health.

While partnerships can create lasting change, there are obstacles to successfully working together. For example, philanthropy and government have their own cultures, time frames, calculus for risk, and ways of doing business. Building successful partnership requires that prospective partners understand these differences, and then work to address them. Public health departments, for example, are typically made up of career civil servants who work for and report to elected officials. Unless public health leaders are willing to take risks and elected officials offer their support, it can be difficult for a public health agency to go on record saying that it needs help or is not as prepared as it ought to be. Additionally, while an elected official may initially demonstrate public support for an effort, the actual work is often left to an underfunded and understaffed health

department. Personnel and funding changes, especially after an election, can be another challenge to partnering with government. Likewise, foundation decision processes are often not transparent to potential government partners. Patience and open communication on both sides are key to successful working relationships.

Many foundations are committed to improving the public health infrastructure by fostering partnerships among public and private stakeholders. Their work reflects a commitment to helping public health agencies improve overall community health, collect and track health data, develop leadership skills, and improve public health system functioning. The California Endowment developed Partnership for the Public's Health (PHH) to do just that in 1999. The \$40 million initiative brought together communities and local public health departments focused on the common goal of reducing health disparities and improving community health. Over five years the initiative, housed at the state's Public Health Institute, fostered partnerships among 14 county and city public health departments and 39 communities throughout the state.

Communities participating in PHH used broad strategies and multisectoral partnerships to improve the



health of Californians. Successes over the course of the initiative include changes to school nutrition policies, increased regulation of tobacco use by youth, increased monitoring and regulation of environmental pollutants, reductions in traffic fatalities, and the creation of community parks to encourage physical activity (Center for Community Health and Evaluation 2006). PHH also demonstrated that collaboration between public health departments and communities lead to new opportunities to address the social determinants of health and health disparities. The diverse talents and perspectives of stakeholders are vital to sorting through complex problems and developing creative, long-term solutions. The initiative also demonstrated the importance of place-based work. Place-based work can effectively identify conditions amenable to policy change within communities that shape their residents' health risks and individual choices. Consequently, the California Endowment has chosen to use this public health-community partnership model for new advocacy initiatives directed at on asthma and obesity prevention. George Flores, senior program officer at The California Endowment, noted that the results of PHH have helped to temper the endowment's expectations for its major obesity prevention initiative, Healthy Eating, Active Communities (HEAC). The partnership process and building the means to change health outcomes take a long time. While the foundation may see changes in policy or physical environments (such as removing soda machines from schools) in the HEAC four-year time frame, they do not expect to see a significant

drop in the number of overweight or obese individuals from this intervention alone.

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# Fast Facts

## Definitions

The Institute of Medicine defines public health as “organized community efforts aimed at the prevention of disease and promotion of health” and its mission as the “fulfillment of society’s interest in assuring the conditions in which people can be healthy” (IOM 1988).

The public health infrastructure is defined as the network of people, systems, and organizations making it possible to carry out essential public services (IOM 1988).

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## Impact of Public Health

Life expectancy has increased more than 60 percent in the past 100 years, mostly attributable to gains in public health (Beitsch et al. 2006).

There is strong evidence that behavior and environment are responsible for more than 70 percent of avoidable mortality (IOM 2003).

Population wide vaccination programs have resulted in the eradication of smallpox and polio in the Americas, as well as control of measles, rubella, tetanus, diphtheria, and other infectious disease in the U.S. and other parts of the world (CDC 1999).

Since 1972, death rates for coronary heart disease have decreased 51 percent. Decline in deaths from coronary heart disease and stroke are the result of risk-factor modification, such as smoking cessation and blood pressure control coupled with improved access to early detection and better treatment (CDC 1999).

In 2005, the average per capita federal investment in public health via the CDC was \$20.99. Per capita CDC funding for states ranged from \$53.36 for Alaska to \$11.38 for Florida (Trust for America’s Health 2006).

Approximately 80 percent of CDC funds are redistributed to states and private partners to support a variety of services and programs, ranging from disease prevention initiatives to bioterrorism preparedness (Trust for America’s Health 2006).

In fiscal year 2005, per capita public health funding from state governments ranged from \$123.10 in Hawaii to \$3.76 in Nevada. On average, states spent approximately \$35 per capita, with nearly 30 states spending less than that (Trust for America’s Health 2006).

## Organization

Under the U.S. Constitution, each of the 50 states has primary legal jurisdiction and responsibility for the health of its citizens. States differ in how they structure and deliver public health services. In some states, the public health system is centralized, and the state has direct control and supervision over local health agencies. In other states, local public agencies developed separately from the state and are run by counties, cities, or townships and usually report to one or more elected officials (IOM 2003).

There are approximately 3,000 local health departments (LHDs) in the U.S. serving populations ranging from fewer than 1,000 people to almost 10 million. More than half (54 percent) of Americans live in the jurisdictions of the 6 percent of LHDs that serve populations of more than 500,000 (National Association of County and City Officials 2005).

An estimated 50 percent of U.S. public health laboratories lack the capacity to exchange electronic laboratory data with partners (Association of Public Health Laboratories 2006).

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## Workforce and Education of Professionals

A public health professional is defined as “a person educated in public health or a related discipline who is employed to improve health through a population focus” (IOM 2002).

In 2003, there were more than 556,000 full-time equivalent public health professionals working for federal, state, and local public health agencies (Gebbie and Turnock 2006).

Approximately 25 percent of public health professionals are public health nurses, 10 percent are environmental professionals, 7 percent are public health laboratory professionals, 3 percent are public health physicians and nutritionists, 1 percent are social workers and dental workers, and 0.5 percent are epidemiologists. The remaining 49 percent represent a variety of positions in office administration, information technology, and administrative support (Gebbie 2001).

In 2005, there were 37 accredited schools of public health in the United States, within 12 private and 25 public universities (Association of Schools of Public Health 2005).

In the fall of 2005 there were 19,443 students enrolled in 36 of the 37 accredited schools of public health. Of this total, 70.6 percent were female and 14.7 percent were foreign nationals. Of the U.S. students, 5,615 or 33.9 percent were members of minority groups.

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## Emergency Preparedness and Response

Nearly half of U.S. states do not use national standards to track disease outbreak information (Trust for America's Health 2005).

Hospitals in over 40 percent of states do not have sufficient backup supplies of medical equipment to meet surge capacity needs during a pandemic flu or other major infectious disease outbreak (Trust for America's Health 2005).

More than one-quarter of states do not have sufficient bioterrorism laboratory response capabilities (Trust for America's Health 2005).

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## Influenza

During a typical year, 5 percent to 20 percent of the U.S. population gets the flu. Of these, more than 200,000 are hospitalized from flu complications, and about 36,000 die (CDC 2006).

U.S. influenza vaccine manufacturers are projecting that as many as 115 million doses of vaccine will be available in the U.S. for the 2006-07 influenza season. This will be the most flu vaccine ever distributed in the U.S. during a single influenza season (CDC 2006).

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Institute of Medicine, *Who Will Keep the Public Healthy? Educating Public Health Professionals for the 21st Century* (Washington, DC: National Academy Press 2002).

National Association of County and City Health Officials, *2005 National Profile of Local Health Departments* (Washington, DC: 2005).

Trust for America's Health, *Shortchanging America's Health 2006: A State-by-State Look at How Federal Public Health Dollars are Spent* (Washington, DC: 2006).

Trust for America's Health, *Ready or Not? Protecting the Public's Health from Diseases, Disasters, and Bioterrorism* (Washington, DC: December 2005).

## Recommended Reading

Beitsch, Leslie, Robert Brooks, Nir Menachemi, and Patrick Libbey, "Public Health at Center Stage: New Roles, Old Props," *Health Affairs* 25(4):911-922, July/August 2006.

This article looks at the many roles and responsibilities of the nation's public health system. With public health in the spotlight, the authors examine new challenges and the resources available to meet them.

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Brodeur, Paul, "The Turning Point Initiative," in Stephen L. Isaacs and James R. Knickman, eds., *The Robert Wood Johnson Foundation Anthology: To Improve Health and Health Care, Volume VIII* (Princeton, NJ: 2005). Available on-line at [http://www.rwjf.org/files/publications/books/2005/chapter\\_05.pdf](http://www.rwjf.org/files/publications/books/2005/chapter_05.pdf).

This chapter in Robert Wood Johnson Foundation's *To Improve Health and Health Care, Volume VIII* reflects on the Turning Point initiative, including the concepts behind this collaborative program with the W.K. Kellogg Foundation to incite improvements in the public health system. It also examines five state Turning Point programs, documenting the challenges they faced and their successes.

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Grantmakers In Health, *Preparedness or Panic: Resources for Grantmakers* (Washington, DC: 2006). Available on-line at [www.gih.org/usr\\_doc/EmergeprepDoc.pdf](http://www.gih.org/usr_doc/EmergeprepDoc.pdf).

This resource guide is designed to help grantmakers working at the local, state, and national levels better understand how they can contribute to strengthening the public health system, as well as become more proactive in their efforts to prepare for and respond to emergencies.

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Grantmakers In Health, *Building a Healthier Future: Partnering to Improve Public Health* (Washington, DC: 2005). Available on-line at [http://www.gih.org/usr\\_doc/pubhealthpartner.pdf](http://www.gih.org/usr_doc/pubhealthpartner.pdf).

This Issue Brief identifies significant opportunities for grantmakers to partner with public health agencies at the local, state, and national levels, as well as with organizations outside of the traditional public health system, such as faith-based communities, employers, and community organizations. Specifically, this report can help further grantmaker efforts to build and sustain public health partnerships.

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Grantmakers In Health, *Strengthening the Public Health System for a Healthier Future* (Washington, DC: 2003). Available on-line at [http://www.gih.org/usr\\_doc/public\\_health.pdf](http://www.gih.org/usr_doc/public_health.pdf).

This Issue Brief examines the nation's public health infrastructure and explores opportunities for grantmakers to strengthen and sustain this troubled system. The report provides an overview of the public health system and its infrastructure weaknesses, as well as the challenges faced by state and local public health agencies. The report also looks at foundation strategies to help buttress the public health system's infrastructure.

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Institute of Medicine, *The Future of Public Health* (Washington, DC: National Academy Press, 1988). Available on-line at <http://www.iom.edu/?id=15251>.

This seminal report declared the U.S. public health system in disarray. It lays out a vision of public health in America and provides recommendations for strengthening the system.

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Institute of Medicine, *The Future of the Public's Health in the 21st Century* (Washington, DC: National Academies Press, 2003). Available on-line at <http://www.iom.edu/?id=16741>.

This report builds on the IOM's 1988 report, *The Future of Public Health*. It examines a broader scope of public health including the roles of government, the health care delivery system, communities, businesses and employers, the media, and academia.



Institute of Medicine, *Who Will Keep the Public Healthy? Educating Public Health Professionals for the 21st Century* (Washington, DC: National Academy Press 2002). Available on-line at <http://www.iom.edu/?id=16743>.

In this report the IOM defines who public health professionals are and looks at the many institutional settings in which they work. It also closely examines how public health professionals are educated and trained, opportunities for leadership development, and the workforce needs of the future.

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Isaacs, Stephen L., "The Robert Wood Johnson Foundation's Response to Emergencies September 11th, Bioterrorism, and Natural Disasters," in Stephen L. Isaacs and James R. Knickman, eds., *The Robert Wood Johnson Foundation Anthology: To Improve Health and Health Care, Volume VII* (Princeton, NJ: 2004). Available on-line at [www.rwjf.org/files/publications/books/2004/index.html](http://www.rwjf.org/files/publications/books/2004/index.html).

This chapter of Robert Wood Johnson Foundation's *To Improve Health and Health Care, Volume VII* reflects how the foundation responded to public health emergencies including the terrorist attacks of September 11, 2001, natural disasters, and bioterrorism. It considers the role of the Robert Wood Johnson Foundation, as well as the broader field of philanthropy.

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*Journal of Public Health Management and Practice*, 11(2), March/April 2006. Articles from this issue May be purchased on-line at [www.jphmp.com](http://www.jphmp.com).

This issue of the *Journal of Public Health Management and Practice* is dedicated to Turning Point, an initiative jointly funded by Robert Wood Johnson Foundation and the W.K. Kellogg Foundation. Articles examine progress made by Turning Point states and communities, as well as the initiative's National Excellence Collaboratives.

Levi, Jeffrey, and Chrissie Juliano, *Shortchanging America's Health 2006: A State-by-State Look at How Federal Public Health Dollars are Spent* (Washington, DC: Trust for America's Health, 2006). Available on-line at <http://healthyamericans.org/reports/shortchanging06/>.

In this analysis, the Trust for America's Health reviews key health statistics and key federal public health funding at a state-by-state level. The report finds funding levels for programs to protect the public's health vary dramatically among states, the country is falling short on achieving federally established goals for reducing disease and improving health, and there has not been sufficient funding to result in wide-scale change.

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National Association of County and City Health Officials, *2005 National Profile of Local Health Departments* (Washington, DC: 2006). Available on-line at [www.naccho.org/topics/infrastructure/documents/NACCHO\\_report\\_final\\_000.pdf](http://www.naccho.org/topics/infrastructure/documents/NACCHO_report_final_000.pdf).

This report provides information about local health department infrastructure. Topics include local health department jurisdictions and governance, financing, workforce, emergency preparedness, activities and services, planning and performance improvement, partnerships and policymaking, and information technology.

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Trust for America's Health, *Ready or Not? Protecting the Public's Health from Diseases, Disasters, and Bioterrorism* (Washington, DC: December 2006). Available on-line at <http://healthyamericans.org/reports/bioterror06/>.

Each year the Trust for America's Health has issued an annual *Ready or Not?* report assessing the level of preparedness in the states, evaluating the federal government's role and performance, and offering recommendations for improving emergency preparedness. The 2006 report states that five years after the September 11th and anthrax tragedies, emergency preparedness is still inadequate in America. The report contains state-by-state health preparedness scores based on 10 key indicators to assess health emergency preparedness capabilities. All 50 U.S. states and the District of Columbia were evaluated. Half of states scored six or less on the scale of 10 indicators.





# Quality of Care

In its 2001 report, *Crossing the Quality Chasm*, the Institute of Medicine (IOM) Committee on Quality of Health Care in America made the bold statement that “Americans should be able to count on receiving care that meets their needs and is based on the best scientific knowledge. Yet there is strong evidence that this frequently is not the case.” Recent results from the National Scorecard on U.S. System Performance, developed by The Commonwealth Fund’s Commission on a High Performance Health System, indicate, in fact, that the system falls short of what is attainable. When judged against 37 performance indicators such as infant

**Americans should be able to count on receiving care that meets their needs and is based on the best scientific knowledge. Yet there is strong evidence that this frequently is not the case.**

—INSTITUTE OF MEDICINE

mortality; childhood immunization rates; activity limitations for non-elderly adults; access to primary care providers; reported errors; and hospital and nursing home readmission rates; the system received a score of 66 out of a possible 100 when compared to benchmark performance<sup>1</sup> (The Commonwealth Fund 2006).

There are four major quality problems affecting the health care system:

- **Avoidable Errors:** Between 44,000 and 98,000 Americans die each year 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).

- **Underutilization of Services:** An estimated 18,000 people die annually because they do not receive effective interventions. Millions more suffer needless complications (AHRQ 2002).
- **Overuse of Services:** One analysis of seven health plans found that one out of every six hysterectomies performed was inappropriate. Another study looking at use of antibiotics for ear infections in children found that medications were used far more often than indicated (AHRQ 2002).
- **Persistent Variations in Use of Services:** Quality improvement is both needed and possible, although the IOM committee warned that “this higher level of quality cannot be achieved by further stressing the current systems of care...the current systems cannot do the job. Changing systems of care will” (IOM 2001).

