Communities Shaping a Vision for America's 21st Century Health and Healthcare

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TABLE OF CONTENTS

EXECUTIVE SUMMARY

PROJECT BACKGROUND

Wye River Group on Healthcare (WRGH) initiated a project in July 2002, called "Communities Shaping a Vision for America's 21 Century Health and Healthcare." This report describes Phase I, which was designed to elicit from health care leaders at the community level their thoughts about the values and principles that should be the foundation of health care in this country. The aim of the project was to launch conversations in various communities that could jump-start a national dialogue about the fundamental values and principles that Americans want to guide U.S. health care policy into the future.

During Phase I, WRGH held a series of Healthcare Leadership Roundtables, or "listening sessions," in 10 diverse communities around the country. During these roundtable discussions, community health care leaders were not asked their views on specific policy issues. Instead, they were asked deeper, more fundamental questions such as whether there is, or should be, a social contract for health care in this country. Participants proved eager to explore these questions, which are rarely asked in the usual forums on health care policy.

This project is fairly unusual – in fact, unprecedented – in its effort to understand how health care stakeholders and consumers view the values and principles underlying our health care system. We used community-based discussions to explore these issues and asked participants to set aside the politics and sector competition that have shaped so much of our health care policy in this country.

What we discovered was a surprising degree of interest and willingness at the community level to offer honest viewpoints about the values and principles in health care, to bring up frustrations and specific challenges, and to pursue collaborative efforts to address key health care issues in their community. Our findings are described in detail in the section of this report entitled "A Community-Based Discussion of Values and Principles for American Healthcare."

HEALTHCARE LEADERSHIP ROUNDTABLES

The Healthcare Leadership Roundtables were held in 10 communities around the country between July 2002 and May 2003. WRGH assembled a diverse cross-section of public and private stakeholders with detailed knowledge of health and health care to participate. They included physician leaders, hospital and health system executives, community and public health officials, pharmaceutical and pharmacy representatives, business leaders, consumer representatives, and government officials. We also worked to ensure that important constituencies such as the elderly, the uninsured, minorities, and people with chronic illnesses were well represented. We believe that, collectively, these leaders have a solid understanding of the health and health care challenges communities face.

Each of the roundtables was a three-and-a-half-hour meeting focused on the shared values and principles that should provide the foundation for health policy in this country. In these discussions, we explored participants' views on the social contract for health care – both as it currently exists and what they believe it should be. We challenged them to define the attributes of a well-functioning health care system and the role that each sector would optimally play in creating and maintaining that system. We asked them to reflect on consumers' expectations of health care. We also tried to raise community leaders' sense of themselves as catalysts for positive change in health care.

Following each roundtable discussion, a professional writer distilled the comments into a "community profile" highlighting the shared values and principles articulated in each community. Draft versions of the community profiles were shared with roundtable participants for their comments, corrections and additions prior to being finalized. The 10 community profiles are included in this report as Appendix A.

As another result of the roundtable discussions, we have developed a roster of 20-25 leaders in each community. This is a practical list of advisers from different sectors in each community who are willing to help us move closer to addressing issues of common concern in health care. Our intent in Phase II of this project is to collectively engage these leaders in activities designed to bridge the gap between local concerns and national public policy.

SELECTION OF SITES AND PARTICIPANTS

The 10 communities in which roundtable discussions were held were carefully chosen to reflect our nation's diversity – not only its diversity of peoples, cultures and values, but also its diversity of health care challenges. The selected communities varied by geography and size, ranging from large metropolitan areas to smaller cities and rural communities, and by cultural and ethnic diversity. The communities also represented a range of regulatory environments, from communities in heavily regulated states to those in states with moderate or minimal health care regulations. We also selected communities that represent both ends of the spectrum when it comes to the percentage of uninsured residents.

The final criteria related to health care costs and quality, using data from the Dartmouth Atlas of Healthcare and a Health Care Financing Administration (HCFA) study published in The Journal of the American Medical Association (JAMA) in the summer of 2000. We selected communities where health care costs per enrollee were much higher than national averages as well as communities where costs were several times lower than national averages. Additionally, some communities were located in states that had been rated very high with regard to quality of care, while others were in the lowest bracket, according to the HCFA study.

Roundtable discussion participants were chosen with equal care. In addition to the chief executive officers and senior executives invited by project sponsors, WRGH recruited a broad cross-section of leaders from each community we visited. Our goal was to balance participation across health care sectors and from a public/private perspective, endeavoring to ensure that the "consumer voice," reflecting the composition of the community, was represented. With the assistance of our supporting organizations, we were able to reach local health care leaders such as public health officials, Medicaid directors, directors of community health centers, representatives from consumer organizations, culturally focused groups and local professional associations, civic thought leaders, and local employers.

SITE VISITS

WRGH traveled to each site 4-6 weeks in advance of the Healthcare Leadership Roundtable in order to gain a meaningful understanding of the unique cultural aspects and health care marketplace dynamics in each community. During the site visit, we met with a broad array of community opinion leaders from virtually every health care sector, both public and private, as well as individuals representing key consumer groups. Through a series of one-on-one meetings and interviews, we elicited their concerns and ideas and developed a sense of the local culture, marketplace dynamics and cross-sector relationships that shape each community's approach to health care. The one-on-one meetings also helped us identify successful community partnerships that became the basis of our "case studies" in
this report, which are intended to provide knowledge transfer among communities and constructive change on the national level.

CITIZEN VOICES

Although this project focused primarily on discussions held at the leadership level in these 10 communities, in 6 of the communities we also conducted informal meetings with groups of local citizens. We wanted to elicit their opinions to balance and supplement the views of their community leaders.

ADVISORY BOARDS

Midway through its 10-city tour, WRGH began to develop a circle of advisers – leaders chosen from different health care sectors and communities – to help us develop recommendations and potential "next steps" in addressing common issues that arose in community discussions. Our intent was to engage these leaders in a process aimed at bridging the gap between local health care issues and a broader agenda with national application.

To organize this aspect of the project, we created "advisory boards" around 6 health care topics – cultural change, access, information infrastructure, incentives, quality, and the role of public health. The advisory board members participated in a series of meetings by telephone that were aimed at identifying opportunities for focused initiatives to be launched in the communities. The boards each developed a topic-specific report describing the crux of their particular issue and suggesting several potential next steps for collaborative action at the community level. The advisory board reports are included in this report.

"SHARED VISION" RETREAT

After roundtable discussions were held in all 10 communities and the advisory boards wrapped up their work, WRGH hosted a retreat July 9-11, 2003, at the Aspen Institute Wye River Conference Center in Maryland. Two key participants from each roundtable discussion and representatives from our sponsoring organizations were invited to participate in the "shared vision retreat," where draft chapters of this report were reviewed, discussed, and edited.

NATIONAL SUMMIT

To announce the "shared vision" that arose from this project, WRGH organized a national summit designed to showcase the findings of the 10-city tour and launch a national dialogue on health care among the American public, policymakers and health care stakeholders. The summit, held in September 2003 in Washington, D.C., provided an opportunity for community and national leaders from all health care sectors to share their insights into our health care future and to articulate their collaborative goals.

PHASE II

In the second phase of this project, we plan to build on the momentum created in Phase I by working with our sponsors, national leaders, and local community leaders to develop and execute a campaign to raise awareness and engage the public in constructive dialogue on health care challenges; create channels for national health policy leaders to gain insight from communities; and demonstrate local solutions from ten diverse model communities that have the potential to be replicated on a national level.

In addition, Wye River Group on Healthcare (WRGH) has created the Foundation for American Healthcare Leadership (FAHCL) to promote and enable the thoughtful exchange of ideas in a neutral environment, among a broad cross section of senior corporate and public sector executives across America. We will convene healthcare leaders to deliberate on and study national healthcare trends and specific contemporary healthcare issues affecting the nations' health and productivity, and advance the outcome of these discussions before public policy experts, private and public sector leadership, and the general public, through multiple educational outlets.

FINDINGS

It is evident from the community roundtables held by WRGH that there is both deep concern about the current direction of health care in this country and a great desire to move forward with constructive changes. One of the fundamental principles that emerged in the roundtable discussions is that the problems in health care today need urgent attention. It is time for elected officials to put health and health care at the top of the nation's list of priorities.

Community leaders said there is a window of opportunity now to engage health care stakeholders, the public, and policymakers in a dialogue aimed at constructive health system change. They called for a national conversation that starts by asking Americans about the values and principles that should form the basis of their health care system. This kind of conversation about health care – one that really gets at the core of what Americans want from their health care system and what they are willing to support – has not yet taken place in this country.

The Lack of a Meaningful Social Contract for Health Care

Most community health care leaders agreed that our country has not developed a social contract for health care that is well-articulated and broadly understood. Over the years, our country has developed an effective social contract in other areas of public policy, such as education. But currently, there is no equivalent in health care. As a result, most Americans do not know what they can and should expect from their health care system. Nor do they understand their responsibility to contribute to the health care system.

Instead, what we have is a patchwork of public and private health insurance, a health care safety net under tremendous strain, and millions of Americans who are uninsured and/or medically underserved. We don't have a clear, shared understanding of health care as a right for all residents. In the absence of a social contract for health care, it is exceedingly difficult to address such fundamental questions as what Americans can expect from their healthcare system, what services should be covered and for whom.

The Public's Expectations

Community health care leaders identified Americans' expectations as a key area that needs to be addressed in a national conversation on health care. There is a general consensus among health care leaders that the public's expectations are often out of line with the reality of what the health care system is able to deliver. There is also recognition that the health care system itself has helped foster these unrealistic expectations and that the health care system does not often provide information about the true costs and availability of services.

According to community health care leaders, most Americans expect high-quality care, on demand, and at little or no cost. Americans don't want to make trade-offs and we don't want to hear about limits. Because of financial constraints on the health care system, this kind of access to inexpensive services may become increasingly unrealistic. Americans need to revisit the discussion about health care as a social contract and also may need to make tough choices about access and availability of health care services.

There is a need to address the expectations that we have of our health care system by increasing Americans' sense of collective responsibility about their health and health care. Instead of focusing only on whether we, as individuals, have access to high-quality, affordable health care, we need to begin thinking about health care as a collective resource. The choices we make about our health and our use of the health care system have an impact beyond our own quality of life and our own pocketbook; they affect whether there will be more or less resources available for others. We need to start seeing the connections in how our personal decisions affect other people and how we are affected by the choices that others make.

In addition, while there is broad support for more consumer responsibility, there is also recognition that it should be balanced with much more institutional and organizational accountability. Community leaders

have also emphasized that there are limits to the responsibilities that sick or vulnerable people can assume and that individuals should not be blamed for their health conditions.

Defining and Confronting the Problem

The first step we need to take, as a nation, is to recognize that our health care system is facing enormous challenges that we need to address. In many areas of the country, health care – especially the safety net – is crumbling; employers and consumers are facing skyrocketing health care costs; many patients are not getting the quality health care services they need; and physicians and other health care professionals are facing serious morale problems.

However, many of our elected officials do not seem to grasp the magnitude of these challenges or the urgent need to address them. Therefore, there has to be an effort to educate and engage citizens and policymakers on health care issues. Not much progress can be made without political leadership and public pressure.

Laying the Groundwork for a National Dialogue

Raising public awareness will require courageous and articulate leadership from all sectors involved in health care, from political leaders to community leaders to health care stakeholders and "the grassroots." Communities can play a critical role in laying the groundwork for a national dialogue about health and health care.

Community-based discussions can be particularly effective because they are likely to reflect the actual conditions in a community, where people know what works in their area and what does not. There can also be productive collaboration among health care stakeholders in communities, outside of the often-polarizing atmosphere of Washington, D.C. In addition, a community-based discussion is more likely to pull in participation from "the grassroots" and therefore will reflect a community's own values and principles.

Translating community-based discussions into a national conversation will require a willingness to move beyond the usual political divisions that pit those who support greater government involvement in health care against those who favor less government and a more market-based approach. This dichotomy has often stood in the way of substantive progress in addressing health policy issues such as the problem of the uninsured.

Transforming the Role of Consumers

Community leaders generally agree that the most important step in moving forward with health system change may be a re-examination of the way that consumers function in the health care system. The traditional consumer role in health care has been relatively passive. But this is changing. The health care market is evolving toward giving consumers more choices, but also more responsibility for the economic consequences of their health care decisions.

Americans need to have the information to be empowered to make good choices that will benefit their own health, and they need to be aware of the finite availability of some health care resources. This will require a shift in the way many of us think about our health. Empowering consumers, and giving them the necessary support and access to appropriate health care services will help them to make good choices about their health. It could also improve quality of life and reduce unnecessary costs for the health care system.

Restoring Confidence and Trust in Health Care

Community health care leaders recognize that health care institutions have lost much of their public credibility, which is a critical aspect of a well-functioning health care system. Skepticism is also prevalent among employers, who are seeing annual, double-digit increases in their health care costs.

It is essential that consumers and patients be able to understand and trust their health care providers. Patients also must be able to feel confidence that their physician is acting in their best interest. Because trust is a two-way street, health care professionals also need to feel confident that their work is valued and supported.

Spending Money Wisely

The issue of financing is at the heart of our nation's health care challenges. There is a sense among community leaders that we need to restore balance in how health care resources are allocated and better align incentives in ways that truly support health. The first priority is to recognize that it is well worth the money for the U.S. to make sure that basic health care is available to everyone. Ensuring universal access to health care, through public or private means, is broadly seen as both socially desirable and economically beneficial. Another key consideration should be to emphasize the value proposition, balancing science and measurable outcomes with relative cost.

In all of the roundtable discussions, participants also emphasized the need to better integrate and coordinate health care services. In particular, there should be a greater focus on the areas of health care that are cost-effective ways to improve patients' quality of care, including primary and preventive care, public health, mental and behavioral health, and care management for patients with chronic illnesses.

Translating Talk Into Action

Community health care leaders said that a national conversation about health care is important, but it is not, in itself, enough. Discussion, even if it is broad-based and gets to core issues, must lead to action in the end.

For action to be possible, the conversation must move beyond the battleground of special interests that have so often stood in the way of change. There will have to be articulate leadership that generates respect for the process and encourages stakeholders to put aside self-interested agendas that stand in the way of constructive change. There will also have to be broad-based support from the public.

All of the health care leaders who participated in these roundtable discussions – all of whom clearly recall the failure of the Clinton health care reform effort in the early 1990s – recognize that this type of effort is an enormous undertaking, but they say the effort must be made. Our current circumstances require it and Americans deserve the best health care system we can design.

REPORT OUTLINE

The Phase I report of this project, "Communities Shaping a Vision for America's 21st Century Health and Healthcare," is comprised of several parts.

First, there is a section titled "A Community-Based Discussion of Values and Principles for American Healthcare," which describes the values, principles, expectations and preferences that were elicited from the roundtable discussions among community leaders and health care stakeholders. These are concepts that could become a template for national health policy development.

Second, there are the advisory board reports including suggestions of "next steps" to address several key health care challenges – access, quality, information infrastructure, incentives, and the role of public health.

Third, the Appendix includes "community profiles" on each of the ten communities in which WRGH held roundtable discussions and 40 "case studies" showcasing community-based partnerships that have found innovative ways to address key health care challenges at the local level.

A COMMUNITY-BASED DISCUSSION OF VALUES & PRINCIPLES FOR AMERICAN HEALTH CARE

Overview

Roundtable discussions hosted by Wye River Group on Healthcare have revealed a consensus among community leaders that the United States needs to make fundamental changes in its health care system. As evidence, these leaders cite mounting problems in health care, especially the skyrocketing cost growth that has made health care coverage unaffordable for millions of Americans. The rapid escalation in health care expenditures is the number one concern that is driving community leaders' interest in comprehensive health system change.