## The Evolution of Quality

The way in which quality is understood has changed dramatically over the last two decades. It has evolved from a time when quality was an ephemeral concept, thought to be knowable only to physicians, to the notion that quality is a measurable product of system performance. This evolution happened at a time of substantial changes in the U.S. health care system, including advances in

<sup>1</sup> Benchmark comparison rates were those achieved by the top 10 percent of countries, states, health plans, hospitals, or other providers.

### EVERYONE IS AT RISK FOR RECEIVING POOR HEALTH CARE

In the *First National Report Card on Quality of Health Care in America*, released in 2006, RAND Corporation assessed how often recommended care was provided to patients for a broad range of conditions in 12 U.S. metropolitan areas. The stunning conclusion: all adults in the U.S. are at risk for receiving poor health care, no matter where they live; why, where, and from whom they seek care; or what their race, gender, or financial status is. Specific findings include:

- overall, adults receive about half of recommended care;
- quality of care varied across conditions, and across communities for the same condition;
- no community has consistently the best or worst quality of care;
- all socioeconomic groups were at risk for poor care; and
- systemwide investments in health care information technology, performance tracking, and incentives for improvements are needed.

Source: RAND Corporation, *The First National Report Card on Quality of Health Care in America* (Santa Monica, CA: 2006).

medicine, technology, and pharmaceuticals; changes in the payment policies and demands of public and private payers; a shift in the locus of care from inpatient to outpatient settings, and new expectations about the roles that consumers should play in the delivery of health care services.

Concern for the quality of health care services started in the early 20th century when the American Medical Association (AMA) and the American College of Surgeons (ACS) began to document the state of health care facilities, review the care provided, and develop minimum standards. The ACS also took on the role of surveying hospitals and determining acceptability for accreditation. This work ultimately led to the creation of the Joint Commission on Accreditation of Hospitals in 1952 (Luce et al. 1994).

Governmental regulation of health care began with state licensing rules for health professionals, first enacted in the late 1880s. For the most part,

however, health care was largely unregulated until passage of the Social Security Act (SSA) in 1935, which set standards for maternal and child services. Hospitals constructed with federal Hill-Burton dollars in the post World War II era led to new requirements to meet minimum codes. Passage of the Medicare program in 1965 led to a higher level of federal involvement. With the U.S. government acting as the payer for services for millions of elderly and disabled beneficiaries, the new law included conditions of participation, a set of rules mandating principles central to operating a hospital, such as professional credentials for staff, 24-hour nursing services, and utilization review. Medicare deemed hospitals accredited by the Joint Commission to have met all the regulatory requirements, with the exception of utilization review (Luce et al. 1994).

These initial efforts primarily focused on the structural aspects of care: the basic characteristics of institutions and health professionals. Over time,

these were complemented by an additional focus on process; that is, not just whether the right people and facilities are available, but also if the right things are being done in the right way. In 1979, the Joint Commission developed new hospitalwide quality assurance programs, incorporating measures such as hospital readmission rates and transfers to intensive care. In 1984, the U.S. Congress created peer review organizations (PROs) to monitor the cost and quality of care received by Medicare beneficiaries (Luce et al. 1994).

During this same time period, John Wennberg and colleagues at Dartmouth Medical School began documenting large variations in health care usage across different geographic areas. The effort to uncover the reasons behind these variations led Wennberg and others to focus their attention on the outcomes of care and the potential of developing practice guidelines that would help professionals practice at a higher standard of quality. The Omnibus Budget Reconciliation Act of 1989 (OBRA) authorized greater federal funding for effectiveness and outcomes research, essential building blocks for quality measurement, as well as a new program to develop and disseminate practice guidelines, clinical standards, review criteria, and performance measures. This work was to be carried out by a new federal entity, the Agency for Health Care Policy and Research (now the Agency for Healthcare Research and Quality). In 1992, the federal Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) established the Health Care Quality Improve-

ment Program, which allowed PROs to compare a hospital patient claims history against practice guidelines, analyze areas for improvement, and assess changes. In 1995, the program's scope broadened to include assessments of care received in outpatient settings (Grant et al. 1996).

A series of seminal reports detailing serious health care quality problems set the stage in the 1990s for the current national conversation on health care quality. In 1998, the President's Advisory Commission on Consumer Protection and Quality, called for a national commitment to improved health care quality, stating that "research documents the fact that today, in America, there is no guarantee that any individual will receive high-quality care for any particular health problem" (IOM 2001). Soon after, RAND released the results of an extensive literature review supporting the findings of the two previous reports. RAND concluded that there was "abundant evidence that serious and extensive quality problems exist throughout American medicine resulting in harm to many Americans" (IOM 2001).

Two other IOM reports, *To Err is Human: Building a Safer Health Care System* and *Crossing the Quality Chasm: A New Health System for the 21st Century*, released in 2000 and 2001, respectively, galvanized the quality improvement movement.

In *To Err is Human*, the IOM documented the magnitude of unnecessary deaths and injuries caused by avoidable medical errors and called on the nation's leadership to make reducing these errors a national priority. The central message of the report was that medical errors are the result of bad systems, not bad people. To fix the problem, the focus should be on redesigning these systems, not on changing individual behaviors.

*Crossing the Quality Chasm* stated that "health care harms too frequently and routinely fails to deliver its potential benefits" (IOM 2001). It identified quality as a property of the health care system and stressed the importance of applying evidence-based research to health care delivery, harnessing the power of information technology, aligning payment policies with quality improvement, and preparing the health care workforce to acquire new skills and new ways of relating to patients. The report also set forth a road map for building a high-quality, 21st century health care system.

Based on the IOM's work, the notion of quality has now moved from simple notions of structure, process, and outcome to being defined as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge

**Medical errors are the result of bad systems, not bad people. To fix the problem, the focus should be on redesigning these systems, not on changing individual behaviors.**

(IOM 2001). Its key dimensions, as set forth by the IOM, are:

- Safety: avoiding injuries to patients from the care that is intended to help them;

The way in which quality is understood has changed dramatically over the last two decades. It has evolved from a time when quality was an ephemeral concept, thought to be knowable only to physicians, to the notion that quality is a measurable product of system performance.

- Effectiveness: providing services based on scientific knowledge and avoiding overuse and underuse of services;
- Patient-Centeredness: providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide clinical decisions;
- Timeliness: reducing waits and sometimes harmful delays for those who receive and those who provide care;
- Efficiency: avoiding waste, including equipment, supplies, and energy; and
- Equity: providing care that does not vary in quality because of person characteristics such as gender, race, ethnicity, or socioeconomic status.

These dimensions of quality encompass both technical aspects of care and the degree to which it comports with patient preferences. Patient care should be delivered by systems that are designed to meet these six dimensions (IOM 2001).

The IOM's work both spurred and refined quality improvement efforts in the public and private sectors and compelled many leaders in the field to call for major systems change. Organizations such as the Institute for Healthcare Improvement (IHI) and the Leapfrog Group for Patient Safety seized the opportunity created by these reports to transform the call for quality improvement into action. Working with hospitals and health systems, these organizations and others pushed for redesigning systems of care through evidence-based guidelines and practices. The IOM report spurred action at the federal level, too. AHRQ, for example, is working to disseminate research findings and educate policymakers, health care practitioners, and the public on a range of quality issues from patient safety and medical errors to finely honed quality measurement tools.

### Measuring Quality

Twenty five years ago, quality, like beauty, was judged to be in the eye of the beholder. While quality measurement remains a developing science, there are now some generally accepted measures that reflect how care is delivered and how patients respond. Clinical performance measures look at how well providers treat or prevent illness. These include process measures such as receipt of preventive care, provision of counseling regarding promoting



healthy behaviors, or screening for treatable conditions. For example, the Health Plan Employer Data and Information Set (HEDIS), developed by the National Committee for Quality Assurance (NCQA) to compare how well health plans perform in key areas, includes indicators such as beta-blocker treatment after a heart attack, control of high blood pressure, breast cancer screening, antidepressant medication management, childhood and adolescent immunizations, and smoking cessation.

Measures have also been developed about other aspects of the delivery system. Measures of accessibility, such as appointment wait times and how long it takes someone to answer the telephone, reflect how easily and quickly consumers receive care. Measures of experience reflect patient opinion about the health plan or provider and the care and services received. This includes patients' ratings as well as reports on their interactions with a doctor or nurse and their ability to get needed information from their plan or provider. AHRQ's Consumer Assessment of Healthcare Providers and Systems, universally known as CAHPS, has become the national standard for assessing individuals' experiences with health plans. It includes more than 40 questions that ask consumers to report on and rate their experiences with aspects of care such as access, communication, timeliness, administrative ease, and courtesy. Finally, structural measures, such as board certification and accreditation, are also used to measure quality. These indicate whether a provider, plan or institution has systems or organizational traits that are associ-

ated with or considered minimum standards of high-quality care (AHRQ 2005).

### Philanthropic Activity

Health grantmakers play a vital role in promoting improvements in health care quality. While the mission statement of most grantmaking organizations may not explicitly refer to improving quality, activities designed to improve the quality of health care fall squarely within the mission of most health care foundations. Specific roles for foundations include convening stakeholders, promoting system improvements, educating consumers, influencing public policy, and funding research. There are opportunities within each of these areas, for grantmakers working at the national, state, and local levels.

### CHALLENGE: TRANSLATING RESEARCH INTO PRACTICE

A major challenge to improving health care quality is the translation of research findings into improvements in patient outcomes. It takes an average of 17 years for new knowledge generated by randomized controlled studies to become part of routine clinical practice. In addition, the implementation of best practices is uneven across provider settings. For example, only about three out of five patients with chronic conditions receive recommended care (AHRQ 2001).

While evidence-based practice guidelines are seen as critical tools for helping physicians and other health professionals make the best decisions about appropriate care in specific clinical circumstances, growth in the number of guidelines available can be daunting. In the state of Colorado, where physicians felt inundated and confused by the many and sometimes conflicting guidelines created by health plans, medical societies, government, and private agencies, The Colorado Trust stepped up to help develop the Colorado Clinical Guidelines Collaborative (CCGC) as part of its three-year \$1.3 million Improving the Quality of Patient Care Initiative. Caring for Colorado Foundation, Robert Wood Johnson Foundation, and the Colorado Department of Public Health and the Environment also provided funding for the collaborative. CCGC is developing a comprehensive set of guidelines for management of adult patients with diabetes, diagnosis and management of adults with depression, screening for colorectal cancer, evaluation and treatment of asthma, appropriate use of antibiotics in upper respiratory infections, pediatric and adult immunizations, tobacco cessation, and gestational diabetes. These are revised on a one-to three-year cycle. Additionally, CCGC will refine and improve upon how the guidelines are shared with the health care community. The initiative is being evaluated by Colorado

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Health Outcomes. The program's evaluation is focusing on the effectiveness of various strategies to disseminate the adult and pediatric immunization guidelines, and to determine which strategy leads to greater implementation by providers. One result of the foundation's quality initiative has been an increased level of collaboration among organizations in the state working on health care quality.

#### CHALLENGE: SYSTEM REDESIGN

Our current system of care does not deliver the level of care patients should receive. The IOM suggests that "health care has safety and quality problems because it relies on outmoded systems of work...If we want safer, higher-quality care, we need to have redesigned systems of care." For example, providers often work in silos, treating patients without complete medical history or information about medications, treatments, or services previously or currently being provided by others (IOM 2001).

The Commonwealth Fund's Health Care Quality Improvement and Efficiency program is based on the premise that system change is most likely to occur when a problem is understood and publicly recognized, when appropriate incentives are identified and implemented, and when stakeholders have the capacity to initiate and sustain change. Consistent with this model of change, the program has funded a number of projects aimed at: providing reliable information about the quality and efficiency of care to the public and the health care industry; evaluating the business case for improving quality and efficiency; improving

coordination of care and teamwork among health care professionals; and facilitating the exchange of information between physicians and patients.

To assess and reduce medication errors, The Commonwealth Fund awarded a series of grants to the Health Research and Educational Trust. The first grant, in 2000, supported the distribution a self-assessment tool to hospitals and health systems throughout the country. Approximately 1,000 hospitals were then contacted to see if they used the self-assessment tool, encourage them to do so, and collect information on the state of medical safety practices. Results showed that the majority of hospitals were not performing up to recommended safety standards. A need for educational strategies that can be implemented by multidisciplinary hospital teams was also identified. As a result of these findings, the foundation awarded a second grant in 2001 to the trust to support activities in several related areas, including communication among hospital staff regarding drug management decisions, drug labeling and nomenclature, and access to drug information at the time clinicians are making treatment decisions. The grant also supported the convening of quality improvement and medical safety leaders to develop core educational curricula and tools for hospitals.

The national 100K Lives Campaign, launched by the Institute for Healthcare Improvement in 2005, seeks to implement key practices that improve health care system functioning, as well as patient outcomes. With support from foundations including Aetna Foun-

dation, Blue Shield of California Foundation, Cardinal Health Foundation, The Colorado Trust, Gordon and Betty Moore Foundation, and Robert Wood Johnson Foundation, the campaign was joined by hospitals and health systems across the country that implemented six proven interventions to reduce avoidable deaths: deployment of rapid response teams; delivering reliable, evidence-based care for heart attack patients; preventing adverse drug events; preventing central line infections; preventing surgical site infections, and preventing ventilator-associated pneumonia. As of June 14, 2006, IHI estimated that the campaign had exceeded its initial goal, saving more than 122,300 lives.

As a campaign partner, The Colorado Trust made a \$3.8 million grant to help 62 Colorado hospitals implement the campaign, measure its progress, and track mortality rates. Participating hospitals were required to submit a progress report to the foundation at the end of the campaign. To generate public awareness of the campaign, as well as to raise visibility of quality issues, The Colorado Trust also funded a comprehensive public awareness campaign.

The foundation is now planning to support a second phase of the 100K Lives Campaign in Colorado, building upon lessons learned in the first round. For example, The Colorado Trust is seeking greater accountability from hospitals by requiring progress reports every six months instead of just one report as required in phase one. Phase two grants will also require increased internal communications among hospital departments in order to more effectively

spread the success of the campaign. The foundation's communication with grantee hospitals will also be strengthened by reaching out to a multidisciplinary team of practitioners, not just executive management or quality officers. In addition, the foundation will seek to increase each hospital's governance and leadership on quality issues by reaching out to CEOs and actively involving them in the campaign. Finally, foundation staff hope to mesh the success of the 100K Lives Campaign with the foundation's clinical guidelines initiative. This would move the quality achievements of hospitals into ambulatory care settings.

One of the earliest coalitions to address patient safety and medical errors is the Pittsburgh Regional Health Initiative (PRHI), a supporting organization of the Jewish Healthcare Foundation. Founded in 1997 as a consortium of Pittsburgh-area health care, business, nonprofit, and civic leaders, the initiative helps its clinical partners improve patient outcomes through proven engineering principles adapted for health care from the Toyota Production System. With support from the Jewish Healthcare Foundation, as well as other area foundations, PRHI partners are implementing best practices in cardiac care, reducing pathology errors, and developing new protocols for the care of patients with chronic conditions such as diabetes. In fact, PRHI's infection control program is among the nation's largest; and 40 Pittsburgh area hospitals have reduced infection rates by at least 68 percent (Jewish Healthcare Foundation 2006). The Pittsburgh Veterans Administration Health System, with coaching from PRHI, elimi-

nated a highly drug resistant strain of staph infection from its surgical units. With additional support from the Jewish Healthcare Foundation, PRHI is now applying its quality improvement model to the long-term care setting.