In Jackson, Mississippi, as in many other communities, we heard that "the crisis is worse now than it was [in the early 1990s]." In addition to the cost issue, health care leaders point to growing problems in health care delivery: over 40 million Americans uninsured at any given-time in a year; safety net providers who are overwhelmed by increasing demands on their resources; workforce shortages; widespread quality problems; and concerns about how the liability system is affecting access to health care.

Not surprisingly, many health care leaders convey a sense of urgency when talking about the need to move forward with health system change. They say the problems are severe, pervasive, and likely to worsen unless significant action is taken to address them. "Time has run out for an incremental approach to health care change," said a participant in San Antonio.

Our health care system is undergoing a period of transition marked by a growing number of employers moving away from a model where healthcare benefits are defined to one where employer financial contributions are defined; workers being asked to share more of the costs of their care; patients demanding more information about their health care options and a greater role in decision-making; and physicians and nurses facing severe challenges to their morale and their ability to care for patients. All of these changes, and the increasing cost pressures on health care payers, make this a crucial period of transition for American health care. This period can be viewed either as a moment of crisis or a moment of opportunity.

Community leaders choose to view it as the latter. They say the growing set of health care challenges presents a window of opportunity to engage policymakers, the health care industry and the public in a national dialogue aimed at constructive change. They say that, as stakeholders, they are more motivated than they have been in a long time to discuss problems and collaborate on solutions. Moreover, the deep concern felt by the health care sectors has begun to spread to the public. "It is becoming a middle-class consumer crisis," observed a Jackson participant. The public is paying attention, which means that policymakers have a strong incentive to become engaged on the issue of comprehensive health system change.

However, these leaders also warn that the window of opportunity to move forward with thoughtful changes is limited. The window will begin to close once the Baby Boomers start flooding Medicare. It could close

COMMUNITIES SHAPING A VISION FOR AMERICA'S 21ST CENTURY HEALTH AND HEALTHCARE

even sooner if more employers decide health care coverage is unaffordable and stop offering it to their workers. Health care leaders say that if there isn't significant progress in the next five to ten years, the problems will become even larger and more intractable, which could prompt a radical shift in U.S. health care policy as a last-ditch effort to control cost growth. "If we don't consciously make significant change, we are headed inexorably to a government-controlled system," said a participant in Salt Lake City.

The prospect of increased government involvement in health care is clearly a lightning rod for disagreement in virtually every community we visited. A large number of participants said they would oppose "government-run health care." There was broad agreement that a one-size-fits-all approach is not likely to be embraced in our pluralistic country, "where values often differ among communities and across generations," said a Salt Lake City participant.

But some health care leaders expressed support for the notion of "single-payer health care." Single-payer supporters seem to share a belief that only a single-payer system can effectively address the inefficiencies and inequities in American health care. However, they do not seem to have a shared definition of the term "single-payer" or a clear sense of how it would achieve their goals.

A few health care leaders in various communities said that – like it or not – they believe the U.S. will one day adopt a single-payer approach out of a collective desperation to control costs. Others disagreed. "I cannot believe the deliverers and financiers of care would allow us to get national [health] care," said an insurance executive. "We will come together before we go over the brink."

Community leaders say there is a role for government and communities in shaping health care. Undoubtedly, health care will continue to evolve, even if policymakers refrain from taking an active role in addressing the current problems. But most health care leaders say the evolution in health care shouldn't be left entirely to the marketplace. "Normally our society resolves problems through the market," said a San Diego participant. "But this [health care] market has a lot of imperfections." Therefore, policymakers need to step up and proactively help to define the direction in which we, as a country, want to take our health care system.

The first challenge in such an effort would be to decide what Americans should expect from their health care system and what they are prepared to actively support. As a health care leader in Jackson observed, "The problem policy-wise in the U.S. is grasping what health is [to us] as a society. Until we get a handle on what we're trying to achieve, I don't know if we can get a handle on the health care system."

In fact, many of the participants pointed out that the U.S. doesn't even have what can be considered a health care "system". It is a "non-system" – fragmented, random and complex, they said. "Health care is not meeting the needs of the 21st century consumer," asserted an Albuquerque participant. "There is no integration." The lack of coordination in health care results in higher costs and lower quality.

Health care leaders say it is time that Americans come together to talk about what health means to all of us as a society and to start developing a national agenda for health care. We need to get clear on what the

— 8 —

problems are in health care and what kind of solutions we would like to see. A Ft. Lauderdale participant said America needs a vision for health care that can be articulated by policymakers and understood by the public. "Without a vision, we'll be treading water," he warned. "We need a simple message that is visionary."

Along the same lines, a North Carolina participant observed that, "the reality is that America does not have an agenda for health care, which should be the driver of the health care system.... We have random acts of improvement going on, but there is no overall vision."

Creating a national vision for health care will require the involvement of all health care sectors, community leaders and the public, but it starts with courageous political leadership. "Unless we have someone who is willing to step forward and very publicly say health care is the agenda, I don't think it's going to take place," said a medical group CEO.

For too long the problems in health care have been pushed aside in favor of other issues. Leaders in every community agree that now is the time for elected officials to put health care at the top of the nation's list of priorities. In the words of one Jackson participant, "If we could declare our health care dilemma as a threat to national security, our country would react as it did in Iraq and act to correct it." The magnitude of the problems that face health care today demands that level of attention and focus.

The Lack of a Meaningful Social Contract for Health Care

In each of the roundtable discussions, health care leaders were asked, "Does our country have a social contract for health care?" This may sound like a simple question, but it revealed a great deal of uncertainty and disagreement about Americans' rights and responsibilities as they relate to health care. Judging from the response of most participants, the question is not one often discussed in this country, even among health care leaders. A typical reply was, "What do you mean by a 'social contract'?"

A basic definition of a social contract for healthcare is an agreement among citizens that defines the rights and responsibilities of the citizens themselves, their government, and their health care system. Under that definition, the U.S. does not have a meaningful social contract for health care, according to most participants. Americans do not know what they can and should expect from their health care system. Nor do they understand their responsibilities for maintaining the health care system. "I don't think the idea of a social contract is in people's daily consciousness," said a New Hampshire participant. "People's self interest should be more connected to the concept of interdependence.... We need to understand interconnectedness and interdependence."

Some agreed with the notion that there are multiple social contracts that often conflict with each other and represent a series of "warring" expectations. Others felt that there are elements of a social contract for health care. For example, our country has put in place health insurance and safety net programs to make

sure that care is provided to certain populations. The Medicare and Medicaid programs represent a kind of social contract, said some participants. But these programs often fall short of meeting people's needs for health care, and are felt by many to represent more of an entitlement than a social contract. Many leaders point out that healthcare should not be an "entitlement" as it requires certain responsibilities from individuals as part of a two-way contract.

Furthermore, many point out that these public programs are underfunded. "If a social contract exists, it has a huge hole in it," said a state Medicaid director.

If there is a social contract for health care in this country, it is certainly minimal, and poorly articulated. It is perhaps manifested as an expectation that vulnerable people will somehow receive the care they need, particularly in an emergency. Indeed, federal law requires hospital emergency departments to treat anyone regardless of ability to pay. But there is no clear foundation for viewing health care as a "right" that is guaranteed to everyone who lives in the United States. An Albuquerque participant pointed out that "from a social justice perspective, we have to acknowledge that our system has not defined health care as a human right."

The question of whether Americans should have a right to health care proved to be very controversial in some communities. A few individuals felt very strongly, for moral reasons, that Americans should have a right to health care that is guaranteed by the U.S. Constitution. Some became more specific. "I'm not sure we have a right to health care," said a public health official. "But I'm sure we have a right to health." Others resisted the idea of health care as a right because of the legal obligations that go with establishing rights. In one community, a hospital CEO recommended a middle-ground response to the question: "Rather than say health care is a right, let's say health care is a privilege to which everyone should have access."

A social contract has two sides: rights and responsibilities. In the U.S., both sides are exceedingly fragile. Although Americans have funded Medicare and Medicaid programs through taxes since 1965, health care leaders say they don't think most people fully understand that they have a collective responsibility to support and fund the health care system on which they depend. While we all want and expect high-quality health care, we are not anxious to pay more for it, nor are we enthusiastic about paying for other people's care.

In our society, we have little appreciation of health care as a common good that requires substantial pooling of community resources. "We do need to get the country to understand that with all rights come responsibilities," said a New Hampshire participant. "Everyone has a responsibility for paying for [health care]," said a health care attorney. "We should be asking, what am I willing to give up, and what am I willing to pay for?"

A North Carolina leader pointed out that, "In our society, health has such a broad definition that to talk about a social contract is difficult unless we define health and health care." A journalist wondered if it would help to initiate a public conversation about what is a public good. Americans should be asked:

"What's a shared responsibility versus what is personal?" A health policy expert in another community stated that, "The reality is that health care is both a public good and a private good. Not one or the other. They are blended. The challenge is sorting them out."

It was suggested in several communities that the public education system could provide a model for viewing health care as a right. "We've reached a consensus that there is universal entitlement to elementary education, but that Harvard and Yale are not for everyone," said a San Diego participant. Perhaps there should be universal entitlement to a basic level of health care as well, several leaders suggested. But if health care is to be universally available, there must be adequate funding for it.

During the roundtable discussions, participants were also asked whether the United States should have a social contract for healthcare. If so, what would it look like? The general consensus was that we should define more explicitly Americans' rights and responsibilities vis-à-vis the health care system but not necessarily codify them in a formal "contract." As a Florida health care leader put is, "The social contract needs to be for health, not health care. This is going to be a multi-generational effort.... As a country, we haven't embraced health yet as a priority."

Before the health care system can move forward, leaders say, we need to go back to square one and talk about the values and principles that should be the underpinning of our nation's health care policy. Both the American public and the health care system would certainly benefit from an explicit discussion about the connection between people's self-interest and the public welfare.

But health care leaders also recognize that developing this kind of agreement will be difficult. Our country has a long history of conflict between competing political ideals: social equality and fairness on the one hand, versus personal responsibility and self-determination on the other. "These are two very powerful belief systems that have endured for more than 200 years," said a medical ethicist. "There is no good principle to balance the ideals of social equality and libertarian self-determination."

"We can't rush this," said a Portland participant, citing the "strong individual rights mentality in this country." While we may not need to reach complete agreement among the American public and policymakers, any reform effort will have little chance of succeeding if these conflicting issues are not openly addressed.

The Public's Expectations

Community leaders say that discussion of a social contract for health care will have to zero in on the issue of expectations. What can Americans reasonably expect from their health care system, and what are the trade-offs? So far, there is no clear answer. But there is a feeling among health care leaders that the public's current expectations are often out of line with the reality of what the health care system is able to deliver. And, in general, the public does not accept the notion of trade-offs when it comes to health care.

Community leaders have two main concerns about the public's expectations of the health care system. One is that expectations are very high, to the point of being almost unlimited. "I think the social contract right now is that people expect everything, everywhere, right now, and for ten dollars," said an insurance company executive. A union official agreed with the statement. Health care leaders say consumers seem to feel entitled to the highest quality care available, and at little or no cost to themselves. "I see an increasing number of patients who have an almost angry sense of entitlement to health care," said a physician. "And they think it shouldn't have to cost them anything." A leader in San Antonio asserted that, "the problem is how to reform an entitlement which has now been passed down to this generation to resolve."

The other concern is that many consumers and patients may fail to appreciate the connection between their personal demands for health care and how those demands affect the health care system and others dependent on it. Consumers, understandably, tend to be concerned about their individual circumstances, such as whether they have access to quality health care at a price they can afford. But they often do not consider how their choices draw on a limited pool of health care resources on which other people also rely. Some health care leaders point out that in today's system, consumers are not even given the opportunity to consider how their use of health care resources affects others. They are not provided with the true cost of various care options.

Community leaders say they recognize that they need to do a better job of communicating to the public that there are limits to what the health care system can do. "Consumers need to understand the rules of the game and the limitations of health care," said a hospital association executive. "The medical delivery system has created unrealistic expectations through our marketing." The public needs a better understanding that when it comes to health care, we are all in the same boat and we all have to paddle.

Defining and Confronting the Problem

Participants in the community roundtables agree that one of the most frustrating obstacles to addressing problems in health care is the public's lack of concern. Most individuals, as well as their elected officials, don't seem to appreciate that there are enormous challenges facing the health care system or how those challenges undermine not only health care but also the economy and society. Consumers may notice their premiums and co-payments going up each year, but they don't see how their own situation ties in to the overall system of health care financing and delivery, a system upon which the United States spent 14.1% of Gross Domestic Product in 2001.

As a nation, we need to acknowledge the serious problems facing health care.

Health care leaders say they would like to see our country confront, head on, the fact that our health care system is facing serious problems. This is a fundamental principle on which community health care leaders agree. In many areas of the country, health care – especially the safety net – is crumbling under the strain of too many demands and not enough resources. The public has to be educated if people are to understand what is at stake, both for the nation and themselves.

There are some hopeful signs that the public wants to engage in health care policy. A New Hampshire participant noted that in Montpelier, Vermont, which has a population of about 8,000, 500 people showed up at a local hospital one night to talk about the health care system. "So people do care," he said.

These kinds of efforts are going on in many parts of the country and they should be encouraged. Health care leaders say that an educated and concerned public would, hopefully, light a fire under its elected representatives to address the problems in health care. "Fundamentally, you've got to have leadership at the top. That's the President and the Congress, for a start," said a San Diego participant. "They have to step up to the plate, make some hard decisions, and communicate that."

But too many elected officials are not well informed on health care policy. "The group that really needs educating is our legislators," said a Portland participant. A lot of legislators not only lack information on which to base their health policy decisions, some of them lack any interest in the subject. "Our county commissioners couldn't care less if we [public hospitals] live or die," said a public hospital executive. Therefore, there has to be an effort to educate and engage consumers, including patients, and policymakers on health care issues. Not much progress can be made without political leadership and consumer support.

Health care stakeholders must come together to engage the public and find solutions.

Health care stakeholders can play a critical role in educating and engaging the public on health care issues, but first they have to be willing to come together and cooperate on a common agenda. Community health care leaders say they want their colleagues to understand the value of coming together in the interest of the health care system as a whole to develop solutions.

These leaders say that more unites the health care sectors than divides them. Yet, each sector typically brings its own narrow perspective to policy discussions with the goal of protecting and promoting its own self-interest rather than advancing what would be in the interest of the community.

The health care industry has often acted as one of the main obstacles to advancing health care reform. "We're in a real battleground of special interests," said a North Carolina participant. "Year after year, issue after issue, it's the special interests that block change." A Mississippi participant agreed: "The special interest groups have the loudest voices."

Admittedly, there is often sharp disagreement within the health care industry about where the system should be headed. "You get quickly into politics and self-interest," said a Portland participant. "There is too much that people have a stake in, and they're not ready to give it up."

But health care leaders in many communities said they want to create an environment that makes it safe for stakeholders to talk about these differences. The scope of the problems facing health care demands a greater effort at cooperation, they said. "There is a lot of distrust in the system," a Jackson participant acknowledged. "But until we understand the perspectives of other sectors, we're going to keep having problems."

Almost a decade after the Clinton health care reform effort collapsed, health care leaders say they would like the various sectors to be able to talk openly and begin moving toward a collective agreement on the future direction of health care. But to begin that process, the various health care sectors must stop pointing the finger of blame at each other. "All stakeholders need to have a voice in the design of the answers and to leave blame outside the door," said a Ft. Lauderdale participant.

We need to launch a national, community-based dialogue about what trade-offs health care stakeholders would accept. Quality care should be clearly defined. Providers should be open to moving quality indicators forward and to being evaluated by them. Insurers should allow access to the pricing of health care services. Consumers, physicians, hospitals, and insurers need to understand that in health care there have to be trade-offs.

Laying the Groundwork for a National Dialogue

A North Carolina physician executive noted that in the last 10 to 15 years there have been two major attempts at initiating broad-based dialogue on health care reform. One was in Oregon under the leadership of Governor Kitzhaber. The other was in Washington, with the Clinton plan. A number of participants noted that the two efforts used very different strategies for developing a health care reform plan.

Oregon used a very open, "bottom-up" process to develop its policy proposal, whereas the Clinton plan was shaped through a relatively closed, top-down process. A number of health care leaders in different communities spoke favorably of the Oregon approach, which they said achieved buy-in from the community on some very difficult choices. However, a Washington thought leader pointed out that while Oregon was successful in defining how services paid for by government would be prioritized, the attempt to do this for the state as a whole produced a plan that was voted down.

Nonetheless, the majority of participants in all communities seemed to agree on the need for a broad and explicit public discourse aimed at developing a national vision for health care. A small minority expressed caution. "It's hard to get people together and get them on the same page," said a journalism professor. "It's important work, but it's hard to get people thinking in new ways." Nevertheless, he said, it's worth trying.

A New Hampshire participant said that in his view, "an explicit debate is unnecessary and probably divisive. Sometimes it's better not to state the obvious." A Portland participant also expressed concern that if a national dialogue focuses on calling attention to the crisis in health care, it could produce "a political vortex of blaming. The place to start is to reacquaint people with their place as part of the community."

A national dialogue must be initiated at the most basic level by trying to develop a common understanding of Americans rights and responsibilities vis-à-vis the health care system. "We need a new way of talking about [values] to better reflect where we are today," said a hospital association executive.

Other advanced industrialized countries that have had this kind of national conversation have benefited from it. But there has been little attempt to really lay health care issues on the table for Americans to fully understand and consider, which has left our country without a social contract for health care that is well articulated and broadly understood.

As a result, there is a lack of common vision that could act as a counterweight to those forces that tend to act as a barrier to reform. "The common thread is that opponents of change are those that have struck the jackpot with the current system," observed a North Carolina attendee. There is difficulty even talking about a common vision for health care. "I'm concerned that we've lost the ability to have a social discourse," said a Portland participant. "It's more about 'me, me, me,' at the national level than about giving."

There is an urgent need for honest and articulate leadership that demonstrates candor and integrity and focuses on the question of where the nation's health care is headed.

Discussion should begin at the community level, as well as in Washington.

Participants in every community say that is important for national political leaders to put health care on the agenda, but they say that people also need to start talking at the state and community level. "Health care, like politics, is local," said a San Antonio participant. "Solutions should be local solutions." An insurance executive in Salt Lake City agreed: "The grassroots level is where things get done."

Community-based dialogue offers several advantages. One is that policies determined at the community level are likely to be based on the actual conditions in a community, where people know what works in their area and what doesn't. Americans live in a diverse country where values and priorities differ from one community to another. "The genius of this country is innovation and diversity," said a New Hampshire participant. "What works in Vermont may not work in Texas."

Another advantage of the community-based approach is that health care sectors are more likely to work together productively within their own communities than they are in the polarizing atmosphere of Washington. "There is so much lobbying in Washington that prevents change," in the words of a Ft. Lauderdale participant. But health care leaders in a particular community tend to know each other well and are accustomed to working with each other, which provides a foundation of trust and collegiality.

Additionally, a community-based discussion is likely to pull in participation from "the grassroots" – that is, it is likely to include the consumer voices that need to be heard throughout the process. "The effort needs to get out to the grassroots and it needs to reflect grassroots values or it won't be sustainable," said a Ft. Lauderdale participant. Health care leaders say they believe consumer and patient voices are too rarely heard at health policy roundtables.

Oregon participants noted that their state has demonstrated that states can achieve health system change by inviting the public into strategic discussions on health care policy. By directly involving the public in

decisions on how resources should be allocated, the process enhanced the community's sense of having a stake and a voice in its health care system.

The dialogue should include all voices, especially those of consumers and patients.

Participants said the problems in health care require a new kind of conversation – one that brings in a diverse, grassroots perspective and reflects a community's values and priorities. Only then can we get to the kind of health care system that people want and are willing to support. The conversation "has got to be very broad-based, community-based, with consumer input," said a health system CEO. "Health care is so personal." A North Carolina participant said that, "It has to be an action-oriented dialogue."

Policymakers need to hear directly from consumers. "I don't think we should be the ones deciding what they need," said an Albuquerque participant. "That's not to idealize the consumer, but they ought to be the ones dictating what they need."

The consumer needs to have a voice. "We need to get to the 'Oprah' level of dialogue," said a Chicago participant. This level of dialogue includes consumers but also ethicists, clergy, and community leaders that don't have a direct role in health care but who can attest to the important role that health care plays in society. "There is incredible power…in a figure like Cardinal George of Chicago saying, 'we value this.'"

Transforming the Role of Consumers

Community leaders generally agree that the most important step in moving forward with health system change is a re-examination of the way that consumers function in the health care system. Already the health care market is evolving in a direction that provides consumers more choice but also requires of them greater responsibility. At the same time, consumers seem to be yearning for more control over their own health care. Many are seeking more information about their treatment and provider options.

Traditionally, consumers have taken a relatively passive role in their health care. They've trusted that their doctor will tell them what they need to know. Their choice of health plans and providers has been limited. They've had little information on which to judge the quality of providers that are available to them.

Though consumers didn't create it, this traditional role has unfortunately led to many of the problems in health care today, particularly in the area of costs. Many participants say that people are not used to thinking about cost as a factor in their health care decisions. Because the current healthcare system does not readily allow consumers and patients to obtain information about actual prices of health care services, they have little or no incentive to restrain the cost of their care.

However, some point out that there is an important distinction. While "consumers," individuals on the healthier end of the spectrum, can and should be held accountable for choosing efficient health plans and

health care services, "patients" are much more reliant on their care providers and others they trust when it comes to decision-making.

Health care leaders say many consumers seem to have lost sight of the fact that someone must pay for the care they receive. A New Hampshire participant described this as "almost a child-like behavior" – consumers feel entitled to virtually anything, without limit or responsibility.

This concern was echoed at one roundtable discussion after another. "We've replaced a sense of community about health care with a sense of entitlement," said an insurance company CEO. "Too large a percentage of our population believes they can do anything they want, and when they get into trouble the doctors and hospitals will be there to help them," said a business leader.

Although many consumers may not be well-informed about their health care decisions, providers and other stakeholders share responsibility for our current healthcare climate. "[We] create expectations by giving antibiotics for upper respiratory tract infections even though it's wrong," said a physician. Consumers may feel entitled, but they have been removed, to a large extent, from the decision-making loop. "To get them back in will be very difficult," said a Chicago participant. "The consumer needs to be re-thought as a focal point," added another. A consumer advocate in North Carolina pointed out that, "I think we need to appreciate the fact that people want to participate in health care; they just don't have the opportunity."

Health care leaders say they want to move the system in a more patient-centered direction – one that will give individuals more control over their health care while also constraining cost growth. This will require that people be given both responsibility for their health care and the tools and incentives to make good choices. For example, they will need reliable information about cost and quality, to help them compare providers and participate in shared decision-making "I think the magic bullet might be consumerism," said a Chicago attendee. "But it's important to look at small steps…."

To the best of their ability, consumers should assume more stewardship for their health care.

There is broad support for more consumer responsibility, but there is also recognition that it needs to be balanced with much more institutional and organizational accountability. In many communities, leaders from different sectors emphasized that efforts to promote "consumerism" and personal responsibility must avoid any hint of "blaming" individuals for their health conditions. They recognize that there are limits to the responsibility that sick and vulnerable people can assume. "The individual's responsibility goes only so far," said a Chicago participant. "In a wide range of areas, there are things that individuals are not in charge of, and we have to take that into account."

A significant number of Americans will continue to rely on the safety net for their care. It's not just the poor or the poorly educated who need the safety net. It's also those who are chronically ill, disabled, or mental ill, and those who need long-term care. As one New Hampshire participant observed, "Lots of choices and information work great for a shopper. But a sick person's world contracts dramatically. So I'm a

little skeptical of pushing choices on sick people." A health care leader in Portland pointed out that, "Not all consumers want to be 'empowered' or can be."

However, most health care leaders seem to agree that until consumers understand the economic consequences of their health care decisions, they will continue to feel little responsibility for costs. During the past few decades, employer-sponsored managed care plans have increasingly distanced consumers from the true costs of their care. "The patient has no idea what the cost of care is," said a San Antonio participant. "They know their premium and co-payment, but not the full cost of their care."

As a result, many consumers believe their benefits package should provide unrestricted access to all forms of health care and to all health care providers. "I think these ideas are in the minds of the public, but it's fantasy," said a Salt Lake City participant. Consumers should recognize that the health care system operates under certain financial constraints. They can't all have unlimited access to top-quality health care services at little or no cost to themselves. "We need to re-introduce the public to the reality of what health care costs," said a Portland participant.

In order to facilitate this process, health plans must work to increase transparency, so that consumers and patients can better access financial information about health care services. Communities should encourage dialogue about the types of trade-offs that consumers, patients, providers and other health care stakeholders would be willing to accept in health care services. The definition of "quality" care and access to that care should be the responsibility of all stakeholders.

The goals of empowering patients and rationalizing utilization are currently driving interest in a concept called "shared decision-making," which enables patients to play a greater role in decisions about their own care. Dartmouth studies have found that informed patients who have support in decision-making tend to be more satisfied with their course of treatment. They also tend to choose the option that is most conservative – in other words, the option that is less risky, less invasive, and generally less expensive. This new paradigm of medical decision-making has found growing support in the health care communities of northern New England, where it is currently being tested.

People need support, education and incentives to help them make health a priority.

In community after community, health care leaders expressed alarm over the increasing prevalence of chronic illnesses that are related to lifestyle. As a cancer society representative pointed out, "thirty percent of cancers are due to behavioral issues." The challenge is to get people to change their behaviors before illness develops. "If you can get people educated before they have pain and see blood, you can go a long ways," said a Ft. Lauderdale participant.

Health care leaders are particularly worried that the number of obese children and adults is rising across the country and so are the chronic conditions – such as diabetes, hypertension and heart disease – that

result. They point out that obesity not only affects people's quality of life and longevity, but also leads to enormous and unnecessary costs for the health care system. A tremendous amount of resources are being spent to treat illnesses that could have been prevented had patients made healthier choices.

Given the toll that obesity has taken on our society, something has got to be done to help Americans better manage their weight. This is not easy in a country where unhealthy food is plentiful and cheap and many people lead sedentary lives. "The popular culture and business interests are going the other way" by marketing fast food, said a Chicago attendee. "We have an epidemic of obesity, but McDonald's is super-sizing everything."

In spite of these challenges, health care leaders said there has to be a focused effort to help people maintain a healthy lifestyle. "We need a national campaign to reach the public on health as a priority," said a Ft. Lauderdale participant.

"Educating patients is something the health care system has really ignored," said a physician. Patients don't know how to care for themselves and stay healthy. Instead, they are bombarded with advertising for pharmaceuticals that seem to fix any condition. "I spend so much time deprogramming patients from wanting [a drug], which they see on TV every night," the physician said.

Several health care leaders recommended developing a unified message on the importance of healthy lifestyle choices but tailoring the message to different audiences. "Address behavioral change that is long term," suggested a public health officer. "And it has to be marketed and targeted."

Several leaders strongly recommended a particular effort to target children. "As [the percentage of] chronically ill patients grows, we're really missing the boat on prevention by not getting kids when they're young," said a Ft. Lauderdale participant. "The numbers are rising and I fear where we're headed."

There was general agreement that health education should be taught in the public schools to a much greater extent than it is now. It was noted that despite the rising numbers of obese and overweight children, physical education classes are often among the first items cut when schools have budget problems. In some states, sex education is not even taught in the public schools. Participants said there is a need to make health a priority in the school curriculum. A community health leader in North Carolina said, "If we are really going to talk about prevention, we need to talk about what is taught to kids in school."

Other ideas for promoting health include educating young mothers, improving the nutritional content of school lunches, giving people a certain amount of time off work each day to exercise, and providing wellness programs in the community. In fact, a growing number of community-based organizations offer wellness programs that are tailored to the needs of their members.

Health care leaders say they would like to see a broad-based effort aimed at supporting and encouraging people to make healthy choices, but most say it should be done without taking a punitive approach.

There was discussion in some communities about whether consumers should have to pay more for their health care if they make choices they know are unhealthy, such as choosing to smoke or to remain 100 pounds overweight. There is some support for charging higher premiums to smokers on the grounds that they are causing themselves serious health conditions that are costly to treat. But most rejected the idea. "I have a strong reaction to this punishment approach to ill health," said a consumer advocate. "When you look at populations where obesity is most prevalent, it looks like punishing poor people and people of color."

Although most health care leaders are opposed to using punitive measures to encourage healthier lifestyles, they are open to ideas that provide positive rewards for healthy choices. Many consumer advocates believe that the real focus should be creation of incentives that encourage individuals to engage in processes that reduce health risks, such as compliance with age-appropriate risk reduction behaviors. Participation rather than results should be rewarded, in order to avoid any potential discrimination against individuals who, because of genetic or other factors, are unable to achieve a particular goal.

Restoring Confidence and Trust in Health Care

During the roundtable discussions, participants were asked what they thought the attributes of a well-functioning health care system were. In response, many health care leaders said they consider trust, at all levels, to be a fundamental attribute and a value that must be emphasized in health care. It is a priority to ensure that people feel confidence in the health care system. But many leaders recognize that health care institutions have lost much of their credibility with the public. "We, as an industry, have a big credibility issue," said a hospital CEO. Reduced trust in the health care system "pervades what we're doing," said an Oregon participant.

Unfortunately, patients have good reason to be wary. "There is a lot of dishonesty in the system," said an Albuquerque participant. "We need to ask ourselves, can our organizations bring more honesty?" A lack of transparency about quality and price makes it particularly difficult for patients to feel confident they are receiving optimal treatment at a reasonable cost.

Skepticism is also prevalent among employers. "We in business and I as an individual don't trust you as an industry," said a business CEO. The business community is particularly skeptical of the health care system's willingness to rein in costs. The health care community recognizes that many employers don't trust them. "Doctors want to be a patient's advocate," said a physician executive in Mississippi. "But if doctors are unwilling to consider population health, we'll never control costs."

Patients should be able to understand and trust the health care system.

Right now, many patients do not feel a lot of confidence in their health care institutions. One reason is that they don't think they are getting all the information they need from their providers. They don't know if

their providers are recommending certain kinds of treatment because it is in the patient's best interest or because of financial incentives.

In addition, consumers are wary of the health insurance industry, particularly when it comes to assisting with quality health care decisions. As noted, increased transparency is needed for both the price and quality of services.

There is a lot of confusion. Many consumers find the health care system very difficult to understand. Indeed, health care is very complex, even for those who are savvy and educated. "I can't navigate my own benefits," said a health plan executive. "And I'm in the industry!"

A number of changes would encourage patients to have greater confidence. One such change would be to provide them with better information about cost and quality throughout the system. Public trust is at an all time low, and without transparency, there can be no trust. "There is virtually no transparency in health care," said another health plan CEO. "People need to be able to determine very quickly whether they are getting good health care," said a San Antonio participant. "If they can't determine that, they won't be willing to pay for it." Currently, there is little reliable data available to patients about physicians, hospitals or health plans.