**Foundation staff hope to mesh the success of the 100K Lives Campaign with the foundation's clinical guidelines initiative. This would move the quality achievements of hospitals into ambulatory care settings.**

Another component of PRHI is Perfecting Patient Care™ (PPC), a curriculum designed to bring engineering disciplines to bear on clinical practice. PRHI staff members teach the curriculum to doctors, nurses, health care administrators, and other health care professionals in an intensive, four-day program known as PPC University. PPC encourages small improvements that are designed, quickly tested, and modified as necessary by frontline workers. Supervisors are partners or teachers in this process and rapid-cycle problem solving and learning are results. PPC University also includes on-site patient-care modules for frontline staff and managers in both long-term and acute-care settings. Topics include communication, conflict management, working within teams, team building/development, basic problem solving, rapid-cycle problem solving, and delegating for success.

#### **CHALLENGE: INFORMATION TECHNOLOGY**

Information technology (IT) is critical for measuring and monitor-

ing the quality of health care. It is also important for communicating quality of care to consumers, policymakers, regulators, and other audiences. Foundations are uniquely positioned to support the spread of information technology and assist in the development of Web-based

**While the amount of health information available has grown by leaps and bounds, consumers often have difficulty interpreting and using such information.**

applications that can improve access to health information and even improve patient-provider communication. For example, the Markle Foundation's Information Technologies for Better Health initiative aims to accelerate consumer use of information technologies in ways that improve health and health care. Under this initiative, the foundation provided support to the Comprehensive Health Enhancement Support System (CHESS) to evaluate ways in which underserved women with breast cancer use and benefit from a computerized patient support system, focusing on women in rural areas of Wisconsin and inner city neighborhoods of Detroit. CHESS provides breast cancer patients with up-to-date health information, software to help weigh treatment options, and 24-hour access to medical experts and other patients via the Internet. The positive evaluation results have led to the program's use as a tool for breast cancer patients in rural areas.

In collaboration with the Partners Healthcare System and FACCT

(Foundation for Accountability), the Markle Foundation also supported the Patient Accessible Electronic Medical Record project. This program has examined the implications of linking patients and physicians to medical records via the Internet. Preliminary findings from the project indicate that, while most patients find the tool useful for administrative tasks, such as renewing prescriptions and requesting referrals, a significant proportion are unsure about whether it improves the quality of communication, affords adequate privacy, or saves time. On the other hand, doctors and administrative staff are relatively enthusiastic about the tool, although they have some concerns, such as the fact that doctors are not financially compensated for their time spent responding to patient e-mails. Analyses are underway on how this Internet tool might enhance quality in the future by altering patient behavior. For example, providers could send electronic reminders to take medication. The tool may also help patients to identify and correct errors in their own medical records in collaboration with health professionals.

In California, a unique collaboration between the Tides Foundation and The California Endowment provides resources, evidence-based programming and evaluation, and education and training to support community health centers and clinics. The Community Clinics Initiative (CCI) has distributed more than \$30 million since 1999 to increase IT capacity in these settings and promote its use to assess and improve health care quality. The initiative began in 1999 with a project to address technological issues associated with the arrival

of the year 2000 (Y2K). This work was the first step in responding to the IT needs of the state's clinics. The program then evolved to address the internal IT needs of clinics by bringing clinics up to a minimum level of IT capacity, as well as supporting connectivity between clinics. This need led to the development of an extranet, enabling CCI staff to exchange ideas and lessons learned from the field, streamline grantee reporting, and improve CCI's ability to deliver technical assistance to clinics.

More recent work has focused on the use of disease registries that allow clinics to efficiently track chronic disease patients. At a basic level, registries allow clinics to follow treatments and services received by patients and to monitor provider performance. They also allow clinics to provide feedback to patients. For example, some of the more sophisticated programs allow a provider and patient to sit at the computer together and graphically look at a patient's progress. Registries can also track organizationwide progress against selected evidence-based guidelines. Information technology also allows community clinics to link patient encounter data with evidence-based medicine. For example, in Alameda County, California, encounter data is linked to practice guidelines to generate quarterly performance reports. The reports allow providers and patients to see how each facility is doing on selected practices. Data can also be sorted demographically and used to report variations in performance based on specific populations.

#### CHALLENGE: CONSUMER ENGAGEMENT

Consumers can play an important role in improving health care quality and the responsiveness of the health system to their needs. Whether they are choosing a health plan or provider, selecting a course of treatment, or incorporating healthy choices into their daily lives, empowered and engaged consumers can be a force for change. While the amount of health information available has grown by leaps and bounds, consumers often have difficulty interpreting and using such information.

Grantmakers have an important role to play in ensuring that understandable and useable information reaches consumers. The Commonwealth Fund, for example, has supported a broad body of work to collect and present quality information. Research supported by the fund found that many of the Web sites that consumers turn to for information on health care providers have missing or out-of-date information, as well as limited search capabilities. By making measures of provider quality available, such tools can help consumers in the selection process and lead to more informed care choices. These findings spurred a grant to the National Committee for Quality Assurance to develop an advisory group to create standards for physician directories. Based on the advisory group's recommendations, the Midwest Business Group on Health conducted a demonstration project in which a group of Chicago-based health plans, hospitals, and physician organizations implemented the recommended standards and evaluated the cost and value of doing so. This work yielded a blueprint for creating physician

directories that meet NCQA recommended standards.

Another way to make information accessible is to produce and disseminate it. California HealthCare Foundation has a strong track record in the area of quality measurement and reporting. An integral part of this work has been to educate consumers about health care quality and to make comparative quality information readily available. The foundation has developed a rich array of strategies, educational materials, and tools to help Californians make informed health care decisions. Specifically, the foundation supported the development of Web sites such as CalHospitals.org and the California Nursing Home Search Web site. Through these programs, quality information is collected, analyzed and then made public. The nursing home search Web site, for example, makes quality performance information publicly available on a quarterly basis in four areas: clinical quality, federal and state deficiencies, economic performance, and staffing. Over time, the foundation has found that these Web-based tools are not only excellent at conveying information to the public, but that public reporting has spurred improvement in quality. For example, in two years, there was a 20 percent decrease in the number of nursing homes not in compliance with minimum nurse staffing standards.

Foundations are also uniquely positioned to assist in the development of Web-based applications that can improve the flow of health information and improve patient-provider communication. The Blue Shield of California Foundation's



Center for Technology and Health supports research on the impact of information technology for both patients and providers. In 2001, the center supported an evaluation of RelayHealth, an on-line communication tool for patients, providers, payers, and pharmacies. RelayHealth facilitates clinical consultations about nonurgent medical symptoms via a secure Internet connection.

## Public reporting on the quality of care offered by different providers has spurred improvement in quality.

Evaluation results of RelayHealth used by patients and providers in the Blue Shield of California health plan network revealed reductions in both office visits and total cost of care. In addition, physician and patient surveys showed that the majority of both groups found the service easy to use, satisfying, and preferable to an office visit. The research also revealed that physician reimbursement was critical to making tools such as this successful. Tools such as RelayHealth can help improve health care quality by increasing patient access to providers in nonemergency situations. It can also improve consumer satisfaction by reducing appointment wait times and unnecessary physician office visits, as well as enhancing access to prescription medications, when needed.

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# Fast Facts

## Definition

The Institute of Medicine (IOM) defines quality as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (IOM 2001).

The key dimensions of quality, as set forth by the IOM, are:

- Safety: avoiding injuries to patients from the care that is intended to help them;
- Effectiveness: providing services based on scientific knowledge and avoiding overuse and underuse of services;
- Patient-Centeredness: providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide clinical decisions;
- Timeliness: reducing waits and sometimes harmful delays for those who receive and those who provide care;
- Efficiency: avoiding waste, including equipment, supplies, and energy; and
- Equity: providing care that does not vary in quality because of personal characteristics such as gender, race, ethnicity, or socioeconomic status (IOM 2001).

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## Some Improvements in Quality, But Gaps Remain

During 2005, the overall quality of U.S. health care improved at the rate of 2.8 percent, the same rate of improvement as 2004. In 44 core quality measurement categories, 23 improved, 19 were unchanged and only two became worse. In 2005 there was a more rapid improvement in some measures, especially where there have been focused efforts to improve performance. For example, measures for heart attack, heart failure and pneumonia showed an annual improvement of 9.2 percent (AHRQ 2005).

The diseases and populations which showed the most improvement in quality measures in the *2005 National Healthcare Quality Report and Disparities Report* were diabetes, heart disease, respiratory conditions, nursing home care, and maternal and child health care. The overall rate of change for these measures was 5.4 percent (AHRQ 2005).

The diseases and populations which showed the least improvement in quality measures were HIV/AIDS, cancer, end stage renal disease, mental health and substance abuse, and home health care. The overall rate of change for these measures was 0.3 percent (AHRQ 2005).

The *First National Report Card on Quality of Health Care in America* concludes that, overall, adults in the U.S. receive about half of recommended care. In addition, quality varies substantially across conditions. For example, about 65 percent of patients with high blood pressure receive recommended care while only 11 percent of those with alcohol dependence received recommended care (RAND 2006).

Insurance coverage does not ensure receipt of quality health care. Individuals with no health insurance receive about 54 percent of recommended care, compared to 55 percent of those with Medicaid or managed care coverage, 57 percent for Medicare enrollees, and 54 percent for those with private non-managed care plans (RAND 2006).

Between 36 percent and 45 percent of English-speaking U.S. residents have basic or below-basic general literacy and lack the literacy skills necessary to deal with health-related tasks (The Commonwealth Fund 2006).

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## Translating Research Into Practice

It takes an average of 17 years for new knowledge generated by randomized controlled studies to become part of routine clinical practice (AHRQ 2001).

Implementation of best practices is uneven across provider settings. For example, only about three of five patients with chronic conditions receive recommended care (AHRQ 2001).

## Patient Safety and Medical Errors

Medical errors are “the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim.” They can occur in practice, products, procedures, and systems (IOM 2006, AHRQ 2000).

Between 44,000 and 98,000 Americans die annually as a result of medical errors, more than from motor vehicle accidents, or breast cancer, or AIDS (IOM 2000).

Medication errors, both in and out of the hospital, result in more than 7,000 deaths each year (IOM 2000).

Approximately 95 percent of medical errors are system errors—the result of characteristics of procedures, equipment, job design, and communication systems (Berwick 2000).

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## Public Reporting and Consumer Quality Information

In New York State, outcomes for coronary artery bypass graft surgery have been reported for all surgeons each year since 1991. Close to two-thirds of managed care plans in the state look at the reports and use them in their contracting decisions. As a result, surgeons with better reported outcomes experienced an increase in market share (Mukamel et al. 2005).

Report cards are primarily used to convey quality information to consumers about health plans, large provider groups, and hospitals. A 2004 survey by The Henry J. Kaiser Family Foundation found that only a third of consumers had seen report cards of any kind. This represented an increase from 27 percent in 2000 (The Henry J. Kaiser Family Foundation 2004).

The Internet is transforming how consumers access and use health care information. While estimates vary, as many as 70 million Americans now use the Internet to retrieve health information and there may be as many as 100,000 health-focused Web sites (IOM 2001).

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## Recommended Reading

Agency for Healthcare Research and Quality, *National Healthcare Quality Report and Disparities Report* (Rockville, MD: 2007). Available on-line at [www.ahrq.gov/qual/nhqr06/nhqr06.htm](http://www.ahrq.gov/qual/nhqr06/nhqr06.htm).

This report is a comprehensive national overview of quality of health care in the U.S. and includes 179 performance measures that can be used to monitor progress toward improved health care quality for all Americans. It presents, in chart format, the latest findings on the quality of health care in the general U.S. population, focusing on four components of quality: effectiveness, patient safety, timeliness, and patient centeredness.

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Berwick, Donald M., *Escape Fire: Designs for the Future of Health Care* (Hoboken, NJ: John Wiley & Sons, 2003).

In this book Don Berwick, president and CEO of the Institute for Healthcare Improvement, outlines new designs for the nation's health care system and suggests practical tools for change. Berwick also identifies innovations and ideas from unusual sources, including a girls' soccer team and the safety standards at NASA.

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Berwick, Donald M., *Escape Fire: Lessons for the Future of Health Care* (New York, NY: The Commonwealth Fund, 2002).

Based on his personal experiences with the health care system, Don Berwick describes "the enormous, costly, and painful gaps between what we got in our days of need, and what we needed." He outlines the problems with the health care system, including medical errors, confusing and inconsistent information, and a lack of personal attention and continuity in care, and then sketches a program for reform.

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Grantmakers In Health, *Considering Quality: Engaging Consumers to Make Better Health Care Decisions* (Washington, DC: 2006).

This Issue Brief explore the challenges inherent in developing quality information, as well as how consumers

use such information. Opportunities for health funders to support health care quality information development and dissemination, as well as patient engagement in health care decisionmaking, are examined.

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Grantmakers In Health, *Rx for Progress: Putting Patient Safety Into Practice* (Washington, DC: 2002). Available on-line at [www.gih.org/usr\\_doc/patsafety\\_11-02.pdf](http://www.gih.org/usr_doc/patsafety_11-02.pdf).

This Issue Brief explores the work of foundations, government, research, and health care organizations to reduce medical errors and improve patient safety. The report draws on both foundation and grantee experiences and highlights specific funding strategies, as well as emerging opportunities for foundations that wish to fund patient safety programs and research.

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Grantmakers In Health, *Advancing Quality Through Patient Safety* (Washington, DC: July 2001). Available on-line at [www.gih.org/usr\\_doc/patientsafety.pdf](http://www.gih.org/usr_doc/patientsafety.pdf).

The Institute of Medicine (IOM) estimates that between 44,000 and 98,000 lives are lost annually as a result of preventable medical errors. This Issue Brief examines the response to the medical errors crisis across the health care delivery system, as well as how grantmakers working at the national, state, and local levels can contribute to advancing quality through reductions in medical errors and improvements in patient safety.

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Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, DC: National Academy Press 2001). Available on-line at [www.iom.edu/?id=12736](http://www.iom.edu/?id=12736).

In this report, the IOM argues for fundamental change to close the quality gap; recommends a redesign of the U.S. health care system; and provides specific direction for policymakers, health care leaders, clinicians, purchasers, and others. The report also offers a set of rules to guide patient-clinician relationships, a suggested organizing framework to align incentives in payment and accountability with improvement in

quality; and key steps to promote evidence-based practice and strengthen clinical information systems.

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This report from California HealthCare Foundation examines increasing consumer involvement in health care decisionmaking. It looks at the various forms and functions of tools available to help consumers make more informed choices, as well as summarizes evidence regarding the effectiveness of these tools. The report also outlines barriers that limit consumers' use of these tools and suggests practical steps to address those barriers by improving the design, content, format, and distribution of information tools.