In many cases it is the health care industry that is resisting disclosure, said a Chicago participant. Whenever someone tries to put out data on providers, "whoever's ox is gored says the data's no good." But without information, patients cannot realistically be expected to make informed choices, and they cannot feel much confidence in their care.

Another critical issue related to confidence is the cultural competence of providers. People who are newly arrived in this country and have limited English proficiency face particular challenges in understanding the health care system, which often results in a lack of trust. A lot of immigrants run into problems accessing health care because they can't find a provider who is culturally sensitive to their needs. "My concern is the growing multicultural population and our inability to reach them," said a health care professional in Florida. "It costs much more to care for them because they do not understand the system and they face other challenges, like financial needs." Another participant in the same meeting said that, "immigrants have a different view of accessing health care." In essence, if they can't find someone they are comfortable with, they will use the ER when they need care.

Patients must be able to trust that their physician is acting in their best interest.

If patients are to have trust in the health care system, they must first have confidence in their own physician. They need to know that their physician is both competent and acting in the patient's best interest.

Health care leaders say patients should be encouraged to develop strong relationships with their physicians and other health care professionals, with minimal interference from outside pressures. "Expecting patients

to understand their choices without some trust in a practitioner is not realistic," said the president of a state medical society. The physician needs to know a patient over time to really make a good assessment, so continuity of care is essential."

At the same time, there is recognition that physicians have a responsibility to use evidence-based medicine when treating patients. "To simply say 'trust your doctor' is absurd," said a Chicago participant. There have to be practice standards, and the standards have to be followed. Some participants say there should be consequences for physicians that do not adhere to evidence-based guidelines.

The integrity of the patient-physician relationship also requires that physicians play a key role as health care educators. "The central role of the doctor is to teach," said a Chicago participant. "To fail to take advantage of that is really to miss the central point." But the current financial model does not reimburse doctors for talking with their patients.

Given the enormous benefits of making sure patients are informed, there should be incentives for physicians to educate. They must also be allowed enough time in their schedule to communicate fully with patients and discuss issues such as compliance with prescription medication, treatment options, and preventive care.

Health care professionals should feel confident their work is valued and supported.

Trust is a two-way street and the health care professionals that serve patients should also be able to feel confidence in the health care system. They need to feel their work is valued and appropriately compensated. But there is a tremendous crisis of confidence in the health care professions these days, participants said. In many places, morale in general is low and frustration high.

Physicians are reporting increased dissatisfaction with the constraints under which they must practice. Feeling squeezed between high malpractice insurance costs and low reimbursement, a growing number are choosing to retire early or switch to other careers. Physicians have been knocked off their pedestal, said a Portland participant. "Some of them needed it, but we're paying for it with morale issues."

There is concern that talented people are becoming less interested in pursuing health care careers. It was noted that 20% of surgical residencies went unfilled during the past year. Many communities are facing a shortage of physicians in certain specialties.

A large part of the problem for physicians is liability. In many states a growing number of physicians can no longer afford their malpractice insurance premiums. Liability costs have made it unaffordable for them to practice. "We're punishing the good guys for the sins of the bad guys," said a physician. "ER docs are in a horrible quandary."

In every community we visited, people said government must act on tort reform. "The professional liability system is strangling us," said a health care leader in Salt Lake City.

It's not only physicians that are experiencing workforce problems. Many communities are even more worried about the nursing shortage than they are about a shortage of physicians. There are just not enough nurses, said participants. Not enough people see nursing, with its heavy workload and other pressures, as an attractive field.

"Why aren't young people going into nursing and other health care jobs?" asked a Ft. Lauderdale participant. "We need to recognize that all of the players [in the health care deliver system] are important in their own right," responded a hospital CEO. "We ought to show our appreciation."

Spending money wisely

Health care leaders recognize that the issue of financing is at the heart of our nation's health care crisis. As one San Antonio participant observed, "Right now we're not talking about where we're going. We're just talking about who's going to pay." A policy expert in San Diego put it this way: "Our ability to do is growing much more rapidly than our ability to finance."

Some participants called for making a larger investment in health care, particularly once the baby boomer generation reaches the age of Medicare eligibility and begins driving up the demand for health care. "What better use of our money is there than health care?" asked a San Antonio participant.

But others maintain that the U.S. already spends more than enough money on health care, noting that the U.S. spends a far higher percentage of its Gross Domestic Product on health care than any other country in the world. The problem, they say, is that the dollars are poorly allocated. "For the vastly more expensive health care in the U.S., we can't demonstrate that we get better outcomes than other advanced, industrialized nations," said a Salt Lake City participant. "Before we spend more, we ought to spend more effectively."

A number of health care leaders pointed out that the nation's health care system is out of balance with regard to how resources are used. "We spend too much and too little," said a health care leader in Chicago. In Salt Lake City, we heard that, "we're spending what we want to spend. Do we want to decide to spend it differently?"

There is tremendous waste and over-utilization in some areas and for some people, but there are also a lot of people who are not getting the care they need because they cannot afford it. Eliminating waste and reducing over-utilization are certainly efforts that have the support of the health care community. A lot of money could be saved. But these leaders also point out that some areas of the health care system – such as public health, mental health and behavioral health – are dangerously under-funded and merit greater investment.

They also point to other areas of the health care system that deserve more funding. At the top of the list is addressing the issue of the 40 million or more Americans who are uninsured at any given time. There is broad consensus – but not unanimous agreement – that basic, affordable health care should be available and accessible to everyone in the United States. It makes sense not only from a moral standpoint, but also from an economic one.

It is well worth the money for the U.S. to make basic health care available to everyone.

When participants are asked to name the most critical issues facing health care today, the most common response, by far, is "access," meaning that we need to ensure that all people have access to timely and appropriate health care and to health care coverage.

Over and over again, in every community, health care leaders say this is a goal they strongly support. "A basic level of care should be available to everyone," said a San Antonio participant. "If we want to move forward on health care, then we must agree that all people deserve access," said a participant in San Diego. "I don't think single payer will work in our country, but we've got to get the coverage," added another in Mississippi.

Many of the leaders mentioned moral reasons for their position in favor of universal access. "The measure of a health care system is how it cares for the 'have-nots'," said the CEO of a community health center. "So the values there are equity and universality."

Some health care leaders caution that Americans who are insured may not be willing to make significant sacrifices so that others can get health care coverage. "Will the majority of the voting public support giving something up to get everyone covered?" asked a psychologist. But others countered that all Americans stand to gain from a system of universal coverage, though the general public may not realize it.

They say it would be money well spent to make sure that all U.S. residents have at least a basic level of health care insurance. It would allow those who are currently uninsured to access primary and preventive services so that illnesses are detected and treated early on and they could stop relying on expensive emergency room care. "Coverage means better care and it reduces the cost of care," said a state Medicaid director.

They think the argument can be made to voters that lack of coverage for some people threatens the quality of care for everyone. "More people realize now [than in the early 90s] that the uninsured represent a threat to all of us," said a primary care physician in a community health center.

Once there is agreement on the need for universal access to basic health care, the question becomes, what is "basic" health care? Even if all Americans had access to some form of health insurance coverage, there is likely to be a tiered system, although one healthcare leader in New Hampshire strongly objected to the concept. Tiered health care exists, he said. "But I don't think it should be an accepted assumption."

Others view it as a given. In fact, one prominent health care researcher pointed out that currently, "we've got a thousand-fold tiered system in this country [based on geography]." A Ft. Lauderdale participant said, "We have to recognize that not everyone can have everything, but we all need the basics." One in Mississippi said, "A lot of people won't like it, having a two-tier system. But I think it's all we can afford." However, another participant in that meeting added that "basic coverage cannot be two- tiered; physicians need to be required to provide the basic services."

The public health infrastructure, prevention and chronic disease management should be funding priorities.

Another important area of health care that deserves a greater investment is public health. In many communities, the public health infrastructure badly needs more resources. "There's been a terrible decline in public health capacity," said health care leader in Salt Lake City. "The public health system, which is intended to make the health care system more effective, is in serious jeopardy," said a San Antonio participant. "There are not enough dollars."

In several communities, participants said there needs to be much more effort put into education, prevention and early intervention, especially for those who are underserved, and that tends to be the function of the public health departments. Again, this would provide a great return on investment by addressing health problems on the front end – or even preventing them – rather than waiting until later when treatment becomes much more expensive. "We're patching up people that don't need to be sick in the first place," said a public health professional.

There is a need to put more resources into public health's ability to do consumer outreach. Medically underserved patients often lack basic information about preventing illness and injury. Someone has to be providing education on nutrition and exercise. "We need to incentivize outreach, prevention and early intervention," said an Albuquerque participant. "Rather than have consumers come to us, let's go to consumers."

In addition, looking at the demographics of our population, the prevalence of chronic illness and costs associated with its management will continue to grow. Investment in chronic disease management should be a greater priority in the health care system.

Mental and behavioral health should be a greater priority in overall health care.

There is broad agreement among community health care leaders that mental health and behavioral health are essential services that need to be integrated into the overall continuum of health care. But too often this aspect of health care is overlooked and under-valued in the health care system. "Mental health is paid at the level of a step-child," said a participant in San Antonio.

Integrating mental and behavioral health services with physical health care would have two advantages. One is that it recognizes that these two aspects of health care are, in fact, indivisible. There is increasing

understanding that mental health and physical health are interrelated. Treating one side of the equation while ignoring the other is inefficient and ineffective.

"The integration of psychological intervention with physical health care, rather than the separation of the two, can save costs and be more effective and more efficient," said a San Diego participant. "Right now we see a bright line between the two."

The second is that integrating mental and behavioral health into health care could have a significant impact on prevention and health promotion. There tend to be psychologically based reasons that people take up smoking or use drugs or let their diabetes spiral out of control. Therefore, mental and behavioral health services can play a key role in reducing these types of unhealthy behaviors that drive up health care costs.

Doing a better job of integrating mental and behavioral health services into health care would also have important benefits for society as a whole. "Over half of our jail population has severe mental illness," said a participant in San Antonio. Many of those who are in jail and have severe mental illness haven't received the mental health care they need – either before or during their incarceration.

Health care leaders said that it is particularly important to do a better job of making mental health care available to children, who often go undiagnosed and untreated for far too long. "If disorders were dealt with early on, a lot of problems could be prevented," said a San Antonio participant.

There need to be incentives that encourage the right care at the right time.

Health care leaders say they are frustrated by incentives in the health care system that often discourage them from providing the most appropriate and effective care. They say there needs to be a vision of health care that aligns incentives correctly so that the right care is delivered in the right place at the right time.

"Incentives get aligned very quickly behind whatever the vision is," said a Portland participant. "If we in this system can get clear on who we're here to serve, I think we can get quickly to aligned incentives."

Health care leaders say there should be a vision of health care that emphasizes the importance of prevention and education, and then backs it up with incentives to provide those services. "When you look at the determinants of health – lifestyle, heredity, behavior, medical services – we spend most of our money on medical services and only a sliver on the other factors," said a San Diego participant. "How do we move more money to address the lifestyle and behavioral issues?"

Preventive care – which everyone acknowledges is important – does not get much support from the incentives structure. "I would love to put in a system that incentives preventive care," said a health plan CEO. "But then I wouldn't have any specialists in my network and no one would buy the product!"

Excellence in care is not rewarded, say providers. "The current financing system has no recognition of excellence or even of adequate outcomes," said a consumer advocate Nor is efficiency rewarded. An Albuquerque health system executive agreed. "We are one of the most efficient states…and the federal government rewards us for that with less funding. Washington should reward us for doing a good job."

There should be more emphasis on coordinating care among providers.

Perhaps one of the first areas of emphasis ought to be creating a true system of care. A public sector official stated that, "We can no longer tolerate the randomness of the system. We have enough resources…. We just have to do a better job of allocating them – not from the top-down in a centralized way, but coming from communities."

There is general agreement that better coordination among providers would reduce inefficiencies in the health care delivery system, decrease costs, and improve the quality of care that patients receive. Health care leaders say there should be more effort and incentives for providers to integrate health care services. Gaps in the continuum of care affect all patients, but particularly those with chronic conditions who rely heavily on the health care system and often receive little help navigating among providers.

There are replicable models that have proven successful in helping patients to navigate the health system and receive coordinated care. For example, Dr. Harold Freeman has succeeded in implementing a patient navigator program in the urban setting of Harlem in New York City. (see case study on the Patient Navigator Program, p. 97) This program provides patients a well-connected individual to provide services such as answering questions, ensuring coordinated care, assistance with appointments, transportation, referrals, and helping patients to access health insurance.

Many large multi-specialty medical groups are working diligently to integrate data systems to enhance communication among multiple providers and streamline care management, especially for patients with multiple chronic illnesses. One example of innovative thinking and action by such medical groups has been the development of Anceta®, the first national repository of de-identified administrative and clinical data from non-affiliated medical group practices. Anceta® is a subsidiary of the American Medical Group Association and is a comprehensive, longitudinal data warehouse that will provide practitioners opportunity to compare their practices and assist patients in understanding their health status or disease state in the context of other patients (de-identified) with similar demographics and diagnoses. (see the case study on Anceta® p. 134)

Similarly, the VA has taken a lead in this arena. "Having worked at the V.A. as a social worker, I saw a multidisciplinary system of case management," said an Albuquerque participant. "I thought it worked very well for patients. As a patient myself, I don't find that coordination of care."

Translating talk into action

Health care leaders say that a public dialogue on all of these issues is important, but it is not enough. Discussion – even if it is broad-based and gets to core issues – will not produce meaningful change unless it leads to action.

These leaders confess to a certain amount of fatigue with health care discussions that have not led to any substantive change. The Clinton health care plan and its failure are still fresh in the minds of many. "A lot of us have been in these dialogues before," said an Albuquerque participant. "The question is how we can do it a different way."

Turning talk into action should be done very carefully, participants warned. "The Clinton plan was dead on arrival because the public never had a chance to understand what it was," said a health care leader in Ft. Lauderdale. Others said the Clinton health plan tried to do too much at once. A Mississippi participant voiced the opinion that "opposition [to the Clinton plan] was so well organized it was impossible to break through."

As with any effort to make changes, "it has a lot to do with who is driving the process," a consumer advocate pointed out. Articulate leadership that demonstrates candor and integrity will generate respect for the process and credibility for the outcome. "We need courage and leaders who have the guts to take on these issues with candor," said a physician.

This effort will also require broad-based support from the health care community and the public, said participants. "The health care community coming together is the way to sell [the vision]," said a Mississippi participant. But the public also has to be willing to buy it. "We have to figure out a way to make change more palatable to people," said a health care leader in Salt Lake City.

This will be an enormous task. All of the health care leaders who participated in these roundtable discussions recognize that fact. But they say the effort must be made. The alternative is to watch our "non-system" of health care continue to drift into deepening crises marked by unsustainable cost growth, growing numbers of uninsured Americans, workforce shortages, and diminished access to services.

Community health care leaders don't want to let that happen. This is their call to action.

COMMUNITY ADVISORY BOARD REPORTS

INTRODUCTION

As mentioned in the Executive Summary, midway through Phase I of this project WRGH developed a circle of advisers – thought leaders chosen from diverse health care sectors and communities – to help formulate recommendations and potential "next steps" for addressing common issues that arose in the community roundtable discussions.

As a result, we created "advisory boards" around 6 major health care topics: cultural change, access, information infrastructure, incentives, quality, and the role of public health. The reports produced by these advisory boards are included in this section, beginning with the short paper below on cultural change, which we've entitled "Addressing Our Expectations of Health Care."