# Racial and Ethnic Disparities in Health

# Racial and Ethnic Disparities in Health

*Despite significant improvements in the overall health of Americans over the past several decades, the health of racial and ethnic minorities continues to lag behind that of whites. For decades, there have been declarations identifying correction of health disparities as a national priority, but progress has been slow and disproportionate suffering, disability, and death continue (IOM 2006).*

Over the last century, advances in medicine and public health have led to substantial improvements in the nation's health, but minority health status continues to lag behind that of whites. In general, African Americans, Hispanics, Asians and

**Minorities suffer disproportionately from many illnesses, even after controlling for socioeconomic status.**

Pacific Islanders, and American Indians and Alaska Natives have poorer health and shorter lives than whites. Minorities suffer disproportionately from many illnesses, even after controlling for socioeconomic status and insurance coverage. Consider that:

- The infant death rate among African-Americans is still more than double that of whites. Deaths from heart disease and cancer are more than 40 percent and 30 percent higher, respectively, for African Americans than for whites. African-American women are more likely to die from breast cancer despite having a mammography screening rate nearly the same as for white women. The death rate from HIV/AIDS for

African Americans is more than seven times that for whites, and the rate of homicide is six times that for whites.

- Hispanics are almost twice as likely to die from diabetes as are non-Hispanic whites. Hispanics account for 20 percent of the new cases of tuberculosis, and have higher rates of high blood pressure and obesity than non-Hispanic whites.
- American Indians and Alaska Natives have an infant death rate almost double that of whites. Diabetes rates for these populations are more than twice that of whites. American Indians and Alaska Natives also have disproportionately high death rates from unintentional injuries and suicide.
- While Asians and Pacific Islanders, on average, are one of the healthiest population groups in the United States, there is great diversity within this population group. Women of Vietnamese origin, for example, suffer from cervical cancer at nearly five times the rate for white women. New cases of hepatitis and tuberculosis also are higher in Asians and Pacific Islanders living in the United States than in whites (CDC 2006a).

## Multiple Factors at Work

Developing strategies for reducing racial and ethnic disparities in health is a complicated task. Addressing them will require work to address the many factors that affect health including: the condition of the social environment, including racism and poverty; access to care; health behaviors; structural aspects of the deliv-



## People of color experience systematic barriers in accessing care.

ery system that affect both quality and patient care experiences; and the condition of the environments in which minorities live and work, including air and water quality and exposure to other environmental hazards. Much of the work in recent decades has focused on improving understanding of how these complex factors contribute to disparities, and documenting the problem as a fundamental step in finding solutions.

Discrimination has had a direct impact on the health of minorities. Minority populations are more likely than whites to perceive discrimination in the delivery of health services, and are less likely to have access to care, to attain care, and then to be satisfied with the care they receive (Hogue 2000). Minority patients still face differences in the treatments they receive. For example, blacks, Hispanics, and Asian Americans all report, in numbers higher than the overall population, having a major problem getting specialty care. Perceptions about discrimination in the health care system can also be a powerful motive in preventing minorities from seeking care.

Race matters a great deal to the understanding of health disparities. Race is more than a qualifier or descriptor—it is an underlying condition that restricts participation in society. As historian David Barton Smith (1999) noted, “Its influence has been so permanent and pervasive that it becomes an almost

unrecognized part of the background of our culture.”

Racism in the health care delivery system has a long history dating back to the pre-Civil War era. More recent experiences include the Tuskegee syphilis experiment which began in 1932 and lasted for 40 years. Although the civil rights movement ended governmental acquiescence in practices that segregated patients by race, segregation persists in physician referral practices, treatment decisions, and residential location. David Barton Smith (2005) calls full integration and accountability in health care key parts of an unfinished civil rights agenda.

The effects of discrimination are also a leading cause in the development of conditions that can lead to illness. The history of discrimination in the health care delivery system merely illustrates the larger social problem of racism in the broader culture. In short, the history of slavery and segregation are at the very root of the substandard neighborhoods, housing, employment opportunities, education, and health care that many minorities face.

The experience of individual discrimination expands when one considers the larger picture of institutionalized racism, the clearest and most pervasive example of which is housing segregation. While the practice of legal segregation began to end more than 40 years ago, the ra-

cial composition of black and white neighborhoods remains largely unchanged. Concentrating poverty through segregation dictates the quality of education people receive and their opportunities for attending college or for employment after leaving school.

Socioeconomic status also plays a key role in determining the health of minorities and access to health care. Researchers have long debated the question of race, socioeconomic status, and their effect on health. In the end, the relative impact of one or the other of these causes of disparities in health may not be determinable, as each are critical components in explaining why minorities are less healthy, have poorer access to quality care, and die sooner than whites. It is indisputable, however, that minorities consistently fare less well on a variety of socioeconomic indicators. They have lower incomes, less wealth, are less educated, and have fewer employment opportunities than whites (Williams 2000).

Minorities are also more likely to live in environments that are hazardous to their health, whether it is the condition of the air, the quality of housing, or the experience of violence in their communities. While environmental hazards that represent potential sources of risk affect all races, a higher percentage of African Americans and Hispanics live in communities with higher levels of air pollutants associated with respiratory symptoms such as asthma and the exacerbation of other ailments (IOM 1999).

The health behaviors of minorities are also important to understanding

health disparities. Data on smoking among minorities are mixed. In the Commonwealth Fund's Minority Health Survey, for example, fewer minorities reported that they smoked compared to whites (Hogue 2000). Data from the National Center for Health Statistics, however, suggest that the prevalence of smoking for survey respondents in the month before being surveyed is highest among American Indian or Alaska Natives. African Americans are only 60 percent as likely as whites to eat a healthy diet at least four times a week, and African-American men are only 70 percent as likely as white men to report that they routinely and vigorously exercise (Hogue 2000). The age-adjusted obesity rate in 2005 was

higher among non-Hispanic blacks and Mexican Americans than among non-Hispanic whites. This is especially true among women (CDC 2006b).

People of color also experience systematic barriers in accessing care. The percentage of adults without health insurance is highest among Hispanics and African Americans. Substantially fewer blacks and Hispanics have reported having a regular doctor than whites. Blacks are more likely than whites to receive care in settings such as emergency rooms, outpatient clinics, and other hospital clinics (AHRQ 2006).

Finally, patients with limited English proficiency encounter many

#### RECENT MILESTONES IN FEDERAL POLICY ON DISPARITIES

**1985:** Publication of the report of the Health and Human Services (HHS) Secretary's Task Force on Black and Minority Health. This report revealed large and persistent gaps in health status among Americans of different racial and ethnic groups.

**1986:** Creation of the federal Office of Minority Health. This in turn led a number of states to establish an official minority health entity (such as an office, commission, council, or center) either through executive or legislative branch action.

**1998:** President Clinton announces a national goal to eliminate racial and ethnic disparities in six areas by 2010. Healthy People 2010 makes elimination of health disparities one of its two overall goals.

**1999:** Passage of the Healthcare Research and Quality Act and the Minority Health and Health Disparities Research and Education Act bolster research funding and create the National Center on Minority Health and Health Disparities at the National Institutes of Health.

**2000:** Publication of federal standards to promote culturally and linguistically appropriate services (CLAS). CLAS standards are primarily directed at health care organizations as recommended national standards.

**2003:** Institute of Medicine releases *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. First *National Healthcare Disparities Report* published by AHRQ.

obstacles including delays in making appointments and misunderstandings about diagnosis and treatment. Many have difficulty expressing their concerns, which may in turn lead to inappropriate tests, or even misdiagnosis (Diversity Rx 2000). The growing minority population also faces cultural barriers in the delivery of health care services. Culture plays a role in how patients perceive

percent of African Americans and 56 percent of Hispanic Americans said minorities received worse care than whites (RWJF 2005).

The Institute of Medicine's 2003 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, has defined much of the work currently underway in both the public and private sector. This includes:

**National attention to the issue of health disparities increased significantly after President Clinton announced a federal commitment to end health disparities in six key areas in 1998.**

their illness, who should be involved in the treatment, the self-diagnosis of symptoms, basic notions about death and dying, and the appropriateness of invasive procedures.

**Eliminating Disparities: What's Next**

National attention to the issue of health disparities increased significantly after President Clinton announced a federal commitment to end health disparities in six key areas in 1998. A PubMed search of articles using health disparities as a key term found only 30 articles published between 1985 and 1999, for example, but 439 between 2000 and 2004 (IOM 2006). Even so, a 2005 poll funded by Robert Wood Johnson Foundation (RWJF) found that 68 percent of Americans are still unaware that health care disparities are a problem. Whites are least aware with 25 percent believing health care is worse for racial and ethnic minorities. In comparison, 44

- improving reporting and collection of access and utilization data by patient's race and ethnicity,
- encouraging use of evidence-based guidelines and quality improvement,
- supporting use of language interpretation services in clinical settings,
- increasing awareness among health care providers and the general public about disparities in care,
- increasing the proportion of underrepresented minorities in the health workforce,
- integrating cross-cultural education into the training of all health professionals,
- expanding use of community health workers,
- improving patient education and empowerment, and
- conducting further research to identify sources of disparities and promising interventions (IOM 2003).

These recommendations were echoed in a project funded by The Commonwealth Fund in 2004 to create a state policy agenda to eliminate health disparities. In addition to many of the IOM recommendations, their agenda includes suggestions for state policymakers to:

- expand health screening and access through expanded insurance coverage;
- establish or enhance state offices of minority health;
- involve all health system stakeholders in minority health improvement efforts; and,
- create a national coordinating body to promote continuing state-based activities to eliminate racial and ethnic health disparities (McDonough et al. 2004).

Since 2003, the federal Agency for Healthcare Quality and Research has been publishing an annual *National Healthcare Disparities Report* that examines racial and ethnic disparities in both access (13 core measures) and quality (46 core measures of quality, the same as those tracked in the companion *National Healthcare Quality Report*). It considers socioeconomic disparities as well. The most recent report (2007) concluded that, while some disparities are diminishing, disparities still exist. Opportunities for improvement remain, and information about disparities is improving.

**DATA COLLECTION AND REPORTING**  
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## Data collection and analysis are fundamental to efforts to end racial and ethnic disparities in health care.

A legal analysis funded by RWJF affirms that collecting race and ethnicity data about patients, when conducted as part of a program to improve health care quality, does not violate federal or state laws or increase the risk of race-based malpractice claims. The report also called for government guidelines to further encourage and shape the practice (Rosenbaum et al. 2006).

RWJF has also helped health plans follow up on the IOM's recommendation for health insurance companies to collect, report, and monitor patient care data as the foundation of efforts to address disparities in care. The RWJF-supported National Health Plan Collaborative is a groundbreaking project to identify how health care quality can be improved for racially and ethnically diverse patient populations, and has brought together nine major health insurance companies to work in partnership with organizations from the public and private sectors. Collaborative members have developed and tested new approaches for quickly estimating race and ethnicity to support disparities reduction in the short term, while they complete the longer process of collecting race and ethnicity information directly from their members. They also developed novel strategies and tools to help efficiently and effectively target interventions, began cultural competency training for health plan staff and provider networks, and tested strategies to educate and

reach out to underserved racial and ethnic populations.

Members of the collaborative shared their initial lessons learned in a report published in November 2006. They report three overarching lessons from their experience:

- Reorienting large organizations and developing institutionwide buy-in to disparities reduction takes time. Success depends on making disparities reduction a core business strategy.
- Companywide education efforts must also extend to the potentially sensitive task of collecting racial and ethnic data on health plan members, with efforts focused on explaining how the data will be used to help reduce disparities.
- Over time, the value of collective action became more apparent to the collaborative's members. Participation in the collaborative raised understanding of disparities within their companies (RWJF 2006).

### LINKING CULTURAL COMPETENCE, LANGUAGE ACCESS, AND QUALITY

In order to be effective in the delivery of health services, health care providers must understand the impact that language and culture have on health and health care. Over the last decade, the foreign-born population in the U.S. increased 44 percent. Nearly 47 million people

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speak a language other than English at home, and more than 21 million individuals are considered limited English proficient (U.S. Census Bureau 2003).

Providing language services is one element of a strategy to mitigate the myriad health and economic consequences of language and cultural barriers. It is also required by federal law. Under Title VI of the Civil Rights Act of 1964, recipients of federal funding are required to provide meaningful access to linguistic services, including interpreters. This includes all providers that accept Medicare and Medicaid patients and applies to their entire patient population. The U.S. Department of Health and Human Services reiterated this longstanding provision by issuing a policy guidance, drafted and enforced by its Office of Civil Rights, which explained the legal requirements of Title VI and outlined several broad strategies. The guidance was first issued in August 2000 and then republished in February 2002. In December 2000, the HHS Office of Minority Health also issued 14 national standards for ensuring culturally and linguistically appropriate services (CLAS) in health care. Currently, the Centers for Medicare and Medicaid Services provides the primary source of federal funding for language services to states under Medicaid and the State Children's Health Insur-

ance Program (SCHIP). Only nine states, however, are currently taking advantage of this funding option.

In the 1990s, cultural competence also came to be defined as intricately linked to the broader movement to improve health care quality. Although the evidence has yet to be fully developed, experts argue that "cultural competence is an essential part of a portfolio of activities to improve quality and eliminate racial and ethnic disparities in health care" (Betancourt 2006). The 2001 IOM report, *Crossing the Quality Chasm*, identified equity as one of the six principles that should guide the health system.

Both The Commonwealth Fund and RWJF have supported research to develop practical tools and evidence about the link between cultural competence and quality. For example, at the fifth National Conference on Quality Health Care for Culturally Diverse Populations in 2006, The Commonwealth Fund released a series of five reports summarizing the current evidence linking disparities and quality, and providing a road map to move from theory to action. The final report in the series recommends that organizations should:

- seek out leaders of community groups to solicit concerns and recommendations;

- make cultural competency a component of disease management, quality improvement, patient safety, customer service, and patient-provider interaction;
- consider how they will evaluate and quantify the positive impact of cultural competency efforts;
- explore the business case and social benefits of implementing cultural competency initiatives;
- recruit a diverse workforce and leadership that are committed to equality in health care; and
- provide time and resources for regular staff training (Wu and Martinez 2006).

Based in one of the most diverse states in the nation, The California Endowment has also made cultural competence one of its priorities since its founding in 1996. The foundation's work is guided by a multicultural approach to health, which is defined not only by race and ethnicity, but also includes financial status, cultural beliefs, gender, age, sexual orientation, geographic location, immigration status, and physical or mental abilities. Culturally competent health systems is one of its three program areas. The framework guiding its work is based largely on recommendations from IOM reports including ensuring patient safety, improving quality, reducing health disparities, and diversifying the health workforce.

The endowment is also using the Healthy People 2010 objectives to increase quality and years of life and eliminate health disparities.



To achieve these goals, the endowment supports activities ranging from policy change to education and training of health professionals, and quality improvements in health systems, plans, and providers. It also supports engagement with patients and consumers, promotion of a diverse health workforce to serve the underserved, efforts to assure equal access regardless of language, and health care services tailored to be effective for diverse populations. The Connecting Worlds Curriculum, for example, is a foundation-supported introduction to health care interpreting that combines a variety of teaching methods developed by a statewide collaboration of key stakeholders. The training curriculum provides bilingual participants an introduction to the skills required to master the consecutive mode of health care interpreting. Participants also have opportunities to apply their new skills through simulated interpreting sessions and case studies (The California Endowment 2006).

The Colorado Trust also began its work in cultural competency in the mid-1990s, when the Visiting Nurse Association (VNA) of Colorado voiced concerns about low rates of flu and pneumonia immunizations among minorities. The foundation responded by committing \$536,000 over three years to the Adult Immunization & Health Screening and Education Project. In addition to setting the goal of improving immunization rates in three counties, the initiative also sought to improve access to health prevention and education services for minority clients.

Between 2001 and 2004, the grant led to vaccinations for more than

7,500 people and increased the numbers of screenings, health education classes, and health information offered to adults in minority communities. An independent evaluation of the initiative found that the combination of three components: having classes in a familiar, easily accessible location; the use of culturally appropriate materials, content, and staff; and support provided by the program staff made this project successful. The evaluators also commented on the importance of the VNA's commitment to and flexibility in responding to community needs. This did not happen overnight; it took time, even for a well-established organization, to establish rapport and assist communities in accepting the program. One reason for initial feelings of distrust among participants was a lack of cultural competence on the part of health providers. Prior bad experiences made community members wary of programs with stated good intentions. Only the program coordinator's openness to learning more about cultural sensitivity

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and differences eventually secured the necessary trust. The evaluation also found that the VNA's extensive relationship building, which laid the groundwork work for tailored health education classes, was effective. All class participants made dietary and lifestyle changes needed to take control of their health.



Building on these lessons, The Colorado Trust designed a seven-year (2005-2012), \$13.1 million Equality in Health Initiative. Under this initiative, nonprofit organizations and educational institutions across the state were funded to bring about improvements in one or more of the following areas: equality in medical treatment, equal access to care,

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equal environmental conditions, and healthy behaviors among racial and ethnic minorities. The initiative includes an independent evaluation to determine whether the cultural competency of grantees changes over time and how these changes influence their work. It also will identify the conditions necessary for an organization to bring about positive changes in cultural competency.

#### IMPROVING WORKFORCE DIVERSITY

The number of minority health professionals has a direct impact on the health of minorities. Having minority professionals can increase the comfort level of minority patients, and increases the likelihood that patients' cultural needs will be met. While racial and ethnic minorities make up one-quarter of the nation's population, with this share growing to nearly a third by 2010, minorities account for less than 10 percent of the health workforce (Sullivan Commission 2004).

Two reports issued in 2004 called for institutional and policy-level strategies to increase diversity among health professionals: *In the Nation's Compelling Interest: Ensuring Diversity in the Health Care Workforce*, issued by the Institute of Medicine, and *Missing Persons: Minorities in the Health Professions* issued by a high-level commission chaired by former U.S. Secretary of Health and Human Services Louis W. Sullivan. Funded by the W.K. Kellogg Foundation, the Sullivan Commission emphasized the need for leadership, commitment, and accountability at the highest levels in educational institutions and professional organizations. It identified strategies to make training in the health professions more attainable and affordable for minority students, including shifting from student loans to scholarships; reducing dependency on standardized tests for admission; and enhancing the role of two-year colleges. In all, the commission made 37 separate recommendations, warning that failure to act quickly will only exacerbate the current disconnect between health care providers and the populations they serve.

In 2005, The California Wellness Foundation launched a \$1 million program to implement a public education campaign promoting the benefits of increasing ethnic diversity in California's health workforce. This program was developed based on the lessons learned from close to four years of previous grantmaking, including the following key findings:

- Overcoming the cumulative effects of inadequate preparation

in reading, math, and science; the absence of career and educational counseling; and the difficult lives lived by high-risk young people of color requires sustained commitment and significant funding.

- Middle school is not too early to start working with youth to prepare them for successful careers in health.
- Building this field requires seeding research and data analysis so that organizations have the evidence they need to make the case for support.
- Entry-level health workers have made tremendous gains when given consistent support and opportunities from their employers and local community colleges.
- Not nearly enough recognition is given to this pressing public health issue which needs more leadership from educational institutions, organizations, and individuals (The California Wellness Foundation 2005).

### Prioritizing Strategies and Targeting Interventions

Funders are working to find the niche where their resources can make a difference. They are funding efforts to improve cultural competence, promote workforce diversity, encourage community engagement in health, advocate for environmental justice, and improve health care quality. Many funders are convinced that there will not be a magic bullet solution to reduce disparities and instead are supporting interventions across this spectrum.

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The Blue Cross Blue Shield Foundation of Massachusetts, for example, has declared that reducing racial and ethnic health care disparities in Massachusetts will not be achieved by a single intervention or program model. Its grant program, Closing the Gap on Racial and Ethnic Health Care Disparities, supports initiatives that take a comprehensive and innovative approach to improving access and reducing barriers to health care and support services for racial and ethnic minorities. Grantees are asked to reduce inequities and gaps throughout the continuum of care by promoting access to culturally appropriate care and equal availability and utilization of services for specific racial and ethnic groups. The foundation is willing to consider a variety of interventions and expects that applicants will be guided by many of the recommendations made by the IOM and others. The goal is to establish a solid base for long-term, institutionalized solutions to reducing health care disparities for racial and ethnic minorities in Massachusetts. The funded programs are expected to serve as the groundwork for developing models that can be expanded and replicated.

Upon its founding in 1999, the Connecticut Health Foundation selected racial and ethnic health disparities as one of its three program priority areas. To date, the foundation has dedicated more than \$4.8 million in grants for work to reduce disparities throughout the state. It also seeks to change systemic and institutional policies that perpetuate health disparities. In December 2003, the foundation created the Policy Panel on Racial and Ethnic Health Disparities as an independent body charged with studying racial and ethnic health disparities in Connecticut, and developing pragmatic policy recommendations to address these inequities. The panel was made up of community, business, nonprofit, and government leaders. After a year of work including educational briefings and three public hearings, the panel released 14 recommendations for policymakers, nonprofit organizations, and private institutions related to social and environmental factors, data collection, language barriers, and workforce diversity. The foundation itself committed to incorporating the panel's recommendations into its strategic plan, and is channeling resources through grantmaking,

technical assistance, and public policy research.

Similarly, the MetroWest Community Health Care Foundation created a steering committee to better understand the nature of disparities in its region and to offer specific suggestions that the foundation could take. The committee conducted focus groups with African-American, Brazilian, and Hispanic residents in various communities, and consulted with provider and community stakeholders to identify community assets that could be deployed to eliminate disparities. Its final report concludes with a set of recommendations to assist providers to develop, implement, and evaluate cultural competency and interpreter services; establish information dissemination and programming activities to support community organizing for health and health care advocacy; assist in minority health professional recruitment and retention; establish and support a MetroWest area data collection system on race and ethnicity work group; and establish a communitywide disparities work group (Gibbs and Bitow 2006).

### Challenges for Funders

There is a fundamental tension between the urgency of addressing glaring disparities in access and quality of health care, and a desire to address the underlying social determinants of health such as poverty, racism, education, environment, housing, and neighborhood cohesion. Former U.S. Surgeon General Dr. David Satcher argues that the elements of a successful action plan include multiple components: “universal health insurance, a primary medical home for every

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citizen, proportionate representation of minority populations in health professions, bias-free interventions, nonviolent and exercise-friendly neighborhoods, nutritious food outlets; educational equality, career opportunities, parity in income and wealth, homeownership, and hope” (Satcher 2006).

Much of the work of the last decade, including that of philanthropy, has focused on disparities in care. Some believe that they will more likely see results if their funding is focused on a specific clinical condition or narrow set of quality indicators. Yet, the evidence base for this work is only now emerging. There is still a critical need for further research, model development, and testing “about community-based approaches to advance health promotion and disease prevention in communities wracked by poverty, racism, and other adverse environmental conditions” (Lavizzo-Mourey et al. 2005). Additionally, a Commonwealth Fund-supported study assessing the evidence base for cultural and linguistic competency in health care found that the field is in the early stages of development, with the preponderance of literature defining the concepts and identifying research questions (Goode et al. 2006).

Responding to this need, Robert Wood Johnson Foundation launched two new national programs in 2005. Finding Answers and Leading Change will test and disseminate potential solutions to the poorer quality of health care that patients from certain racial and ethnic backgrounds are more likely to receive. The two programs are working in coordination to identify and implement practical solutions to racial and ethnic disparities in health care, under the guidance of national experts in disparities and quality improvement.

Critics have also noted that “improving the health care system can reduce the effects of health disparities, but can do little to eliminate them” (Bell and Standish 2005). That is, health disparities cannot be addressed unless placed in a broader context of socioeconomic disparities, racism, and cultural empowerment. Those taking this broader view and focusing on community-based strategies are gaining a growing understanding and appreciation of the need for cross-sectoral partnerships to address the broad determinants of health.

The time frame necessary to see results in reducing disparities remains largely unknown, with changes in health behaviors and environmental factors possibly taking years to show results. Moreover, given the complexity of these issues, causal relationships between programs and outcomes cannot be easily determined. A 2005 analysis of rates of high-cost surgical procedures illustrates how difficult and slow change can be. Looking at rates of cardiac artery bypass graft, carotid endarterectomy, and total hip replacement in 158 hospital-referral regions, the authors sought to determine whether efforts in the 1990s to eliminate differences in the use of these procedures according to patients' race were successful. They found no evidence, either nationally or locally, that efforts to eliminate racial disparities in the use of these procedures were successful (Jha et al. 2005). An article published in the same volume of *The New England Journal of Medicine* showed, however, that quality of care for elderly Medicare beneficiaries in managed-care plans improved substantially from 1997 to 2003 for most, but not all, of the quality measures studied (Trivedi et al. 2005).

### Moving Forward

The current state of research on health disparities led one observer to recently write, "it is time to stop documenting disparities and turn our efforts to doing something about them" (Lurie 2006).

Health funders are doing something, but they will likely continue to struggle with how best to accelerate progress to reduce suffering and eliminate the unacceptable

**Health disparities can not be addressed unless placed in a broader context of socioeconomic disparities, racism, and cultural empowerment.**

disparities that plague the nation's population. Moving forward will require dedicated efforts to learn what approaches work best in what circumstances. It will be important to continue to assess and track outcomes of interventions to guide future practice. Sharing results with others in the field of health philanthropy and beyond will help build the evidence base, spread knowledge, and lead to real change in the health of racial and ethnic minorities.

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# Fast Facts

## Increasing Diversity

The U.S. is becoming more racially and ethnically diverse, and future efforts to improve Americans' health will be shaped by important changes in demographics.

In recent decades, the percentage of the population that is Hispanic or Asian has more than doubled.

In 2005, nearly 30 percent of adults and almost 40 percent of children identified themselves as Hispanic, black, Asian, American Indian or Alaska Native, or Native Hawaiian or other Pacific Islander (CDC 2006).

The U.S. Census Bureau projects that by 2050, Hispanics will comprise nearly one quarter of the total U.S. population (U.S. Census Bureau 2004).

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## Poverty

People of color are more likely to have family incomes less than 200 percent of the federal poverty level than are whites. Over half of Latinos, African Americans, and American Indian or Alaska Natives are poor or near poor, compared with 25 percent of whites and 32 percent of Asian or Pacific Islanders. The proportion of children who are poor or near poor is even higher (The Henry J. Kaiser Family Foundation 2003).

The overall poverty rate for blacks was 24.9 percent and 21.8 percent for Hispanics in 2005, compared to 8.3 percent for whites (U.S. Census Bureau 2006).

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## Life Expectancy

Between 1990 and 2004, life expectancy at birth increased more for the black than for the white population, thereby narrowing the gap in life expectancy between these two racial groups.

In 1990, life expectancy at birth for the white population was 7.0 years longer than for the black population. By 2004, the difference had narrowed to 5.0 years (CDC 2006).

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## Infant Mortality

Large disparities in infant mortality rates among racial and ethnic groups continue to exist.

In 2003, infant mortality rates were highest for infants of non-Hispanic black mothers (13.6 deaths per 1,000 live births), American Indian mothers (8.7 per 1,000), and Puerto Rican mothers (8.2 per 1,000); and lowest for infants of Cuban mothers (4.6 per 1,000 live births) and Asian or Pacific Islander mothers (4.8 per 1,000) (CDC 2006).

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## Death Rates

Overall mortality was 29 percent higher for black Americans than for white Americans in 2004, compared with 37 percent higher in 1990.

In 2004, age-adjusted death rates for the black population exceeded those for the white population by 44 percent for stroke, 30 percent for heart disease, 23 percent for cancer, and 774 percent for HIV/AIDS (CDC 2006).

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## Insurance Coverage

In 2004, persons of Hispanic origin and American Indians under 65 years of age were more likely to have no health insurance coverage at a point in time than were those in other racial and ethnic groups. Non-Hispanic white persons were the least likely to lack coverage (CDC 2006).

The uninsured rate in 2005 for non-Hispanic whites was 11.3 percent (22.1 million) and 19.6 percent (7.2 million) for blacks. The rate for Asians was 17.9 percent (2.3 million).

The uninsured rate for Hispanics, who may be of any race, was 32.7 percent (14.1 million) in 2005.

Based on a three-year average (2003-2005), 29.9 percent of American Indians and Alaska Natives were without coverage. The three-year average for Native Hawaiians and other Pacific Islanders was 21.8 percent (U.S. Census Bureau 2006).

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## Usual Source of Health Care

In 2002, Hispanics (32.8 percent), Asians (27.1 percent), and blacks (20.9 percent) were all more likely than whites (15.2 percent) to lack a usual source of care.



Both Hispanic children and non-Hispanic Asian children were more than twice as likely as non-Hispanic white children to lack a usual source of care in 2002 (AHRQ 2006).

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### Health Care Quality

The 2005 *National Healthcare Disparities Report* finds that significant disparities between whites and minorities continue, with some signs of improvements.

In measures related to the quality of care, more racial disparities were narrowing than widening.

Despite these trends, blacks received poorer quality of care than whites in 43 percent of the core measures, and American Indians and Alaska Natives received poorer quality of care than whites in 38 percent of measures.

In access to care, there were reductions in most racial disparities affecting blacks, Asians, and American Indians and Alaska Natives. However, this trend has been reversed for Hispanics, where disparities in quality and access to care are growing wider in a majority of areas. Only 41 percent of quality disparities were narrowing for Hispanics, while 59 percent were growing larger.

The report also indicated that disparities were growing for Hispanics in most measures related to access. For example, the quality of diabetes care declined among Hispanic adults as it improved among white adults. In addition, the quality of patient-provider communication (as reported by patients themselves) declined from among Hispanic adults as it improved among white adults. Access to a usual source of care increased more slowly among Hispanics than among whites.

Overall, the *National Healthcare Disparities Report* shows that low-income people, regardless of race or ethnicity, experienced many of the largest disparities health care quality and access. (AHRQ 2006).

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### Injuries and Suicide

In 2003, young American Indian males 15–24 years of age continued to have substantially higher death rates for motor vehicle-related injuries and for suicide than young males in other race and ethnicity groups. Death rates for the American Indian population are known to be underestimated (CDC 2006).

### Obesity

Obesity, a major risk factor for many chronic diseases, is occurring in people across all socioeconomic and ethnic groups, although African Americans, Hispanics, and American Indians are disproportionately affected.

Fifty-one percent of black non-Hispanic women age 20 and over were obese in 2001–2004, compared with 39 percent of women of Mexican origin and 31 percent of non-Hispanic white women (CDC 2006).

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### Health Workforce

Minorities account for 26 percent of the population, but African Americans and Hispanics compose only 12 percent of the health professional workforce (IOM 2004).

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## Recommended Reading

Agency for Healthcare Research and Quality, *National Healthcare Quality Report, 2006* (Rockville, MD: 2007). Available on-line at <http://www.ahrq.gov/qual/nhdr06/nhdr06.htm>.