We begin with this report from the "cultural change" advisory board because it is recognized among our sponsors and participants as the umbrella for all of the other advisory board topics. Cultural change was the constant theme running through all of the advisory board discussions and through all of the community roundtable discussions.

Our notion of cultural change in health care is that in order to address topics such as "access" or "quality", there must be an effort to understand the cultural aspects, at both the organizational and individual level, that affect these issues. Cultural change is critical if comprehensive health system change is to occur. Our findings and recommendations on this subject are detailed below.

Addressing Our Expectations of Health Care

There is broad agreement across the spectrum of health care stakeholders, including among consumers, that constructive health system change will require us to talk, as a society, about the "culture of entitlement" that pervades health care. This concern about "culture" has no connection to the usual understanding of culture in terms of ethnic heritage or tradition. What we are talking about is the behavior of individual consumers, physicians, and health care organizations, and their expectations with regards to health care.

Many community leaders share the opinion that changing the culture – i.e., the behavior and expectations – of those who participate in the health care system is one of the most critical tasks that communities can tackle. They say that communities are well-positioned to facilitate and guide transformation of the health care culture from one of entitlement to one of collective responsibility, compassion for others, and conservation of shared health care resources.

We need to be more honest about what the system can and cannot do. Part of the problem is that expectations are fueled by a disconnect between the incredible abilities we have, thanks to medical advances, and our consideration for the cost that goes with these abilities.

It's too narrow to try to change the way the system works by changing individuals one by one. We need to focus on behavior and expectations from the organizational and community perspective.

Clearly, our health care "culture" supports certain elements of our health care system that are self-defeating, inefficient, and ineffective. Once we begin to address these elements, we will be in a better position to work through them collectively.

An important starting point might be to identify the individual elements of our health care "culture" that need to be changed in order to "get from here to there." This task can be facilitated through community dialogue, a media campaign, and education. We need to "seek first to understand" by listening more to each other's ideas and concerns.

The new paradigm needs to focus on empowerment, not blame. We need to support and encourage efforts to take responsibility, while also recognizing that some among us need additional support because, for whatever reason – economic, linguistic, etc. – they cannot assume more responsibility themselves. This requires shifting from a culture of unrealistic expectations to one of taking responsibility for ourselves and recognizing the need to provide care for others. As a society, we must view health care as a precious, finite, shared resource.

We also need to recognize that "the system", including medical training, health system advertising, and financing, has distorted and reinforced certain expectations and behavior among both patients and providers. We need to foster a culture of collaboration among professions.

Already, the system is changing. Consumers are changing, along with their demands and expectations. The opportunity we have is to make sure that this natural evolution reflects our more stable social values. Collectively, we have an opportunity to shape our future and create a more satisfying system through shared responsibility for a mutually defined vision of health and health care.

Below, we describe "next steps" for cultural change. All of the components that we describe here can and will be applied to the Phase II work products that are envisioned for the other 5 advisory boards' recommendations in this section.

Next Steps For Communities

Highly Recommended:
- Formalize a Community Healthcare Leadership Board to serve as a catalyst and define a governance process to support, oversee and/or promote the process of change locally.
- Expand the process begun through a series of community forums/dialogues coordinated by each community leader with his/her constituents and local citizens designed to elicit meaningful consideration of the public's views on healthcare values and tradeoffs. This engagement should result in identification of common achievable goals and tangible actions for public and private sectors that should lead to better health system outcomes.
- Identify cultural advisers/cultural navigators in each community to help engage diverse community groups in the discussions of healthcare values.

Next steps supported by media/PR elements of Phase II:
- Develop brief issue white papers and talking points highlighting the challenges we face and the way a community can meet them, to be used in local speeches to civic groups/social organizations.
- Raise the level of sophistication local journalists employ when writing about healthcare, through a series of educational briefings by a diverse group of community healthcare leaders.
- Launch a local outreach effort employing media in the constructive education of citizens in healthcare matters and concerns.

Other considerations:
- Conduct leadership interviews, video/audio taped for distribution in schools, businesses and public policy circles designed to engage the public in community health efforts.
- Conduct "on the street" interviews with citizens, capturing their views on contemporary health and healthcare issues and develop educational tools to encourage the community to get involved in its' collective health.
- Develop and conduct seminars on the importance of self-development and what constitutes personal responsibility and accountability.
- Popularize healthcare through contemporary art and humanities works. Organize contests for healthcare education through poems, letters, plays, short stories, videos, and songs. The themes could reflect the importance of a community approach.
- Augment the oversight of healthcare institutions in such a way as to restore community connectedness by establishing a board of directors adjunct comprised of local citizens, lay and professional, public and private.

Potential multi-community collaborative projects:
- Public safety and public health are useful models to study. Review examples where leaders and institutions communicated with and motivated a change in collective behavior and the culture of the community.
- Consider the de-normalization of tobacco use and the process for successful cessation once addicted, as a general approach to culture change.
- Develop an elementary school-based curriculum designed to educate children about their health and healthcare and motivate them to adopt good health practices.

ACCESS TO HEALTH & HEALTH CARE

Americans want to feel confident that they will have access to the health care they need, when they need it. We know that all of us will fall ill at some point in our lives, and a growing number will live with chronic diseases for many years. For all of us, our quality of life depends on our ability to access high-quality health care.

Given the importance of health in our lives, Americans generally agree that everyone should have access to appropriate and effective health care services. In the health care community, there is a broad consensus that all Americans should have access to "rational health care" – health care that is high quality, efficient, evidence-based, and non-wasteful. It is an unfortunate reality in this country that each person's level of access to health care depends in large part on his or her ability to pay for services. However, there is general agreement that our society has an obligation to ensure that everyone has access to at least a basic level of quality health care.

This view is based on certain underlying, reciprocal values. First, society has a moral obligation to ensure that all Americans have access to health care services. Second, there is a moral imperative for individuals to act responsibly in how they use health care services and to ensure, as much as possible, that the services they use are paid for in some way. For example, individuals should purchase health insurance if they can afford it, or enroll in public or private sector programs for which they are eligible.

Discussions about health care access often boil down to the problem of financing. Although most people recognize there are moral grounds for ensuring everyone has access to health care, there is uncertainty about whether our country can afford it. But in recent years health care institutions and others have increasingly pointed out the heavy financial cost, to our society and economy as well as individuals, of not ensuring access for everyone to comprehensive and rational health care.

Currently, many people in our society do not have access to rational health care. Millions of Americans lack health insurance coverage, which compromises their ability to access appropriate services – particularly in the areas of primary and preventive health care. Having a system where uninsured people resort to using hospital emergency departments to access non-urgent care is not a solution. Health care leaders have been trying for years to draw attention to the peril associated with using hospital ERs as an all-encompassing health care safety net. We need new strategies to address access issues.

Access problems are not limited to those who lack health insurance. Appropriate access to health care requires more than insurance coverage. It requires adequate numbers and distribution of all necessary primary care and specialty services. It requires a community-based health care infrastructure that delivers, coordinates, and integrates services as needed. And it requires a sustainable means of financing that supports the integration of a continuum of health care services.

Attention should also be paid to the fact that not everyone in the United States comes to health care from the same set of circumstances. Access has logistical, cultural, social and moral components. It requires that "culturally and linguistically competent" providers be conveniently available and willing to meet the needs of different populations. As our country becomes ever more diverse, the issue of access to health care involves an increasingly diverse set of challenges. Ensuring access means that health care providers must do more to reach out to people where they live and work and to address the circumstances they present.

We used to think of health care mainly as acute care or trauma care. But now there is greater recognition of the role of primary and preventive care in optimizing a person's quality of life. As a result, chronic illness can be diagnosed and treated at an earlier stage, and chronically ill people can now live for decades if they manage their illnesses correctly with access to appropriate and timely health care services, providers, and support. Many people can avoid dying of cancer or heart disease if they are screened, diagnosed and treated early. People with mental illness can live a productive and satisfying life if they receive early intervention and consistent treatment. Health care now encompasses a much broader spectrum of possibilities than it did years ago. Therefore, access to health care must be viewed in a more comprehensive and systematic way as well.

There is broad agreement that Americans should have access to health care that includes not only acute care and trauma care, but also primary and preventive care, chronic disease management, oral health services and behavioral and mental health care. All of these aspects of care are crucial to optimizing the health and functioning of an individual in society. It would benefit all of us if they were integrated into a rational continuum of care to which every American is assured access.

There is particular concern among the communities we visited about barriers to mental and behavioral health care services. Too often there are disincentives that prevent both insured and uninsured patients from seeking care. There is also not the degree of outreach that is necessary to ensure that everyone receives the mental and behavioral health care they need. This is especially true for children, who often remain undiagnosed and untreated. Ensuring access to health care must mean ensuring access to care that fully integrates mental and behavioral health with physical health.

Another area of growing concern is access to long-term care services. Given the nation's aging population and the increasing numbers of Americans living with multiple chronic illnesses, there is a need to address the problem of access to long-term care and how these services will be financed. Otherwise, patients will continue to bounce around among fragmented health care settings without the coordinated care that meets their needs.

Although there is broad agreement that all Americans deserve access to rational, high-quality health care, this does not mean "one size fits all." Our health care system's pluralism is one of its great strengths; it appropriately reflects our diversity of cultures, generates innovation, and avoids the rigidities and stagnation evident in non-pluralistic systems. National uniformity in health care delivery systems is unachievable, and probably undesirable, in our pluralistic society.

Fortunately, there are many communities around the country that are seeking to improve their residents' access to health care in ways that make sense for their community. All communities want their residents to have access to comprehensive, high-quality health care, but there is tremendous variation from one community to the next in the particular needs of their residents and the kind of resources that are available. Embracing community-based solutions and encouraging local innovation has more potential to realistically and effectively address the problem of access to health care than any top-down, uniform approach.

Stimulating Community-Based Action

Around the country, communities are exploring innovative ways to make rational health care available to all residents in a health-promoting as well as cost-effective manner. In many of these communities, local healthcare organizations – from public health agencies to hospitals to community health clinics – are providing important leadership in efforts to improve access.

In San Diego, CA, more than two dozen local health-related organizations came together in 1995 to form Community Health Improvement Partners (CHIP), a groundbreaking collaborative that assesses local health needs and supports community efforts to expand access to medically underserved populations. The collaborative has become a model of what public-private cooperation can achieve, even in a highly competitive health care environment such as San Diego County, whose diverse population includes a high percentage of uninsured residents. [See case study on Community Health Improvement partners, p. 130]

In Pittsburgh, PA, a dozen health care and social service agencies came together in 1998 to form the Coordinated Care Network, an umbrella organization that coordinates care for the city's poorest and sickest patients to make sure they have access to the health care services they need. These patients, many of them covered by Medicaid, had been falling thorough the cracks in the safety net and were ending up in hospital emergency rooms, often when it was too late to really help them. Coordinated Care Network has developed an effective outreach and case management program that targets these patients. [See case study on Coordinated Care Network, p. 130]

These "locally grown" initiatives demonstrate that communities can come together and address the problem of access to care in ways that are effective because they reflect the particular needs of their community and take advantage of the specific resources of their community. Yes, access to health care is a national problem. But as these communities have shown, innovative and effective solutions can often emerge at the local, state or regional level. There appears to be tremendous creativity and dedication to problem solving at the community level, particularly when there is leadership from community health care organizations.

Community decision-making is a strength that can be applied to this problem of ensuring access to health care. A good starting point is a community self-assessment that brings together local leaders in health care and other fields to take an inventory of the community's health care needs and resources.

Such a community inventory is a tool for identifying gaps in access to health care. It should focus on how health care services look from the perspective of those who use the services, not those who provide them. In particular, the inventory should ask how people who are low-income and uninsured, and those who face challenges based on language, literacy, culture or geography, view their ability to access health care in their community. It would also be important to include an

evaluation of health care funding streams. Key questions would include: How fragile or secure are each of the funding streams? Is each source of funding appropriate to the objective it is funding? Does funding appropriately reflect priorities?

Once the inventory is complete, the community could come together to discuss how to build on its strengths and to address the gaps and deficiencies in its health care delivery and financing. The inventory would probably suggest the need to reevaluate some roles and examine appropriate accountability, but not to overhaul the entire system. Community leaders could identify areas where inadequate funding leads to gaps in access and request additional targeted funding on that basis. They could also decide to seek more flexibility in funding from all available sources in order to tailor solutions to local needs. It would be up to each community to decide its own path.

An inventory of access points and services could also serve as a starting point for reevaluating service delivery, with an eye toward organizing for more efficient and effective care – from the perspective of patients.

This community self-assessment and decision-making could be a catalyst for change and inspire community leaders to work in partnership to find ways of improving on the status quo. Local planning helps identify disconnects, focuses attention on the problem, and provides a process that can influence the overall direction of public policy. National policymakers should support these kinds of community-based solutions that are intended to meet locally identified needs.

Health Care Financing That Supports Access

As the Institute of Medicine (IoM) and others have pointed out, "we all share a destiny" with regard to health care. The fact that there are millions of Americans who are uninsured does not mean lower health care costs for those who are "appropriately" insured. To the contrary, it means the cost of care for the uninsured is shifted to providers, private payers, and taxpayers. It also means there is a value loss to our society and our economy. People who are uninsured are more likely to have less-than-optimal health status, which negatively affects their quality of life and productivity, and causes them to seek care at a more advanced stage of illness and in high-cost settings such as hospital emergency departments.

We need to work constructively toward consensus on how care is to be financed. Today we do not have agreement on the relative appropriate contributions to health care from federal, state and local governments, employers and individuals. This disagreement may be related to the limited capacity of the different financing components and the varying abilities of each to control health care costs.

We must recognize explicitly that current funding is principally derived from employers and government health insurance programs. To the extent that these health care financing systems are serving various populations and are sustainable, we need to capitalize on and expand what is working, while addressing clear deficiencies.

A real barrier to access is the multiplicity of funding sources with little motivation to integrate to create efficiencies. Financing is fragmented and often leads to a "silo mentality." As a result, one funding source may cut costs in a particular area that it pays for even if it leads to higher overall costs and poorer outcomes. Fragmentation creates the potential for competition for resources, contradictory incentives for improvement, and duplication of efforts. Furthermore, we need to acknowledge the "hydraulics" of the health care system – in other words, the ability of each of the funding streams to exert pressure on the others.

It is often said that a fundamental problem in health care is that access "follows the dollars" rather than being derived from the underlying needs of the population. Health care stakeholders need to work constructively toward a consensus on how health care can be financed to truly support access. This effort will require public/private collaboration and community leadership. It will also require a global view of the costs and benefits of investments in our population's health. Failure to take this global view means that important connections and consequences will be missed as policies are debated.

Re-framing health care service delivery to address gaps in access

Regardless of financing mechanisms, the delivery of health care services takes place at the local level, between an individual patient and his or her health care practitioner. There is widespread agreement among the communities we visited that certain changes in health care delivery could directly improve access to health care. These recommendations address not only the way that care is organized, but also the way that cultural and social factors in health care delivery affect access.

First, a primary "health care home" would help ensure that all individuals can access care in an appropriate setting. A "health care home" could be, for example, a primary care practitioner who sees a patient on a consistent basis, knows the patient's medical background, and has a relationship of trust and open communication with the patient. This primary care provider would help ensure access to other primary care, such as oral and behavioral health, and specialty services as needed. If everyone were to have this type of "health care home," they would be much more likely to access timely, appropriate, and cost-effective care.

Second, access to culturally and linguistically competent providers would increase the likelihood that patients of diverse backgrounds are able to access care in a timely manner and in an appropriate setting. Third, coordination of services, especially for patients with multiple chronic illnesses and other vulnerabilities, would ensure that care is well managed, seamless, and covers the range of needed services.

Fourth, a focus on aggressive and effective outreach to underserved populations would enhance the appropriate use of access points. Patient navigator programs have been effective in this regard. [See case study on the Patient Navigator Program, p. 97] And last, there should be an appreciation that the medical encounter is heavily influenced by local practices and acceptable cultural, linguistic and social norms, which are often unique to a community or to a community within a community.

The problem of access is also linked to the issue of quality in health care. Many believe that improving quality and reducing waste in health care delivery will free up substantial resources that could be used to provide health care coverage for all Americans. According to studies by the IoM, the Juran Institute, and the Center for Evaluative Clinical Sciences at Dartmouth, there is significant waste in health care that is caused by a variety of factors: overuse, under-use or misuse of health care services, fraud, greed, defensive medicine, lack of continuity and administrative inefficiencies.

Re-evaluating health care delivery from a systems perspective is likely to yield positive results for both quality and access. Process improvement should become a priority for health care delivery by focusing on the "six sigma" standard used successfully in other sectors of our economy. The issue is discussed further in the Quality Advisory Board report. At the same time that we work to improve healthcare quality we must take steps now to ensure that all individuals have broad access to a continuum of health case services that promote the health of individuals and communities.

Creating a Broader Definition of "Access"

When discussing the importance of access to health care, we want to remember that the goal – first and foremost – is to optimize the health of individuals and our society. We want to act collectively, as a community, to create a "health-achieving environment" that optimizes each person's ability to maintain and restore his or her personal health.

There are several dimensions to creating this health-achieving environment. One dimension is ensuring access to a comprehensive range of health care services, as has been discussed above. But other dimensions involve public health and personal health. Creating "health" requires looking at the health of the community from a population-based health perspective. It also requires empowering individuals with the knowledge and tools to optimize their own health. As pointed out in the Healthy People 2010 Initiative, "health literacy" plays a key role in empowering people to self-manage their personal and family health. This "action" term communicates the importance of understanding preventive measures as preconditions for improved health.

There is a need for proactive outreach at the community level to ensure access to services and educate people about their health. Health should be "pushed out" to the public. This is an important role for public health departments and community health workers, also known as "lay educators". This is also something that needs much greater emphasis in public schools. Comprehensive health education should be considered part of the "access" equation. Children need to learn about what they can do to maintain their own health and access health care.

It is imperative that people understand the importance of doing all they can to maintain their own health and that society support this understanding with a shared ethos that values health. Our society has a moral obligation to ensure access to health care. At the same time, all of us as individuals have an obligation to do what we can to use health care responsibly and judiciously. Health care is a precious resource and it comes at a price. It is up to each of us to be aware of that when we make choices that impact our health.

A Role for Public/Private Sector Partnerships

Public/private collaboration may hold the key to addressing the problem of health care access. Both the public and private sectors play important and beneficial roles in the U.S. health care system. Therefore, addressing the problems that affect access to health care should be based on constructive collaboration between the two sides.

As the largest purchaser of health care services, the public sector plays a central role in health care financing and a substantial but more limited role in health care delivery. Government also acts as the guarantor of coverage for seniors and low-income families and individuals through Medicare, Medicaid, and the State Children's Health Insurance Program.

In these capacities, federal and state governments can use their collective weight to move the health care system in a direction that expands access to more Americans. Government can start by partnering with private-sector stakeholders to bring clarity to some important questions. How do we define "vulnerable populations" that need special support to access health care? How much support should be provided and in what form? Currently, there is no clear, unified direction on these issues.

Government can collaborate with private health care organizations to create a national vision to guide local communities in their efforts to expand access to health care. Government can also be an agent of change and a facilitator of collaboration between the public and private sectors at the local level. Assuming these roles is not without challenges, especially in light of government's sometimes conflicting roles as facilitator, purchaser and regulator. Nor does this "change agent" role for government reduce or eliminate the responsibilities of other participants in the health care system to foster improved access and quality. Many health system participants have sizable resources, clear responsibilities, and opportunities to implement real changes that can improve patient care and foster broader, systemic changes.

Next Steps for Communities

Highly recommended:
- Conduct a self-assessment of your community's health care needs and its strengths.
- Gather a diverse group of community and health care leaders – people at the local, regional and state levels who are involved in health care decision-making, including consumer and patient advocates.
- Begin with an assessment of needs. Take an inventory of the services that are currently provided. What are the gaps in access and services? How does health care look from the perspective of patients who are uninsured or face barriers that are linguistic, cultural or geographic?
- Evaluate the funding streams for services. Identify the sources of funding and assess their fragility and potential flexibility. Is the source of funding appropriately matched to the objectives? Are core services "under-prioritized" and subject to volatile funding?
- Reach a joint agreement on how the community will address the gaps in access and other issues identified during the self-assessment. Discuss opportunities to use resources more effectively to ensure broad access to a continuum of services that promote the health of individuals and communities.
- Educate the community about how to access health care and make healthy choices.
- Communities that have already had success in addressing access problems could develop and share a template that provides a roadmap for other communities.
- Assess the level of cultural and linguistic competence of providers in the community, examining the elements of awareness, sensitivity, equity and competence. Identify cultural and linguistic advisers/navigators in each community to help address gaps.

Other possibilities:
- Generate community support for health policy/governmental action:
  - Integrate funding streams from public and private sources in ways that improve access to the full continuum of health care services.
  - Encourage local and state governments to be part of the community assessment process and to promote best practices.
  - Regionalize health care assets, where possible, so that they don't just stop at state borders.

HEALTH CARE QUALITY AND SAFETY

The United States needs a national effort to make dramatic improvements in the quality and safety of health care. According to the Institute of Medicine, a quality movement would cut medical errors and improve health care outcomes. It would also reduce the wide variation in medical practice from place to place. Instead of geography setting the destiny of health care, an indictment leveled by health care researcher Jack Wennberg, high quality should guide health care across the nation.

Industrial quality experts recognize that most effective quality interventions occur as far "up-stream" as possible. Process improvement should become a priority for healthcare education and delivery, for example, through a focus on the "six sigma" standard used successfully in other sectors of our economy. Optimizing safety and quality of health care requires a broad systems approach that addresses basic issues such as how people learn to take care of themselves and how doctors are trained. However, this paper limits itself to considering discrete approaches and interventions that communities can adopt today.

Led by health professionals, employers, health plans, and national experts, a fledging health care quality movement can be a guide for communities. It moves beyond medical licensure and litigation as the primary way to protect patients. Instead, it envisions quality as giving patients the outcome and experience they want while sticking to professional standards for health care. It prompts questions like: do surgical centers meet minimal volumes of surgery which produce consistently good outcomes, and do physicians enable their patients with diabetes to control their blood-sugar levels?

The role for communities in the quality movement is broad. Indeed, community-level action may be one of the few ways to make large scale changes. Communities can enable patients to make better, more informed health care choices, establish quality standards that apply to all health professionals regardless of patients' choices, facilitate collaboration among health professionals, protect vulnerable populations who often receive lower quality care, reduce disparities across racial and socioeconomic lines, and make it easier for individuals to take control of their own health.

Communities can also help individuals set appropriate expectations about the care they deserve and define new responsibilities for how people care for themselves. People no longer need to be passive patients. Patients will seek higher quality care if they feel engaged in the process. To do so, they must have information relevant to their situation, so they can ask the right questions before choosing a health professional or course of treatment. Communities can encourage both physicians and patients to seek out and use decision-support tools that use evidence-based guidelines for care. Such tools tell doctors and patients if there's scientific evidence to justify a given decision. Without such guidelines, the thousands of medical research articles published every year make it impossible for doctors and patients to keep up with the latest health care research.

Engaging patients in their own care will also accelerate a change in patient expectations that doctors are somehow god-like, beyond reproach, and incapable of making mistakes. Instead of expecting perfection, patients should expect that doctors will aim to recognize, recover, and reduce errors.

Another important benefit to improving quality is cost restraint. That's because medical mistakes are costly and prevention often saves money and lives down the road. Some health care researchers believe that a true high quality health care system would cost 20 to 30 percent less than what we are spending today. Over time, however, higher quality care that produces better health and better value will still cost more. If people see more value in health care than in other areas of consumption, then they should be free to spend more.

An agenda for community action to improve health care quality should focus on three goals: 1) identify how health care safety and quality affects the community and individuals; 2) assess local activities on quality improvement; and 3) start with one quality improvement effort.

Health Care Quality in a Community

Health care quality is important to us as members of a community. Quality health care makes a community a better place to live. It helps to limit the financial and human toll from wasteful or harmful health care practices. To constructively discuss quality issues, community leaders need a common understanding. The Institute of Medicine (IoM) offers this definition:

"[Quality is] the degree to which health care services for individuals and populations increase the likelihood of desired outcomes and are consistent with current professional knowledge...Desirable personal outcomes include improvement (and prevention of deterioration) of health status and health-related quality of life, and management of physical and psychological symptoms. Desirable outcomes also include attention to interpersonal aspects of care, such as patients' concerns and expectations, their sense of dignity, their participation in decision making, and in some cases reduced burden on family and caregivers and spiritual well-being." (from IoM report Crossing the Quality Chasm).

Some aspects of quality are universal and objective, and some are local and personal. For example, there is a standard of care for people with diabetes (e.g., annual feet and eye exams) set by expert panels assembled by the National Institutes of Health. These panels examined the best available research and heard from top clinical experts. Individual preferences and local factors will (and should) determine how such care is delivered, for instance, in a large, group practice or in a loosely affiliated group of physicians practicing independently.

One of the challenges in using the IoM definition is discovering the outcome and experience that patients desire. It is a chicken and egg kind of problem. Patients can't speak as a group to tell doctors what they desire and doctors cannot decide how to measure improvement without knowing what patients desire. Of course, there are some reasonable assumptions that doctors can make. For example, patients do not like to wait for an appointment. But communities can catalyze this process by organizing a dialogue between patients, doctors and other providers about prioritizing a quality agenda.

Fortunately, communities do not have to start from scratch to develop a quality agenda. Many performance-based quality standards have been developed but have not been widely adopted. Most people are not aware of their existence. As communities sort through how to apply nationally developed standards for their local area, they should examine standards developed by groups like the National Quality Forum, Consumer-Purchaser Disclosure Project, NCQA's HEDIS measures; JCAHO's ORYX standards; and the Leapfrog Group. Ideally, communities would have a guide to existing quality standards that can weed out bad health care. Such a compendium would facilitate discussions about how various quality standards work, to whom they apply, the benefits and costs of implementing them, and assessments of their success in driving improvement.

Assessing Local Activities on Quality Improvement

Once the importance of quality improvement is understood as a community issue and before a strategy for improvement can take shape, it is important to know what is already happening in a community. For example, many local organizations have established quality improvement partnerships with other sectors that are not widely known.

Other possible sources for local quality improvement efforts include: quality improvement organizations that have evolved from state-based peer review organizations established under Medicare. Public health agencies may have programs for improvement related to specific diseases. Health plans in states like California are cooperating on quality improvement data and incentives. Medical societies and other professional organizations may have taken on specific problems like medical errors.

A local assessment should include a review of existing data. Community level data should be used as much as possible. Physicians and community leaders may not readily accept the reality of heath care quality problems unless they can see it in local data. The data review should cover both overall quality indicators and quality variation in vulnerable populations.

Finally, a local assessment needs to consider capacity and resources to launch and sustain quality improvement efforts. A champion and a realistic potential for improvement are critical for a successful effort.

Adopting a Quality Strategy

While no community can address all local quality problems, each community can address something. One general approach might be to organize a web-based template that communities could use to develop and implement an improvement strategy. The template would help a community create its own web site focused on its priorities and concerns. The template would include directions to resources. It would be easy to access, easy to use. It would need to be kept current and updated with new information on community health status and other performance indicators. This would enable the community to track its progress. A community could start by picking a single area for quality improvement where the evidence is clear and then aim for 100 percent success.

Some communities are adopting a local quality improvement strategy focused on reducing the burden of a specific disease. Diabetes, stroke, acute myocardial infarction and cancer prevention, screening, and treatment, where guidelines exist, are potential candidates. For example, one goal would be to give aspirin to most heart attack victims. Despite undisputed research on the benefits, physicians 30 percent of the time omit this treatment. Adopting some manageable area of concern could make a significant difference, and also demonstrate that similar efforts are viable for other areas. [See case studies on MBGH's Diabetes Collaborative, p. 109 and Taking on Diabetes with Community Guidelines for Clinical Care, p. 120]

For some health care leaders, the problem of simple tasks left undone argues for an aviation safety approach to quality. Checklists similar to what pilots use could be developed for doctors and nurses to ensure the completion of basic tasks. Others, however, believe that while such checklists may be helpful in some areas, they would not account for some essential ingredients needed to successfully care for individual patients. Because of the unique complexity and changing quality of disease patterns and personal preferences, the actual care undertaken is often individualized.

Communities may also choose to focus on a community-wide, integrated approach that combines disclosure of provider performance with incentives from insurers and employers to reward improvement, known as pay for performance. This approach is mentioned in the "Incentives" Advisory Board report.

Another general strategy for a community quality collaborative is to tackle complex issues that are too big for any one segment of the health care system to handle independently. For example, a reliable system for preventing harmful interactions from prescription drugs requires doctors to agree on a common way to enter, transmit, and examine patients' drug records. It also necessitates significant investment in information technology. But which comes first, the standards or the investment? Few doctors would want to make the investment without the standards, and standards cannot become operational without the investments in systems that use the standards. A community agreement upfront can facilitate both the development and acceptance of standards as well as the investment in appropriate systems.

In a similar vein, local monitoring of progress on quality standards could do much to reinforce the importance of improvement efforts, but without computer software in physician's offices to track individual patients, it is virtually impossible to track a whole population. And without either the external pressure to improve performance or the opportunity for physicians to have the satisfaction of figuring out what is working in their community, why would doctors invest in computer software?

These barriers to quality improvement are cited in the "Infrastructure" Advisory Board report.

Just what to measure for quality improvement is the conundrum. Some argue that patients' health outcomes should be the focus in order to drive innovation in how the outcome is achieved. Others believe that the process of care should be measured and periodically updated when new evidence emerges from scientific studies. This is probably a false choice because most existing measures of quality include both process and outcome measures. Outcomes can be too far off to create accountability for quality, and processes can make it harder for providers to change how they do things when new evidence emerges. A careful balancing of the two types is necessary.

Another issue around quality measurement is the extent to which consumers use quality reports. To date, there's not much evidence they use them much. On the other hand, providers do react to quality reports, which have caused improvements even without much consumer involvement.

A final question about quality measurement is which health care entity should be assessed. Measurement of performance against peers is very effective in changing physician practice patterns and standards of performance are applicable to almost every other profession—many being highly regulated. However, many experts point out that health care is increasingly a team effort, and assessing individual physicians, rather than the group or practice, may be counterproductive to facilitating constructive collaboration.

The American Medical Group Association advocates that a balance of ideals can exist by assessing individual physician performance and quality in the context of their practice environ, such as the multi-specialty medical group practice. Results of AMGA's individual member surveys that measure provider satisfaction as well as patient satisfaction have served to stimulate practitioner behavior both for personal improvement but also for the professional enhancement of their group's collaborative capacities in quality care.