The *National Healthcare Disparities Report* examines national disparities in both the ability of Americans to access health care and in the quality of health care. It includes an analysis of disparities related to socioeconomic position as well as to race and ethnicity. The report provides baseline data to measure the effect of national initiatives to reduce disparities, and includes 46 core measures of quality, the same as those tracked in the companion *National Healthcare Quality Report*, along with 13 core measures of access to care.

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Agency for Healthcare Research and Quality, *Racial and Ethnic Differences in Health Insurance Coverage and Usual Source of Health Care, 2002* (Rockville, MD: March 2006). Available on-line at [www.meps.ahrq.gov/data\\_files/publications/cb14/cb14.shtml](http://www.meps.ahrq.gov/data_files/publications/cb14/cb14.shtml).

This report presents current estimates of health insurance coverage and usual source of health care services for various racial and ethnic populations, based on data from the Medical Expenditure Panel Survey (MEPS).

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The California Wellness Foundation, *Reflections on Increasing Diversity in the Health Professions* (Woodland Hills, CA: 2005). Available on-line at [www.tcwf.org/pub\\_reflections/dec\\_2005.htm](http://www.tcwf.org/pub_reflections/dec_2005.htm).

This report looks at the foundation's grantmaking; offers lessons learned from grants given to academic preparedness programs, research and advocacy efforts, and leadership development programs; and offers some thoughts on areas for future attention.

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The Commonwealth Fund, *Cultural Competency: Moving the Agenda Forward* (New York City, NY: 2006). Available on-line at [www.cmwf.org/topics/topics\\_show.htm?doc\\_id=421983](http://www.cmwf.org/topics/topics_show.htm?doc_id=421983).

At the fifth National Conference on Quality Health Care for Culturally Diverse Populations in 2006, The Commonwealth Fund released a series of reports exploring the role of cultural competency in improving quality and outcomes for patients, reducing disparities, and helping patients become more active and engaged in their care.

The reports include:

- Beach, Mary Catherine, Somnath Saha, and Lisa A. Cooper, *The Role and Relationship of Cultural Competence and Patient-Centeredness in Health Care Quality*,
  - Betancourt, Joseph R., *Improving Quality and Achieving Equity: The Role of Cultural Competence in Reducing Racial and Ethnic Disparities in Health Care*,
  - Goode, Tawara D., M. Clare Dunne, and Suzanne M. Bronheim, *The Evidence Base for Cultural and Linguistic Competency in Health Care*,
  - Ngo-Metzger, Quyen, Joseph Telfair, Dara H. Sorkin, et al., *Cultural Competency and Quality of Care: Obtaining the Patient's Perspective*, and
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Fadiman, Anne, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors and the Collision of Two Cultures* (New York, NY: Farrar, Straus and Giroux, 1998).

Award-winning reporter Anne Fadiman turned what began as a magazine assignment into an anthropological exploration of the Hmong population in Merced County, California. Following the case of Lia (a Hmong child with a progressive and unpredictable form of epilepsy), Fadiman maps out the controversies raised by the collision between Western medicine and holistic healing traditions of Hmong immigrants.

Grantmakers In Health, *For the Benefit of All: Ensuring Immigrant Health and Well-Being* (Washington, DC: 2005). Available on-line at [http://www.gih.org/usr\\_doc/GIH\\_Issue\\_Brief\\_24\\_FINAL.pdf](http://www.gih.org/usr_doc/GIH_Issue_Brief_24_FINAL.pdf).

This Issue Brief explores the unique health, social, and policy issues that affect immigrant populations. It looks at attitudes toward immigration and how these influence support for social programs and the provision of public benefits, and highlights philanthropic activities to improve health care access and coverage for immigrants and their families.

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Grantmakers In Health, *Erasing the Color Line: Philanthropy's Role in Eliminating Health Disparities* (Washington, DC: 2003). Available on-line at [http://www.gih.org/usr\\_doc/Erasing\\_the\\_Color\\_Line\\_Report.pdf](http://www.gih.org/usr_doc/Erasing_the_Color_Line_Report.pdf).

This portfolio of information and resources on racial and ethnic health disparities contains two-page resources on the following topics: poverty, racism, environmental health, access, healthy behaviors, mental health, workforce diversity, cultural competency, men, women, children, and aging populations.

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Grantmakers In Health, *In the Right Words: Addressing Language and Culture in Providing Health Care* (Washington, DC: 2003). Available on-line at [http://www.gih.org/usr\\_doc/In\\_the\\_Right\\_Words\\_Issue\\_Brief.pdf](http://www.gih.org/usr_doc/In_the_Right_Words_Issue_Brief.pdf).

This Issue Brief, based on an April 2003 Issue Dialogue, calls on grantmakers to take a leadership role in shaping the language access agenda to ensure that all individuals have equal access to quality health care.

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Grantmakers In Health, *Strategies for Reducing Racial and Ethnic Disparities in Health* (Washington, DC: 2000). Available on-line at [http://www.gih.org/usr\\_doc/Issue\\_Brief\\_5.pdf](http://www.gih.org/usr_doc/Issue_Brief_5.pdf).

This Issue Brief, based on a May 2000 Issue Dialogue, begins by documenting disparities for six health conditions targeted by the federal government and explores some of the underlying causes of health disparities. The

report presents examples of philanthropic strategies, as well as federal and state initiatives, and offers reflection on the challenges foundations are likely to face in working to eliminate health disparities.

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The Henry J. Kaiser Family Foundation, *Key Facts: Race, Ethnicity & Medical Care* (Menlo Park, CA: 2003). Available on-line at [www.kff.org/minorityhealth/upload/Key-Facts-Race-Ethnicity-Medical-Care-Chart-book.pdf](http://www.kff.org/minorityhealth/upload/Key-Facts-Race-Ethnicity-Medical-Care-Chart-book.pdf).

This report is intended to serve as a quick reference source on the health, health insurance coverage, health care access, and quality among racial and ethnic minorities in the United States. It highlights the best available data and research, providing a selective review of the literature. It includes sections on the demographic characteristics of the U.S. population, health status, measures, patterns of health insurance coverage, and findings on access to and use of primary and specialty medical care.

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Institute of Medicine, *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business* (Washington, DC: The National Academies Press, 2006).

The NIH *Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities* is intended to provide an overarching structure and coordination for research being conducted by various NIH institutes and centers. This report assesses how well the plan provides needed guidance and recommends ways to improve oversight and coordination of these research efforts.

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Institute of Medicine, *In the Nation's Compelling Interest: Ensuring Diversity in the Health Care Workforce* (Washington, DC: The National Academies Press, 2004).

The report examines institutional and policy-level strategies to increase diversity among health professionals. The report includes an assessment and description of the potential benefits of greater diversity among health professionals and an assessment of strategies that may increase diversity in five areas: admissions policies and practices of health professions education institutions; public sources of financial support for health professions

training; standards of health professions accreditation organizations pertaining to diversity; the institutional climate for diversity at health professions education institutions; and the relationship between community benefit principles and diversity.

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Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: The National Academies Press, 2003).

In this landmark report, a panel of experts presents a consistent body of research that shows significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. The book explores how persons of color experience the health care environment, and how disparities in treatment contribute to health disparities. The report offers recommendations for improvements in medical care financing, allocation of care, availability of language translation, community-based care, and other arenas. The committee highlights the potential of cross cultural education to improve provider patient communication and offers a detailed look at how to integrate cross-cultural learning within the health professions. The book concludes with recommendations for data collection and research initiatives.

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LaVeist, Thomas, *Race, Ethnicity, and Health: A Public Health Reader* (Hoboken, NJ: Jossey Boss, 2001).

This compendium brings together articles from the best peer-reviewed research literature. The book provides a historical and political context for the study of health, race, and ethnicity, with key findings on disparities in access, use, and quality.

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Lowe, Jane Isaacs and Constance Pechura, "The Robert Wood Johnson Foundation's Commitment to Increasing Minorities in the Health Professions," in Stephen L. Isaacs and James R. Knickman, eds., *The Robert Wood Johnson Foundation Anthology: To Improve Health and Health Care, Volume VII* (San Francisco, CA: Jossey-Bass, 2004).

This chapter reviews the strategies Robert Wood Johnson Foundation has pursued to increase the number of minority physicians, nurses, and other health care providers. It discusses the motivation behind this interest, which is to improve access to and the quality of care for minority patients, and includes analysis of the 2003 Supreme Court decisions on affirmative action and their potential effect on programs to increase minorities in the health care workforce.

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McDonough, John, Brian Gibbs, Janet Scott-Harris, Karl Kronebusch, et al., *State Policy Agenda to Eliminate Racial and Ethnic Health Disparities* (The Commonwealth Fund: New York, NY, June 2004). Available on-line at [http://www.cmwf.org/programs/minority/mcdonough\\_statepolicyagenda\\_746.pdf](http://www.cmwf.org/programs/minority/mcdonough_statepolicyagenda_746.pdf).

This report provides state policymakers with a menu of policy interventions that have been implemented to address disparities in minority health and health care. The authors divide these state and local programs into those targeting infrastructure, management, and capacity, and those targeting specific health conditions.

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Robert Wood Johnson Foundation, *Americans' Views of Disparities in Health Care* (Princeton, NJ: December 9, 2005). Available on-line at [www.rwjf.org/files/research/Disparities\\_Survey\\_Report.pdf](http://www.rwjf.org/files/research/Disparities_Survey_Report.pdf)

In September 2005, the Harvard School of Public Health and the Robert Wood Johnson Foundation conducted a survey to examine the extent to which the American public is aware of racial and ethnic disparities in health. This report provides in-depth information on how Americans view the problem of health disparities, and shows that most of the population does not think that the problem of getting quality health care is any worse for racial and ethnic minorities than it is for white Americans.

Smith, David Barton, *Health Care Divided: Race and Healing a Nation* (Ann Arbor, MI: University of Michigan Press, 1999).

David Barton Smith offers a complete chronicle of racial segregation and discrimination in health care in the United States using vivid first-hand accounts as well as current evidence of inequity in patterns of use and outcomes. Smith details judicial and federal efforts to address these disparities, discusses their persistence in more subtle forms, and offers possible strategies for ending them.

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The Sullivan Commission, *Missing Persons: Minorities in the Health Professions* (Chapel Hill, NC: Duke University School of Medicine, 2004). Available on-line at [http://www.amsa.org/advocacy/Sullivan\\_Commission.pdf](http://www.amsa.org/advocacy/Sullivan_Commission.pdf).

The Sullivan Commission on Diversity in the Health-care Workforce released its findings in this report funded by the W.K. Kellogg Foundation. The Sullivan Commission aims to increase diversity in America's health professions education training programs at all levels of preparation, across the country. The report recommends strategies to increase the numbers of students from underrepresented and underserved communities available for service in the nation's health care system.

# Social Determinants of Health



# Social and Environmental Determinants of Health

*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 2005).*

The past twenty five years have seen major advances in the practice of medicine including discovery of immunosuppressive drugs that make organ transplantation possible, development of new procedures such as in vitro fertilization and microscopic surgery, invention of new diagnostic tools like the PET scanner, and approval

**There is a rich research literature both documenting the impact of social and environmental factors on health, and making the case for the pathways by which these conditions affect health outcomes.**

of new medications such as those extending the lives of individuals infected with HIV. These innovations have made a major difference for many patients and their families. Yet despite the positive impact of these new technologies, they do not address the root causes of morbidity and mortality. As Bell and Standish (2005) note, “health status is largely a function of factors beyond the bounds of the health care system including income, race, behavior, genetics, and environmental conditions.”

Emphasis on social and environmental determinants is not a new phenomenon. Indeed, some have suggested that the large decline in infectious diseases often attributed to immunization and hygiene efforts of public health pioneers, were actually the result of improved nutrition,

diminished social crowding, and declining birth rates (McKeown 1990). Still, the past several decades of research have resulted in more precise definition of both the physical dimensions of the environment that are toxic to health as well as conditions in the social environment, such as social exclusion, racism, educational achievement, and opportunities to advance in the workplace, that shape behavior and access to resources that promote health. In Canada, the 1974 publication of the Lalonde Report first brought international attention to the importance of factors outside the health delivery system on health status. In Great Britain, the controversial Black Report, published in 1980, called attention to the persistence of health inequalities in a fully insured population. In the United States, Healthy People 2000, and later Healthy People 2010, the national health promotion and disease prevention agenda, focused heavily on social and environmental determinants.

## What Have We Learned

There is a rich research literature both documenting the impact of social and environmental factors on health, and making the case for the pathways by which these conditions affect health outcomes. This section considers how income and social class, social capital, and the physical environment affect human health. The impact of another important social factor, race and ethnicity, is discussed under the tab, Racial and Ethnic Health Disparities.

## INCOME AND SOCIAL CLASS

Nearly 37 million Americans (12.6 percent of the population) were living in poverty in 2005. Of these, 43.1 percent could be considered severely poor with incomes below

### THE SOCIAL DETERMINANTS TEN TIPS FOR BETTER HEALTH

The Centre for Social Justice, a Canadian advocacy organization with its roots in the Jesuit social justice movement, offers the following tips for better health, as a complement to the more traditional tips to stop smoking, eat more fruits and vegetables, and wear sunblock.

1. Don't be poor. If you can, stop. If you can't, try not to be poor for long.
2. Don't have poor parents.
3. Own a car.
4. Don't work in a stressful, low-paid manual job.
5. Don't live in damp, low-quality housing.
6. Be able to afford to go on a vacation and sunbathe.
7. Practice not losing your job and don't become unemployed.
8. Make sure you have access to benefits, particularly if you are unemployed, retired, or sick or disabled.
9. Don't live next to a busy major road or near a polluting factory.
10. Learn how to fill in the complex housing benefit/shelter application forms before you become homeless and destitute.

Source: Centre for Social Justice, *Social Determinants Across the Lifespan*, <<http://www.socialjustice.org/subsites/conference/resources.htm>>, accessed October 2006.

half of the federal poverty line of \$15,577 for a three-person family (Center on Budget and Policy Priorities 2006).

Poverty rates are cyclical, and are generally in tune with the general pattern of growth and recession of the U.S. economy. Twenty five years ago, the share of individuals living in poverty was similar to today (13 percent) with periods of higher poverty during the early 1990s when poverty rates reached as high as 15.1 percent (U.S. Census Bureau 2006).

It is important to look at more than poverty rates to assess the vulnerability of the nation's poor. Despite the most recent economic recovery, for example, the average amount by which the poor fall below the poverty line (about \$3,200) is at its highest level ever. Income inequality

also appears to be growing with the top 1 percent of U.S. households receiving over 40 percent of the 2004 increase in household income (Center on Budget and Policy Priorities 2006).

What are the implications of these statistics? First, poverty is commonly identified as a risk factor for poor health. Being poor influences individual risk behaviors and resources that are conducive to good health and creates chronic stress. Second, deficits in health both aggravate and perpetuate poverty. Both short and long-term disability compromise one's ability to get an education, enter the workforce, and advance to higher levels of control and income. In addition, low-wage work and unemployment compromise health by increasing the risk of exposure to workplace injuries

and psychological stressors (MRDC 2006).

Numerous studies have found a strong linear relationship between socioeconomic status and health, including the Black Report noted above. Because health status for groups at the higher rungs of the socioeconomic ladder is consistently higher than for those on the lower rungs, there is an assumption of causality between resources (measured by education, income, occupation, and wealth) and better health (PolicyLink 2000).

The Whitehall studies of the British civil service found a gradient between health and social class, even within a fully employed, non-poor population. As Canadian health economist Bob Evans noted in a plenary speech before Grant-makers In Health in 1999, “this is an argument that the overall structure of hierarchy somehow has a significant effect on health, over and above the general issue of whether people are suffering from material deprivation.”