Quality is also integrally related to access. Attempting to master one's health is no easy task, and may be impossible - especially once one is injured or stricken by a disease. Family physicians are in no position to act as guides when their main unit of reimbursement is an office visit. Other modes of interaction can be more convenient, effective, and less costly: the telephone, e-mail, drop-in group medical appointments, web-based resources are all tested and cost-effective, satisfying alternatives to the one-on-one visit to the doctor's office. Nurses and physician assistants can often be effective in delivering such services. Finally, patients who see multiple physicians need someone to coordinate their care because no one is paid to do that as part of a typical reimbursement system. Several models of patient navigation have proven effective in this regard. Communities may want to retool the role of physicians in family practice or other specialties so they can coordinate care or encourage the use of health care guides or coaches. Case managers can also be very effective in reducing fragmentation in the system and feedback regarding their work from physicians, patients and families is generally very positive.

Communities also need to consider how issues like medical liability and confidentiality effect quality. In a culture of blame, few are willing to step forward and take responsibility for mistakes. And with systematic errors, it may be difficult, if not impossible, for one individual to do so by his or herself. Instead of disclosing, discussing, and fixing mistakes, the fear of lawsuits can drive problems underground. Communities could establish "health courts," which would employ physicians as impartial experts. Another approach might be to develop patient safety organizations for voluntary and confidential reporting of errors so that providers could police themselves. Federal legislation has been introduced to develop both health courts and patient safety organizations.

Finally, cultural and linguistic competence affects the quality of care at all levels. It can stop a patient from questioning a doctor's decision or even knowing how to deal with a doctor in the first place. Communities can turn such diversity into an advantage by committing to serve everyone equally and engage those who are left out. Patient navigators can help patients who face cultural or language barriers.

Quality improvement cannot occur in a vacuum. It requires cultural acceptance of the approach and the right incentives for stakeholders. For example, quality initiatives with physicians have traditionally focused on passive education or externally imposed "requirements." Collaborative inquiry into current practices and outcomes among physicians is far more likely to succeed. Colleagues talking to one another about what they do and the results that they get is much more effective than pressure from an outside force. Doctors need to become leaders of care instead of acting solely as authorities. [See Case Study of the Dartmouth Coop Project, p. 92]

Conclusion

The science of health care quality improvement is in its nascent stage. Indeed, much work remains for the US Department of Health and Human Services Agency for Healthcare Research and Quality and other research groups. Nonetheless, much of what is already known about quality improvement constitutes a substantial opportunity for action by communities, providers, and individuals.

Examples of quality collaboration and resources for action include:
* Welcoa provides "well-city" awards
* "Site Selection" rates communities by health measures
* *Men's Health* had a story on the healthiest communities for men
* *Expansion Management* published an article on making health care costs a site selection factor in its February, 2003 issue
* National resources that have links to local data include The Dartmouth Atlas published by the American Hospital Association and the National Association of Health Data Organizations
* The Department of Health and Human Services is planning a series of demonstration programs for quality improvement based on the recommendations of the Institute of Medicine. In addition, the Robert Wood Johnson Foundation's Rewarding Results project will be providing grants soon to communities to focus on quality areas.
* As a test of "public engagement" to reduce deaths from hearth attacks, the state of New Mexico distributed 500 defibrillators in grocery stores, airports, etc.
* The Northern New England Cardiovascular Disease Study Group, whose success was driven by self-directed exploration and reflection on the process of care, rather than formal physician education.
* Healthcare Collaborative Network – About 20 hospitals, private corporations and government agencies have joined a demonstration project under which they will exchange standardized clinical data in hopes of improving patient care. Initially, New York Presbyterian Hospital, Vanderbilt University Medical Center, Nashville, and Wishard Memorial Hospital, Indianapolis will exchange clinical data among themselves and with the CDC, the CMS, the FDA

- American Health Quality Association. PROs/Quality Improvement Organizations – Their efforts are largely limited to working through hospitals to reach doctors, but they offer a good source for basic and achievable quality initiatives.
  > http://www.ahqa.org/
  > National Quality Forum http://www.qualityforum.org/
  > Common Good http://cgood.org/for health courts/
  > American Medical Association consortium on quality [need link]
  > Federal legislation on health courts and patient safety organizations.
  > Institute for Safe Medication Practices

Next Steps for Communities

Highly Recommended:
- Develop an agenda for community action to improve health care quality focused on:
  - data collection or surveys to identify how health care safety and quality affects the community and individuals;
  - local activities on quality improvement (hospital, health plan, employer)
  - capacity and resources to launch and sustain quality improvement efforts
  - selection of one initial quality improvement effort (potential examples in text.)

- Create an 'intellectual exchange' for physicians to interact peer to peer, either within the community or between communities

Other Considerations:
- Create activities that encourage both physicians and patients to seek out and use decision-support tools that employ evidence-based guidelines for care.
- Collaborate with a local medical school to develop and provide training for medical students and residents in quality principles.

Community support for health policy/governmental action:
- Advocate for tying federal/state funding streams to public medical schools to the provision of specific curricula, e.g., quality training. Encouraging quality metrics to be integrated into professional education has precedent, e.g., in some engineering programs.

Potential multi-community collaborative projects:
- Consider reviewing national activity to create a shared base of knowledge for the community effort.
- Consider developing a guide to existing quality standards to facilitate discussions about how they work, to whom they apply, the benefits and costs of implementing them, and assessments of their success in driving improvement. Assess applicability for the community.
- Develop a template for communities to use the web to develop and implement an improvement strategy.

ALIGNING INCENTIVES IN HEALTH CARE

Incentives, both positive and negative, are the key driver in most areas of human endeavor. Health care is no exception. Most individuals recognize they have a personal incentive to try to stay healthy and avoid illness. But the absence of value-based behavioral and economic incentives distinguishes health care from nearly every other service industry. Aligning incentives to promote the rational and effective use of health care services is a major challenge.

Standing in the way is an entrenched, third party payer system that separates the consumer of services from the purchaser. In health care insurers pay most of the bills, not patients. As a result, consumers have little incentive to "shop around." Health care providers determine the level and intensity of services that consumers should receive. The results, predictably, are rapid cost growth, frustrated payers, and unengaged consumers.

Cost is not the only concern driving interest in the use of incentives in health care. Incentives can be an important tool for improving the quality of care when used appropriately and can also be used to encourage consumers to avoid unhealthy behaviors. Virtually every area of health care is affected by incentives. Therefore, if we want to change health care, we have to change the incentives.

The movement from a strictly fee-for-service system to one where managed care predominated represented a major effort to shift financial incentives. These two models for health care have very different incentives for providers. Under fee-for-service, payers simply reimburse the providers for services rendered. The more services provided, the more a provider gets paid. There is incentive to treat illness and injury but not to help consumers stay healthy and avoid illness.

The promise of managed care was to shift incentives to encourage providers to maintain patients' health and wellness. But because HMOs typically required only minimal cost sharing at the point of service, managed care achieved little success in connecting patients more directly with the impact of their choices.

It remains a major goal in health care to better align incentives for both consumers and providers, including physicians, hospitals, and insurers. We need to create a new "ethos" in health care that will encourage consumers to take responsibility for maintaining their health and the health system to be accountable for providing quality health care. The right incentives for all stakeholders—physicians, hospitals, insurers and consumers—are the key to achieving this goal.

Creating Incentives for Consumers: Financial Tools are Sometimes Appropriate

In some areas of health care, and for some consumers, financial incentives are an appropriate tool for affecting health care decision-making. For example, financial incentives are appropriate for encouraging a prudent choice of health plan. They can also be used effectively to encourage consumers to choose routine, low-intensity medical care, such as planned interventions, and treatment options that cost less but have been shown to be equally or more effective than higher-cost methods. In some cases, for example, a generic is as effective as a brand-name drug.

However, financial incentives must be carefully evaluated for their potential impact on the basic building blocks of workable insurance. Both healthy and sick individuals must be in the same risk pool in order to assure cross-subsidization. If financial incentives result in healthy individuals purchasing fundamentally different insurance coverage than sick individuals, a viable insurance pool will not be possible.

Similarly, incentives should be structured to encourage individuals to purchase health coverage before they face serious medical problems to avoid the problem of individuals refusing to participate in the insurance system while they are healthy, but purchasing insurance coverage when illness strikes.

In discussing the role of financial incentives in affecting consumer choices, it is important to note that not everyone can approach health care from a "consumer perspective." Those who are very ill, for example, should not be considered consumers, but patients. "Consumers" are those individuals on the healthier end of the spectrum who can and should be held accountable for choosing efficient health plans and health care services. Patients, on the other hand, cannot necessarily be expected to make good choices. They are reliant on their care providers and others they trust when it comes to decision-making. However, they should be offered the opportunity to participate in a process of shared decision-making, if appropriate. [See case study on Shared Decision-Making in Spinal Conditions, p. 91]

Many health plans and providers are creating new kinds of incentives designed to affect patient choices in a non-punitive manner. For example, in Las Vegas, patients are rewarded if they notify their health plan of their pregnancy in the first trimester. A health plan in California is rewarding patients who complete a Health Risk Assessment (HRA) and engage in activities that reduce their lifestyle-related health risks. These types of financial incentives encourage consumers to assume more responsibility for their health and their health care choices.

Key elements in using financial incentives to engage consumers will include understanding what quality healthcare is, alongside price transparency. Price drives most purchasing decisions in areas other than health care because consumers both know what things cost and are responsible for paying the cost. In health care, consumers have no idea what services cost or what constitutes quality health care. They generally pay little if any of the costs of specific services. At a minimum, price transparency with access to quality health care information would give consumers a way to compare providers on the basis of price. Government agencies, in concert with the private sector, should enable consumers to learn the true cost of services.

The movement toward consumerism may also help individuals become more sensitive to value in purchasing routine care. However, medical science is complicated, and outcomes are uncertain. Given the potential for serious consequences if "the wrong choice" is made, consumers will need a great deal of help to navigate the health care system effectively.

Another point to consider is that the real costs in health care are in hospitalizations and chronic disease, not in routine care. Therefore, health plans must identify and focus on individuals with risk factors for high-cost care and make sure there are incentives for them to participate in self-care and disease management programs.

Other Types of Incentives for Consumers: Creative Ideas Emerge

Creating incentives in health care is not about "blaming" or "punishing" individuals for their health status and behavior. Incentives should be focused on empowering people to make good choices for themselves, with the appropriate support and education.

Tangible, community-based support and encouragement can serve as powerful incentives to help people adopt healthier behavior. In Bladen County, N.C., a homegrown health care outreach and education organization has had a major impact on the health of county residents, particularly in the areas of diabetes and obesity.

Called "Bladen Healthwatch", the organization has created a number of initiatives, including the "Healthwatchers at School" program that started walking campaigns to encourage students to walk during the day near their home, school or church. Schools set up designated walking trails and gave incentives to both teachers and students to participate. [See case study on Bladen HealthWatch, p. 104]

In Philadelphia, the Keystone Mercy Health Plan established the "Health Ministry Program for Women," which provides low-income, African-American women with information about how to access preventive health care services and wellness programs. Workshops are offered in church settings, which provide a welcoming, supportive environment for women to learn about managing stress, controlling diabetes and detecting breast cancer. [See case study on A Health Ministry Program for Women, p. 98]

Information can be another powerful incentive for consumers. There is a lot that most people don't know about their own health. In a recent survey conducted by the American Cancer Society, only about 1% of those surveyed knew that obesity is a major factor contributing to an individual's risk of dying from cancer. Often, people just don't have the information that would motivate them to make changes. [See case study of Patient Navigator program on p. 97]

There needs to be positive, non-punitive incentives that encourage Americans to get educated about their health and to take action on the basis of what they learn. If education is available and accessible, consumers are more likely to use it to make healthy choices.

Creating More Appropriate Incentives for Providers: An Ongoing Challenge

The movement toward pay-for-performance and outcome-based payment mechanisms makes sense. There is an urgent need to restructure the payment system in ways that promote continuity and coordination of care and access to the entire continuum of care, including prevention and mental and behavioral health services.

But there continue to be many challenges associated with creating the right financial incentives for providers. Among them are the lack of strong evidence for many medical interventions, the unsophisticated state of performance-based pricing, the failure to identify and pay for quality systematically, and the inability to define rules and mechanisms that align all stakeholder interests financially. There is also cultural resistance by physicians to what is sometimes perceived to be "cook-book medicine." However, having physicians involved in the development of guidelines can go a long way toward facilitating acceptance.

Another challenge is the legacy of the Medicare/Medicaid amendments passed in 1965, which specified that physicians be paid "usual, customary, and reasonable" payments for services but did not provide for the setting and periodic reevaluation of levels of payment for newly developed procedures and treatments. This has led to very high levels of payment for newly developed procedures and services, while old ones are held at much lower levels. As a result, there are powerful financial incentives for providers to perform newer procedures, causing distortions in medical practice.

An additional complication is the need to distinguish between specific services, which generally fall into two categories. Scientifically proven interventions are one, relatively small, category. Even here, we must be cautious, as "proven" interventions may change over time as we learn more. In this situation, the incentive should be for physicians to provide the service. The goal should be to remove disincentives and reduce barriers for patients – for example, by waiving co-payments and ensuring convenient access when it comes to preventive care and immunizations.

In the other category are services for which a "gold standard of treatment" has not been determined and where conservative therapy may have as good an outcome as more aggressive or invasive interventions, which are generally more expensive. Here, incentives are needed to involve the patient in a shared decision-making process focused on ascertaining which treatment is most appropriate for that patient, given his or her preferences and values. An effective process of shared decision-making requires both incentives and decision support information related to costs and relative value.

But given the challenges inherent in creating the right financial incentives for providers, there are other types of incentives that need to be considered. For example, there is broad agreement among providers that reducing the "hassle factor" can be a strong incentive. Eliminating unnecessary paperwork could make a physician's day a lot easier and serve as a major motivator. Similarly, in cases where there are evidence-based, easy-to-use clinical guidelines for care, waiving the approval requirement could serve as a powerful incentive for physicians.

Sometimes merely instituting regular feedback and reporting on performance is enough of an incentive to cause physician "outliers" to change behavior. Some payers provide regular performance feedback to physicians regarding their accomplishment of evidence-based preventive services (primary, secondary and tertiary) in comparison with their peers, and they provide bonuses to those with consistently better performance. Physicians generally believe they practice good quality medicine. Showing them data that contradicts that belief can be a powerful motivator. But the feedback has to be provided in an easy-to-use fashion and on an ongoing basis.

Other examples of current initiatives to align incentives:

- Kaiser Permanente's Care Management Institute is encouraging its network physicians to practice evidence-based medicine by "making the right thing easy to do."
- Multiple entities, including payers, employers, government, patient advocacy associations, etc., have created online, telephonic, and print health decision support services to help consumers make better value and evidence-based purchasing decisions.
- Payers provide episode-of-care payment rates for bundled services, which may include primary care, specialist, laboratory, imaging, pharmacy and surgical services.
- Payers offer payment for e-visits, in which physicians confidentially collect information and dispense medical advice to their patients on-line. This could reduce office visits by 30% or more.
- Employers offer health plans that provide incentives for employees to bear more of the costs of discretionary health services while fully covering the costs of evidence-based preventive services.

Next steps for communities

Highly recommended:
    Request the appropriate government leaders to support incentives by taking certain steps, for example:
- Urge public sector payers to reward efficient providers who demonstrate good quality indicators with higher payments.