#### SOCIAL CAPITAL

Harvard epidemiologist Ichiro Kawachi (1999) defines social capital as “those features of social organization—such as the extent of interpersonal trust between citizens, norms of reciprocity, and density of civic associations—which facilitate cooperation for mutual benefit.” People with a greater number of social relationships live longer, are less likely to be depressed, are less likely to experience severe cognitive declines as they age, and appear to recover more rapidly from illness. Moreover, even the perception that others will be there to provide

People with a greater number of social relationships live longer, are less likely to be depressed, are less likely to experience severe cognitive declines as they age, and appear to recover more rapidly from illness.

support predicts more positive health outcomes in the face of stressful events (RWJF 2003).

There are several explanations of how social capital affects health. “There have to be biological pathways through which social factors operate,” notes Evans (1999) “because at the end of the day, death and disease are biological events.” Social factors take their toll on the body in part “by cumulative wear and tear through repeated activation of physiological stress responses” (Berkman and Lochner 2002). Data from the Whitehall study, for example, showed increases in blood pressure during the work day for both high-status and low-status civil servants. What was notable, however, was not that work created physiological stress, but that upon leaving the stressful work environment at the end of the day, the high-status workers experienced a sharp drop in blood pressure, returning quickly to normal levels. Low-status workers also experienced a decline but of a smaller magnitude (Evans 1999).

Kawachi and his colleagues (1999) offer a complementary explanation, suggesting that social connectedness influences individual health behaviors. Personal relationships and connections to institutions thus may promote the diffusion of information on health, create norms for

adopting healthy habits and discourage behaviors with negative consequences, increase access to services and amenities, and create an environment of affective support.

#### THE PHYSICAL ENVIRONMENT

Environmental factors, such as air and water quality, exposure to pesticides and toxic waste, and housing conditions, play a major role in health and human development. Poor air and water quality have been directly associated with diseases such as cancer, asthma, certain birth defects, and some neurological disorders. Many cancers are linked to toxins in the environment, such as dioxin, polychlorinated biphenyls, and mercury. Airborne particulate matter, tobacco smoke, and ground-level ozone, have been shown to trigger asthma attacks in children. Exposure to lead, found in peeling paint or in the soil and air in many low-income communities, can impair cognitive and behavioral development, lead to low birthweight among infants born to exposed mothers, and cause kidney damage.

The environmental health movement began coalescing in the 1960s, eventually leading to passage of the Clean Air Act, the National Environmental Policy Act, the Clean Water Act, and the Superfund Act (Wikipedia 2006). The Environmental Protection Agency was established

in the early 1970s and the Center for Environmental Health at the Centers for Disease Control and Prevention in 1980 (Wikipedia 2006; National Center for Environmental Health 2006). During the 1970s and 1980s, the contamination of the Love Canal, accidents at the Three Mile Island and Chernobyl nuclear power plants, and the explosion of a chemical plant in Bhopal, India drew media attention to environmental threats to human health.

**The term, environmental justice, refers to the fair treatment and meaningful involvement of all people in the development, implementation, and enforcement of environmental policies.**

Yet despite overall gains in environmental quality since the 1970s, mainstream environmental policy neglected problems in low-income communities of color that often lack the political and economic resources to defend themselves. For example, when ocean dumping was banned in New York, the city transported its sewage sludge (much of which was contaminated or laden with heavy metals) to Sierra Blanca, a small town in Texas that is 80 percent Latino. In essence, the town became the new dumping ground for New York City's trash. During the 1990s, 200 such sites were created in the state of Texas (Faber and McCarthy 2001).

The term, environmental justice, refers to the fair treatment and meaningful involvement of all people in the development, implementation, and enforcement of environmental policies. This movement has achieved impressive results since its start in 1982. "In

low-income towns and communities of color, hazardous waste sites are now being cleaned up, brownfields are being redeveloped, incinerators are being shut down, parks and conservation areas are being established, local pollution threats are being eliminated, cleaner and more accessible means of public transportation are being adopted, and unique habitats and wild lands are being protected" note Faber and McCarthy in their monograph, *Green of Another Color*, published by the Aspen Institute. The creation of the National Environmental Justice Advisory Council and other federal actions have also significantly improved the performance of the Environmental Protection Agency with regard to policy design, implementation, and enforcement.

Another development in environmental health practice has been the adoption of what is known as the precautionary principle. Although the precautionary principle has a number of different interpretations, it essentially states that prudent action should be taken to avoid harm to humans and the environment, even when scientific certainty has not been established. Such precautions are warranted, advocates say, because, while we have some understanding of the effects of acute exposure to individual substances, we know very little about the results of cumulative exposure over time, and even less about the dangers posed to children, the elderly, pregnant women, or those with suppressed immune systems. Furthermore, we are only beginning to learn about the additive and synergistic effects of exposure to a variety of these substances in the environment. The successful reduction and elimination of lead in

gasoline, paint, and pipes is an example of action guided by the precautionary principle. In the case of lead, steps were taken to remove the metal from a number of sources, rather than waiting for conclusive evidence indicating which source was most offensive to human health.

### Philanthropic Activities

Health grantmakers are working in a variety of ways to address the social determinants of health. They are creating jobs and improving the quality of low-wage jobs, addressing environmental degradation in low-income communities of color, working to create stronger social connections, taking on institutional racism, improving education, and addressing substandard housing. We focus here on the first three of these.

#### ADDRESSING EMPLOYMENT AND POVERTY

In 1995, the board of The California Wellness Foundation designated work and health as one of five priority areas. This decision led to a \$20 million commitment to four programs. (In addition, the foundation also made available \$5 million to support unsolicited requests.) Computers in Our Future focused on enhancing job mobility, offering opportunities for low-income youth to develop technological skills. Eleven community technology centers were funded across California, eventually serving more than 25,000 people. Another accomplishment was the creation of a policy workgroup that became a voice for community investment in technology as an economic development strategy. Winning New Jobs offered a reemployment workshop for dislocated workers. Over four years, the program reached more than 5,000 Californians and raised awareness

### Funders are also helping low-income families rise out of poverty by helping them take advantage of federal tax relief and public benefit programs.

among employment agencies of the health and mental health consequences of unemployment, improving their ability to meet the needs of all clients, not just those served under the grant. The Health Insurance Policy Program focused on analytic activities to document the key links between health insurance, employment, and health in California. Studies by University of California researchers were shared with policymakers and advocates to focus attention on these issues. Finally, the Future of Work and Health supported research to identify and understand how structural changes in the state's economy and workplaces were affecting health. A large grant funded the California Work and Health Study, a three-year longitudinal study combining work and employment variables with health measures. Survey results received extensive coverage in the popular press and peer-reviewed journals; they also served as the basis for briefings with state legislators (Brousseau and Peña 2002). Moreover, long after the foundation's commitment ended, about half of the computer centers are now providing services at greater levels than during the grant period. Research grantees have also been able to continue work on the connections between work and health with funding from new sources (TCWF 2006).

The California Endowment has also supported efforts to improve health by creating employment opportunities. In 2000, it teamed up with the Rockefeller Foundation to launch

California Works for Better Health, supporting collaboratives in Fresno, Los Angeles, Sacramento, and San Diego to research issues and emerging markets within their regions and develop grassroots efforts to improve access to and the quality of local job opportunities. These efforts could focus on reducing employment barriers (for instance, by offering vocational instruction in English as a Second Language) and encouraging employers to provide a safe working environment and health benefits to their workers. The effort is being evaluated by MRDC. As the initiative sunsets, the Prevention Institute has been engaged to help the collaboratives with the tools they will need to connect their work to other efforts focused on reducing and eliminating health disparities and improving underlying social conditions.

The foundation has also committed significant resources (\$50 million) to improve working conditions for farm workers and families, beginning with publication of an unprecedented study, *Suffering in Silence*, in 2000. Since then it has funded direct delivery of health care services to farm workers, model programs that link health services with the provision of safe, decent and affordable housing in rural communities (including a low-interest loan pool), health education programming on Spanish-language radio stations broadcasting in agricultural areas, capacity building for advocacy organizations, research on farm worker health and safety



issues, and public policy development. The most recent program launched by The California Endowment is Poder Popular Para la Salud del Pueblo which focuses on collaborations to advocate for policy and systems change in 10 communities. Promotoras, lay health workers, are working locally to deliver services and create strategies to nurture leadership among farm workers.

Funders are also helping low-income families rise out of poverty by helping them take advantage of federal tax relief and public benefit programs. The Earned Income Tax Credit (EITC) is a refundable tax credit for low- and moderate-income people who work. It can reduce their tax burden; increase their refunds; and, for some, offset other taxes they may pay, such as payroll taxes (Center on Budget and Policy Priorities 2004). Qualified federal income tax filers who are raising children can receive part of their EITC in their paychecks throughout the year, boosting their income; these families receive the rest of their EITC in a check after filing a federal tax return. The credit ranges from just over \$380 to over \$4,200, depending on income and household characteristics. Nationally, The Annie E. Casey Foundation is a leader in providing information, technical assistance, and financial support for efforts to educate low- and moderate-income populations about tax issues and provide tax preparation assistance. Through its National Tax Assistance for Working Families campaign, the foundation is supporting work in 23 sites to promote greater awareness of tax credits, including the EITC and the Child Tax Credit; provide low-cost or free tax preparation; and encourage the use of tax refunds to help low- and

moderate-income families build assets by contributing to a savings account, starting a business, or purchasing a home.

Local foundations are also playing a key role in catalyzing community-based tax outreach and assistance campaigns. The Quantum Foundation in Palm Beach, Florida, is partnering with the board of county commissioners, the local United Way, and others to educate low-income individuals and families about the EITC and help them claim unclaimed credits in Palm Beach County. Together, the partners supported free tax preparation services at centers that are open during the entire tax season at locations and times that are convenient for working people. In 2005, the effort led to \$14 million in total refunds, \$6 million in EITC refunds, and saved \$1.3 million in fees, increasing household income by 12 percent. The Prosperity Campaign, as it is known, is also serving as a gateway to eligibility for other programs serving low- and moderate-income individuals and families. Three years in, the campaign is now offering services at 40 sites.

#### ELIMINATING ENVIRONMENTAL HAZARDS

In 2003, The California Wellness Foundation awarded a \$130,000 grant to the Center for Community Action and Environmental Justice (CCA EJ) to help communities in southern California reduce harmful environmental threats. CCA EJ provides local groups with environmental health education programs, helps develop leadership skills, and maps out action plans to motivate local governments and industries to act more responsibly. These partnerships allow CCA EJ to connect with



residents with diverse skill sets such as researching issues, motivating volunteers, and organizing events.

When a group of residents identifies an environmental health threat in their community, CCAEJ provides guidance on developing an effective action plan that includes fostering community-based leadership. CCAEJ leadership development uses a hands-on approach. Each group develops its own strengths, learns new skills, and uses these skills to advance the issue identified. CCAEJ also works with these groups to plan under different scenarios and prepare for a range of responses from opponents. The community groups mentored by CCAEJ have won significant policy changes. For example, in Riverside County, a group successfully mounted a three-year battle against diesel emissions in the community, resulting in action by county planning commissioners to halt the building of additional warehouses in the area and to consider the need for a wider buffer zone between any diesel source and homes and schools. Particulates contained in diesel exhaust emissions are associated with higher rates of asthma and other respiratory problems (TCWF 2005). According to foundation program director Fatima Angeles, the model used by CCAEJ is “particularly effective because it starts with a core group and builds outward. The skills that group members learn are shared over time with others, resulting in an expanded body of capable community leaders willing to tackle environmental health challenges.”

A range of environmental hazards threaten residents of some communities in El Paso, Texas and neigh-

## The Blue Cross and Blue Shield of Minnesota Foundation recently embarked on a major new direction in its work, focusing on the social determinants of health in four focus areas.

boring Ciudad Juárez, Mexico. The Paso del Norte Health Foundation is working to reduce environmental health risks such as asthma triggers, contaminated water and sanitation, lead, pesticides, uncontrolled solid waste dumping, and other risks to families through its Healthy Homes and Handwashing initiative. The goals of this \$3.2 million, five-year initiative were identified through a series of meetings with leaders of regional environmental organizations, academic researchers, and community activists. These binational meetings generated dialogue regarding priority issues as well as effective approaches for addressing them, and set the stage for developing a broad based collaboration (Paso del Norte Health Foundation 2005).

Foundation staff also looked to the lessons learned from past grants to improve environmental health. A 2000 effort, the When Water Works for Health campaign helped improve local sanitation. The foundation’s grantee, the Center for Environmental Resource Management (CERM) at the University of El Paso, used school-based education and community-based outreach efforts to improve public awareness of the importance of sanitation and purification of drinking water. The campaign also helped procure and install 300 prefabricated fiberglass latrines in some of the poorest neighborhoods in Ciudad Juárez. The wet, bacterial decomposition technology used in the latrines proved successful in

reducing exposure to waste, however, heat and sun exposure caused the fiberglass units to become brittle and crack over the long-term (Paso del Norte Health Foundation 2005). Using this lesson, foundation and CERM staff members sought a new approach. The result was a partnership with a nonprofit organization building latrines out of cinderblocks or bricks that used an alternative technology to decompose waste. The new latrines were safe and effective. They also stood up to the region’s climate. Secondary benefits of this work included a partnership to support a microenterprise toilet building business, as well as workshops and training on how to build latrines and handwashing stations (Paso del Norte Health Foundation 2005).

The San Francisco Foundation employs a multidisciplinary approach to its environmental health grantmaking. For example, to reduce air contaminants produced by idling trucks and buses, the foundation supported the Bay Area Ditching Dirty Diesel Collaborative, a grassroots campaign designed to reduce the level of diesel emissions, contaminants linked to asthma, lung cancer, and other respiratory conditions. Although a law limiting diesel truck idling to only five minutes was implemented in 2004, it had only been loosely enforced. As part of the collaborative’s work, residents of San Francisco, Oakland, Richmond, San Leandro, and Sonoma counties

launched a campaign in October of 2005 by passing out 8,000 door hangers to educate truck and bus drivers, as well as residents about the impacts of diesel idling. Increased awareness and grassroots advocacy eventually led elected officials and community and labor leaders to join forces and lobby the California Air Resources Board. As a result, the board passed a new regulation stating that truck drivers asleep in sleeper cabs must now turn off their engines or switch to alternative battery power or a non-diesel fueled engine for overnight and long-term idling.

#### FOSTERING SOCIAL CONNECTEDNESS

The Blue Cross and Blue Shield of Minnesota Foundation recently embarked on a major new direction in its work, focusing on the social determinants of health in four focus areas. Social connectedness is one of these (others are early childhood development, housing, and the environment), an interesting choice in a state often considered the nation's most friendly and caring. Yet the Twin Cities region is among the most racially and socioeconomically segregated metropolitan areas in the U.S. (Blue Cross and Blue Shield of Minnesota Foundation 2006a). The foundation's work in social connectedness places its emphasis on the mental health and healthy adjustment of Minnesota's immigrant population. Immigration is up 130 percent in the state since 1990 and it is now home to the country's largest Somali population and its second largest population of Hmong and Liberians. To respond to the needs of these groups, many of them political refugees, the Healthy Together initiative will fund capacity development in the mental health sector in ways that respond to the

special needs and cultural beliefs of immigrant communities, capacity development of immigrant-led organizations, and efforts to build trust, exchange, and relationships between immigrants and long-time residents of the areas where they have settled (known as receiving communities). This work is still new; the first grants were made in 2006 to organizations including the Centre for Asians and Pacific Islanders to partner with the Minneapolis public schools to improve mental health and education-related outcomes within the North Minneapolis Hmong community. Another grantee, the Korean Service Center, was awarded \$50,000 to help establish a culturally competent assisted living program for Somali elders in public housing in Minneapolis' Cedar-Riverside community. The initiative builds upon prior learning from the foundation's efforts to increase access to and use of preventive medical and dental services by children of foreign-born parents, tribal communities, and other communities of color (Blue Cross and Blue Shield of Minnesota Foundation 2006b).

The Kansas Health Foundation, long interested in the social determinants of health, has also built a reputation for its statewide media campaigns. Launched in January 2001, "Take a second. Make a difference" asked Kansans to make small everyday gestures, even a smile and a wave, that would make a connection between adults and children. The eight-month media campaign was built on the premise, supported by research, that children who are connected to caring adults take better care of themselves, are less likely to engage in risky behaviors, and make greater contributions to their communities. In addition to

television and radio spots, newspaper ads, a Web site, and public relations efforts, the campaign included work in almost 30 communities to help them become better places for young people. Surveys of randomly selected community residents found that the campaign's messages were being heard. Nearly all (97 percent) of those surveyed engaged in specific behaviors as a result of their interactions with the "Take a second. Make a difference." effort. Many also reported reaching out to local policymakers, encouraging them to change programs and policies to better serve children. In late 2002, a statewide youth summit culminated with specific commitments by youth and adults to make a difference in their communities (Self Help Network 2002a, 2002b). The foundation's evaluation showed that its work was effective in reinforcing the positive awareness and behaviors of adults who are already concerned about children. Future work will look for success with the harder to reach adult population.

Health funders are even delving into affordable housing as a strategy for fostering social connections, drawing on research that neighborhoods with high rates of home ownership have healthier residents who are more likely to be engaged in civic life. In Portland, Oregon, the Northwest Health Foundation, through its Kaiser Permanente Community Fund, is helping support the Healthy Communities Initiative of HOST (Home Ownership One Street At A Time) Development, Inc. Their goal is to help 53 families in a historically low-income, African American neighborhood become first-time home owners.

### BUILDING THE KNOWLEDGE BASE

Finally, health funders are supporting further development of the knowledge base about the impact of social determinants of health and the pathways by which these factors affect human biology. Since 1997, The John D. and Catherine T. MacArthur Research Network on Socioeconomic Status and Health has brought together leading researchers from the fields of psychology, sociology, psychoimmunology, medicine, epidemiology, neuroscience, biostatistics, and economics to create data for use in policy discussion and develop knowledge that can be used to inform social, medical, and public policy interventions. The network has active working groups on the social environment, psychosocial factors, allostatic load (the ability of the body to maintain stability under conditions of change), and developmental and life course effects.

### Moving Forward

Many health grantmakers, particularly those with public health backgrounds, understand that the factors affecting health extend far beyond the medical care system and have invested significant resources in health promotion and disease prevention. A number of newer health foundations have even adopted the World Health Organization definition of health as part of their mission and vision statements. Yet relatively few focus their grantmaking on determinants such as race, social class, the adequacy of housing, educational opportunity, environment, and civic engagement.

There are at least three hurdles that a health foundation must scale. First is answering questions about focus and mission. How far should we go

as health funders? Is this our job?

Will our board, community, and current grantees understand and value such work as a legitimate expression of a health mission? Funders must feel confident in presenting the theory of change by which work in these areas will affect health. They must educate themselves and their communities about the connections. Second, achieving measurable changes in health status can be daunting, both in the time needed to accomplish such changes and in the attribution of such changes to work supported by foundation funding. Grantmakers have to be willing to commit for relatively long periods of time and to look for intermediate outcomes.

Third, health funders cannot go it alone. According to Berkman and Lochner (2002), “public health programs alone cannot ameliorate the social forces associated with poor health outcomes.” The complexity of the factors leading to inequalities in health status requires multifaceted and multisectoral action. Moreover, health funders have to reach out to funders working on education, economic development, and civic engagement. For example, community foundations may be important allies in work on social determinants since many have long been interested in social capital. The Social Capital Community Benchmark Survey was fielded in 2000 with support from several of the nation’s most prominent community foundations. But while reports about this survey’s results lauded the importance of trust, cooperation, and neighborliness in building strong communities, they rarely referred to health as a positive outcome of these factors (Social Capital Community Benchmarking Survey 2001).

Building relationships with these funders will require both learning their language and the policies and practices that define their disciplines, and teaching them about how social factors affect human health.

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# Fast Facts

## Income

Income inequality in the United States has increased over the past three decades; between 1977 and 1999, the after tax income of the richest 1 percent population more than doubled, while the after tax income for the poorest 20 percent declined by 9 percent. Health improvements for the U.S. population as a whole are due to gains among the higher socioeconomic groups; lower socioeconomic groups continue to lag behind (Institute for the Future 2000; HHS 2000).

Countries with relatively unequal income distributions have higher rates of infant mortality than countries with similar gross income but a more equitable income distribution (Waldmann 1999).

In an analysis of 50 states, the Robin Hood Index (a measure of income inequality based on the distribution of household income) was found to be significantly related to overall homicide, firearm homicide, firearm assault, and robbery (Kennedy et. al 1999).

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## Education and Employment

Among U.S. adults between the ages of 25 and 64, the overall death rate for those with less than 12 years of education is more than twice that for people with 13 or more years of education. The infant mortality rate is almost double for infants of mothers with less than a high school education compared to their more educated peers (HHS 2000).

A meta-analysis of 46 epidemiological studies found association between unemployment and many different poor health outcomes including lower self-esteem, higher rates of depression, excess suicides, increased alcohol consumption and even immunological functioning (TCWF 2000).

The relationship between job stress and such conditions as mood and sleep disturbances, upset stomach, headache, and strained personal relationships has been well-documented. Evidence is now mounting that chronic stress, including situations where workers have little control over the job environment, plays an important role in development of cardiovascular disease, musculoskeletal disorders, and psychological disorders (National Institute for Occupational Safety and Health 1999).

## Environment

Worldwide, one-quarter of preventable disease is attributable to poor environmental quality. In the U.S., air pollution alone is associated with about 50,000 premature deaths annually as well as an estimated \$40 billion to \$50 billion in health-related costs (HHS 2000).

Air pollution is widespread and occurs both indoors and out. In 1997, 43 percent of Americans lived in areas designated as having unhealthy levels of ozone. Between 1988 and 1994, more than two-thirds of nonsmokers were exposed to environmental tobacco smoke. In 1995, an estimated 15 million children were exposed to secondhand smoke in their homes (HHS 2000).

In 2001, 20.3 million Americans had asthma. Environmental exposures, such as house dust mites and environmental tobacco smoke, are important triggers of asthma attacks (CDC 2003).

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## Social Capital

Individuals lacking social ties have two to three times the risk of dying from all causes as compared to well-connected individuals; in one large longitudinal study, depressed and socially isolated individuals were four times more likely to have a heart attack than others who were neither depressed nor isolated (Kawachi et al. 1999; Institute for the Future 2000).

In a study of susceptibility to the common cold, increased diversity in individual ties to friends, family, work, and community was found to be significantly related to increased resistance to infection (Institute for the Future 2000).

In surveys of 40 communities participating in the Social Capital Community Benchmark Study, social connectedness was a much stronger predictor of the perceived quality of life than the community's income or educational level. In the five communities with the highest levels of social trust, more than half (52 percent) rated their community as an excellent place to live, the highest possible grade. In the five communities with the lowest levels of social trust, less than one-third (31 percent) felt as good about their quality of life (Social Capital Community Benchmark Survey 2001).

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## Recommended Reading

Berkman, Lisa F., and Ichiro Kawachi, eds., *Social Epidemiology* (New York, NY: Oxford University Press, 2000).

*The New England Journal of Medicine* called this book “an extraordinary work of scholarship.” Chapters focus on working conditions, social cohesion, discrimination, health behaviors in a social context, depression and mental illness, and health and social policy.

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The California Wellness Foundation, *Reflections on the Connections Between Work and Health* (Woodland Hills, CA: 2000). Available on-line at [http://www.tcwf.org/pub\\_reflections/jun\\_2000.htm](http://www.tcwf.org/pub_reflections/jun_2000.htm)

This publication describes lessons learned by The California Wellness Foundation in its Work and Health Initiative, one of the foundation’s initial priority areas. The first phase of the initiative (1995-2000) was funded at \$20 million plus an additional \$1 million annually for responsive grantmaking. In 2000, the board of directors committed to at least an additional five years of support.

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Fullilove, Mindy, *Root Shock: How Tearing Up City Neighborhoods Hurts America, and What We Can Do About It* (New York, NY: One World/Ballantine, 2004).

Fullilove, professor of psychiatry and public health at Columbia University, makes the case in this book for how old-style urban renewal projects create social and economic disadvantage. Focusing on black neighborhoods in Pittsburgh, Newark, Philadelphia, and Roanoke, Fullilove tells the story through history, statistics, and personal narrative.

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Grantmakers In Health, *Social Inequalities in Health: Keynote Addresses from the 1999 Annual Meeting on Health Philanthropy* (Washington, DC: 1999). Available on-line at [http://www.gih.org/usr\\_doc/49537.pdf](http://www.gih.org/usr_doc/49537.pdf)

GIH’s 1999 annual meeting explored the roots of social inequalities in health. Nicole Lurie of the U.S. Department of Health and Human Services kicked off the meeting with her remarks focusing on the efforts of the federal government, particularly in addressing racial

and ethnic disparities in health, and opportunities for collaboration between the public and private sector. Robert Evans of the University of British Columbia set the issue in context with his analysis of multiple sources of data documenting the range of determinants affecting health. Velvet Miller of Children’s Futures-New Jersey commented on the possibilities of philanthropy, speaking from the perspective of someone moving from state government into the grantmaking arena.

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Klinenberg, Eric, *Heat Wave: A Social Autopsy of Disaster in Chicago* (Chicago, IL: University of Chicago Press, 2002).

This book tells the story of how social isolation, the institutional abandonment of poor neighborhoods, and the retrenchment of public assistance programs, contributed to more than 700 deaths among the elderly during a week-long wave of unprecedented heat and humidity in Chicago in 1995. Klinenberg is an academic sociologist but writes like a journalist.

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McGinnis, J. Michael and William H. Foege, “Actual Causes of Death in the United States,” *Journal of the American Medical Association* 270(18):2207-12, November 10, 2003.

This article is considered by many to be the seminal argument for a population-based approach to health improvement with a strong focus on factors outside the medical care system.

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PolicyLink, *The Influence of Community Factors on Health: An Annotated Bibliography* (Oakland, CA: 2004). Available on-line at <http://www.policylink.org/pdfs/AnnotatedBib.pdf>

This document contains more than 150 citations for research on how community factors affect health. Funded by The California Endowment, *The Influence of Community Factors on Health* also nicely summarizes the literature on the determinants of neighborhood health, and comments on the program and policy implications.

*The Society and Population Health Reader* (New York, NY: The New Press, 1999).

This collection of scholarly articles, reprinted from peer-reviewed journals, is packaged into two volumes. Volume I, *Income Inequality and Health*, was edited by Ichiro Kawachi and Bruce Kennedy of the Harvard School of Public Health. Topics covered include presentation and critiques of the relative income hypothesis, social cohesion, sociobiological translation, and the effects of income across race and gender. Volume II, *A State and Community Perspective*, was edited by Alvin Tarlov, former president of The Henry J. Kaiser Family Foundation and Robert St. Peter of the Kansas Health Institute. Topics covered in this volume include child development, adult health, and perspectives on public policy implications.

# About GIH

With a mission to help grantmakers improve the health of all people, Grantmakers In Health (GIH) seeks to build the knowledge and skills of health funders, strengthen organizational effectiveness, and connect grantmakers with peers and potential partners. We help funders learn about contemporary health issues, the implications of changes in the health sector and health policy, and how grantmakers can make a difference. We generate and disseminate information through meetings, publications, and on-line; provide training and technical assistance; offer strategic advice on programmatic and operational issues; and conduct studies of the field. As the professional home for health grantmakers, GIH looks at health issues through a philanthropic lens and takes on operational issues in ways that are meaningful to those in the health field.

## Expertise on Health Issues

GIH's Resource Center on Health Philanthropy maintains descriptive data about foundations and corporate giving programs that fund in health and information on their grants and initiatives. Drawing on their expertise in health and philanthropy, GIH staff advise grantmakers on key health issues and synthesizes lessons learned from their work. The Resource Center database, which contains information on thousands of grants and initiatives, is available on-line on a password-protected basis to GIH Funding Partners (health grantmaking organizations that provide annual financial support to the organization).

## Advice on Foundation Operations

GIH focuses on operational issues confronting both new and established foundations through the work of its Support Center for Health Foundations. The Support Center offers an annual two-day meeting, The Art & Science of Health Grantmaking, with introductory and advanced courses on board development, grantmaking, evaluation, communications, and finance and investments. It also provides sessions focusing on operational issues at the GIH annual meeting, individualized technical assistance, and a frequently asked questions (FAQ) feature on the GIH Web site.

## Connecting Health Funders

GIH creates opportunities to connect colleagues, experts, and practitioners to one another through its Annual Meeting on Health Philanthropy, the Fall Forum (which focuses on policy issues), and day-long Issue Dialogues, as well as several audioconference series for grantmakers working on issues such as access to care, obesity, public policy, racial and ethnic health disparities, and health care quality.

## Fostering Partnerships

Grantmakers recognize both the value of collaboration and the challenges of working effectively with colleagues. Although successful collaborations cannot be forced, GIH works to facilitate those relationships where we see mutual interest. We bring together national funders with those working at the state and local levels, link with other affinity groups within philanthropy, and connect grantmakers to organizations that can help further their goals.

To bridge the worlds of health philanthropy and health policy, we help grantmakers understand the importance of public policy to their work and the roles they can play in informing and shaping policy. We also work to help policymakers become more aware of the contributions made by health philanthropy. When there is synergy, we work to strengthen collaborative relationships between philanthropy and government.

## Educating and Informing the Field

GIH publications inform funders through both in-depth reports and quick reads. Issue Briefs delve into a single health topic, providing the most recent data and sketching out roles funders can and do play. The GIH Bulletin, published 22 times each year, keeps funders up to date on new grants, studies, and people. GIH's Web site, [www.gih.org](http://www.gih.org), is a one-stop information resource for health grantmakers and those interested in the field. The site includes all of GIH's publications, the Resource Center database (available only to GIH Funding Partners), and the Support Center's FAQs. Key health issue pages provide grantmakers with quick access to new studies, GIH publications, information on audioconferences, and the work of their peers.

## Diversity Statement

GIH is committed to promoting diversity and cultural competency in its programming, personnel and employment practices, and governance. It views diversity as a fundamental element of social justice and integral to its mission of helping grantmakers improve the health of all people. Diverse voices and viewpoints deepen our understanding of differences in health outcomes and health care delivery,

and strengthen our ability to fashion just solutions. GIH uses the term, diversity, broadly to encompass differences in the attributes of both individuals (such as race, ethnicity, age, gender, sexual orientation, physical ability, religion, and socioeconomic status) and organizations (foundations and giving programs of differing sizes, missions, geographic locations, and approaches to grantmaking).



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