- Make it possible for payers to use the CMS database in "real time" to provide on-going feedback to providers in order to improve patient safety and assess guideline adherence.
- Create Medicaid and Medicare waivers to reward for quality. States and communities can and should serve as laboratories for incentives.
- Urge Medicare to allow providers in high-quality, multi-specialty groups to decide how to structure management around care of chronically ill patients to achieve more efficiency, then decide how reimbursement should be structured.
- Establish standards for information reporting and use public and private sector networks to encourage consumers to fully appreciate the costs of services and educate them about quality health care services.
- Request the federal government to consider devising a new system for setting and periodically resetting the payment level under Medicare and Medicaid for physician services, treatments and tests. The level would reflect the training, skill and time required to perform the service. A societal "desirability factor" could also be added, i.e. a higher value for services preventing illness or disability than one for improving cosmetic appearance.
- Communities could work with political leadership to encourage expansion of state-based demonstration projects on IT, case management, patient incentives, etc., and waivers to achieve them.

Communities could also:
- Advance models that would facilitate care coordination, improve outcomes and decrease costs by considering the creation of a patient-centered clinical database between hospitals in each community that would help multiple care professionals track and coordinate efficient and effective interventions. Providers would have appropriate and protected access.
- Work together to devise a national health risk assessment, followed by a national campaign to encourage everyone to adhere to the appropriate risk reduction strategies.. There are two aspects to such a strategy. First, the health risk assessment must be based on objective and authoritative evidence and be endorsed by a nationally recognized panel of experts. Next, the physician and consumer must routinely refer and keep track of completing and adhering to desirable health behaviors and actions. It would be critical that scores be kept confidential and that health status not become a barrier to insurance.
- Encourage organizations to consider recommending new ways to evaluate "technical" interventions, or new ways to apply old methods, e.g., cost-effectiveness analysis.
- Urge provider organizations to create incentives for physicians to be involved in best practices guideline development.

INFORMATION INFRASTRUCTURE

Information technology has transformed many industries. It has made everything from getting news to investing in the stock market more convenient, less expensive, and ultimately more democratic. In health care, however, it has not been used effectively despite the potential for even greater benefits. After all, health depends on how well individuals, health care professionals and administrators, and public health officials use information.

Information technology can be helpful in health care in many ways. It can help people learn how to deal with health problems as many already do on the Internet. It can help doctors make health care safer, higher quality, and more coordinated by providing timely access to patients' records. It can help doctors make better decisions based on the latest research as it applies to each patient. It can eliminate duplicative lab tests and X-rays that today are lost in thick files. It can reduce simple administrative hassles like verifying a patient's insurance coverage. It can help people make informed choices about their care, their doctor, and their health plan. It can give doctors feedback about the quality of their care and enable employers and insurers to reward higher quality providers. It can help address public health problems like tracking diseases and bioterrorist threats. It can improve research on what works best in health care and on how genetic and environmental factors influence health.

Information technology can make health care more convenient and effective by shifting the locus of care out of the doctor's office and hospital. Imagine how much easier it would be to communicate with your doctor by e-mail to get confidential routine test results and answers to basic questions. If you are trying to stay healthy, caring for a sick child, or dealing with a chronic condition, you are the primary caregiver and your home or office is where you can receive information to support care needs. The nation needs a health care information infrastructure that is as mobile as its citizens.

There are also critical low-tech components to information infrastructure, for example, lay educators and natural helpers. In many communities, individuals and volunteer organizations step forward to help others get what they need. Sometimes, they assume such a role after a personal struggle with a disease. In other cases, they are in a good position to know how to connect people to the right resources, e.g., a nurse, physician or patient navigator in a small town who knows how to get things done for patients beyond the normal call of duty. The Indian Health Service has, in fact, deliberately cultivated the use of community health representatives. Such people will be increasingly important to those who are not "wired." IT can help create a network to support helpers and deliver information to be used in a socially and culturally palatable format that recognizes the informal aspects of health care.

Vision for an Information Infrastructure:

An information infrastructure should be patient-based. It should encourage health care providers and facilities to use IT to keep and analyze patient records and to store them confidentially. It should permit the creation of networks that connect isolated databases in hospitals and elsewhere patient-by-patient. It should enable patients to use their own data to filter information about their health and health care.

An information infrastructure needs to protect patient's privacy and ensure confidential use of information. Patients will not trust an information infrastructure without having safeguards to protect their privacy. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) has safeguards that prevent individual doctors, hospitals, and other institutions from violating patient's privacy and it gives patients access to their own medical records. But it does not give patients control over the creation of networks that link together their medical records that exist in various places.

An information infrastructure should enable getting the right information to the right person at the right time in the right place. In health care many information needs are primarily business or administrative, e.g., processing claims and payments for medical services and gathering, analyzing and reporting of performance measurement data to ensure accountability. Other information needs are more clinical in nature, e.g., electronic medical records, integrated with point of care decision support to enhance decision-making and promote patient safety. There are also patient education needs to enhance consumer choice and self-management and facilitate shared decision-making. Finally, communities need to be able to track illness and monitor community health indices.

In order to meet all of these needs, the creation of an information infrastructure must begin with an accurate and ongoing evaluation of the needs of the end user and the purpose of the information. Building from the user's view is necessary to create a seamless informatics system that will make sense to the end user. Being easy to understand and use is critical for adoption.

Challenges:

Achieving this vision requires an integrated system that moves appropriate information to and from responsible parties in a paperless, electronic system. Yet, there are several key challenges to the creation of a robust information infrastructure that must be addressed: trust, leadership, standards, incentives and transparency.

The current fragmented system, created within an industry where incentives encourage "siloed" approaches, lacks any systematic cohesiveness. With the exception of multi-specialty groups and integrated systems, physicians generally practice as independent agents interacting with other parts of the system in an ad hoc fashion. Funding streams for programs and institutions are independent, volatile and often fragile. These historical facts suggest information infrastructure lacks a galvanizing agent, but that can change.

One of the biggest challenges is trust. Information is closely guarded in health care, and sharing information raises many fears. Patients may fear losing their job or health insurance if their employer finds out about a health problem. Doctors may fear other doctors stealing their patients or trial lawyers trolling for lawsuits. Hospital departments may fear losing control over their operations under centralized hospital databases.

Trust must be earned, of course, but it can be nurtured through governance. If each group affected by information sharing has a clear and strong voice in determining the use of the information, then they are more likely to trust how it is shared. Establishing governance across institutions is difficult, but communities can be leaders in garnering support.

Government can also play a role in collaborative leadership. Government has a vested interest in realizing smooth administration and efficiency. As a payer for approximately 45 percent of all medical services and as a provider of tax subsidies for much of the rest of health care, it can use its leverage to pursue a national strategy, one that is commensurate with the magnitude of the task at hand. Recommended enabling activities include:

- Facilitating and supporting creation of and, when necessary, enforcing national standards for data (including connectivity, security and confidentiality aspects);
- Facilitating development of a national health performance measurement and outcomes database;
- Funding research and demonstration projects;
- Stimulating innovation by creating incentives for IT investments to be made by private institutions or more broadly at the community level (possibly modeled after the 20th century utility or telephone rural coops);
- Functioning as an honest broker in data gathering and dissemination; and
- Convening and coordinating activities.

Supporting the development of standards is a particularly important role for the government because they require investments in creating products that everyone will use but which no single private institution will benefit enough from to pay for the cost of producing them. Standards range from a common language for defining health conditions electronically to rules about measuring, assessing and reporting on quality.

The transparency of health care prices and quality is a critical component of engaging individuals more actively in their own health and health care. Without transparency, individuals cannot understand and evaluate their health care decisions. Some providers urge caution in disclosing less than perfect information, but information about quality will never be perfect. We need to do what we can with what exists and make it better. The Centers for Medicare and Medicaid Services (CMS) is taking steps to release quality indicators about hospitals and nursing homes, and many believe that government can do more to promote transparency at many levels. HIPAA, although a well-intended regulation that is currently driving most of the work on infrastructure, will require that organizations proceed cautiously.

In order to advance transparency, the state and federal regulatory and administrative agencies need to develop standards for disclosure of performance information, help enable the creation of patient records and help to ensure institutions comply with these standards. Standardizing information, release of performance information, setting data and transmission standards are all prerequisites to a high performance health care system. There is already broad support from the insurance industry for standardization and the enthusiasm of other health care sectors is likely to be enhanced as the appreciation of its value in infrastructure development grows.

Many believe consumers are ready. Others express concern that as we ramp up measurement and launch public debates about the shortcomings of institutions and providers of care, we can expect confusion and uneasiness on the part of individuals, who may want to believe that poor quality and outcomes may happen to others, but not to them. As part of the healing process, patients have a strong need to believe that their physicians and hospital provide appropriate and

effective, high quality services. Nonetheless, physicians must begin to transfer ownership of their patient's health to the patients, at least figuratively, if patients are to take more responsibility for their health. In both disclosing information about quality and engendering self-care, both the credibility of the messenger and methods must be trusted.

From the providers' perspective, if feedback on performance is to be accepted and result in appropriate behavior change, the focus should be on improvement, not fault-finding. It is widely believed, however, that if creating an information infrastructure makes it easier for doctors to care for patients, they will willingly give up some control and get "on board." This viewpoint reinforces the importance of designing IT systems to meet the end users' needs, in this case, physicians.

One example of innovative thinking and action in this regard has been the development of Anceta®, the first national repository of de-identified administrative and clinical data from non-affiliated medical group practices. Anceta® is a subsidiary of the American Medical Group Association, an organization whose member groups are some of the largest, most prestigious integrated health care delivery systems in America. The ultimate utility of Anceta® will be to foster greater and more knowledgeable patient-directed influence in the accessibility, quality and cost of his or her own health care. Thus, both the practitioner and the patient can benefit as the end users of this data. [See case study on Anceta®, p. 134]

Can we learn from other industries?

Perhaps. Historically, banking was a "cottage industry" not unlike health care. The resistance to transparency and networks for exchanging information was overcome because the industry realized it needed to make transactional services clearer, easier to access, convenient and less expensive. It had to get away from bureaucratic "interventions" that would slowly grind progress to a halt. Today's complex banking infrastructure, e.g., ATM cards, is easy for consumers to use and understand and works across most banking systems. Given the potential benefits to all the stakeholders in health care, especially providers who make it easy to do business with them and who focus on patient needs, champions of infrastructure development and transparency will emerge sooner or later. Communities can grab this opportunity and curb the waste by taking action today.

Conclusion:

Currently our "system" is anything but! A well-functioning system uses information to prevent and fix problems even as it continuously updates itself to optimize its functions. Our systems also need inter-disciplinary coordination and more accountability. In addition to a leadership role for communities and government, successful creation of the necessary components of an information infrastructure also depends whether vested stakeholders recognize its value and willingly make the necessary financial and cultural commitments.

Resources
    National Alliance for Health Information Technology http://www.bridgemedical.com/nahit.shtml
    National Patient Safety Foundation http://www.npsf.org/
    Patient Safety Institute http://www.ptsafety.org/
    Crossing the Quality Chasm, IOM report
    US Dept. of Defense, "Reach to Recovery"

Next Steps for Communities

Highly recommended:
- Develop and advance programs to educate community health workers and "lay educators," such as patient navigators, to enable other less informed citizens to learn more about their own health and the health of their community and to bridge cultural and linguistic barriers to accessing information'
- Prepare case study vignettes of approaches at the local level that are addressing identified information needs—relative to individuals, the delivery system or the community. The vignettes will outline critical success factors and serve as a vehicle for knowledge transfer among interested parties.

Other considerations:
- Consider advancing a local bond election to fund healthcare infrastructure.
- Create or bestow trust in a third party organization to exchange information across institutions as areas of the country (e.g., as Indianapolis, IN; Santa Barbara, CA, Delaware) have done.

Potential multi-community collaborative projects:
- Examine the progress of public and private initiatives currently underway for local adoption or demonstrations, including the E-Health Initiative, the work of the National Committee for Vital Health Statistics, National Alliance for Healthcare Information Technology (NAHIT), and others. Identify the goals of each effort, determine gaps or opportunities for greater collaboration that may serve to accelerate the pace of progress.
- Develop a list of principles framing the infrastructure question and determine appropriate actionable steps to address them. Begin with a review of the NCVHS "National Health Information Infrastructure" white paper.
- Research development of infrastructure in other industries (e.g, banking, utilities, telecommunications, etc) to identify common drivers, incentives, funding streams, governance.
- Develop a white paper to outline the principles, the status of progress being made and recommending enabling activities for government, including financial and regulatory strategies.

Community support for health policy/governmental action:
- Review HIPAA with an eye toward reducing unnecessary requirements especially in view of a more robust information network and infrastructure. New ways to include more stakeholder input and to pilot test standards locally should be considered. Funding for HIPPA compliance should be considered, too.
- Promote research on basic information systems to facilitate care and translation of research into practice. AHRQ at $300 million in contrast to the billions at NIH.
- Encourage payers to create incentives for the adoption and use of IT and information networks.
- Reevaluate medical training with a goal of overcoming entrenched resistance among physicians to transparency and accountability.
- Address environmental factors that are barriers to change, for example inappropriate medical liability.
- Integrate the use of information in schools as a tool for teaching children about health promotion and disease prevention at the earliest possible age.

PUBLIC HEALTH: THE "GLUE" THAT BINDS A COMMUNITY'S HEALTH

Any attempt at comprehensive health system change must start by addressing a fundamental question: How do we achieve "health" as individuals and as a society? The nation's public health system must be recognized as a key part of the answer. Public health performs an essential role as the glue that supports a community's health and health care infrastructure. However, public health's role is often ill-defined, poorly understood, and under-resourced. It is time for communities to re-examine how public health can best be used to support their populations' health needs in the 21st century. Addressing public health problems is one of the most pragmatic means for facilitating community change.

There is no monolithic approach to public health. Traditionally, public health serves certain "core functions", such as tracking community health status and containing disease outbreaks. But there is enormous variation in the range of functions that public health departments perform. For example, in many states, public health delivers a wide array of screening and primary care services to uninsured patients. In some states, public health delivers only a very limited menu of primary care services, such as immunizations and well-baby care. In other states, public health doesn't deliver any primary care at all. As a result of this state-by-state approach, there are 50 different models of public health and 50 different definitions.

One result of such wide variation is a great deal of confusion about just what "public health" is. Some people think of it simply as indigent health care. The public's perceptions of public health's functions are often far narrower than the reality. On the other hand, the Institute of Medicine defines public health in very broad terms, as "… what we, as a society, do collectively to assure the conditions for people to be healthy." In most communities, the reality lies somewhere in between. Public health is more targeted than the IoM definition suggests but more comprehensive than much of the public may realize.

There needs to be an effort to redefine public health and its place in our overall health care system. Mark Rothstein, Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville, writes that, "Greater clarity and consensus on the meaning of public health is likely to lead to more efficient and effective public health interventions as well as increased public and political support for public health activities." Bringing "greater clarity and consensus" to public health is an important step communities can take, especially now, when our national security depends more than ever on maintaining a well-functioning public health system.

Unfortunately, there are many communities whose public health systems are falling apart. A recent IoM report on public health in the 21st century cites serious deficiencies in public health, such as lack of workforce training, outdated technology and labs, and ineffective communication networks. It seems that those communities that have the most need for a strong public health infrastructure often have the fewest resources. Public health depends largely on county, state, and federal dollars, which can be pretty fragile funding streams.

It is the position of many community leaders that public-private partnerships could serve a useful role in bolstering a community's public health infrastructure in certain areas. Traditionally, public health has been seen as a purely governmental responsibility, but this mindset may be limiting public health's potential. In considering public health's role in the broader social determinants of health and disease, perhaps it makes sense to view it as a bridge between the public and private sectors involved in health care.

Public health professionals believe that the CDC Office of Public Health Practice should work with health departments, perhaps through the National Association of County Health Officers, on an accreditation process, similar to what the hospitals did voluntarily more than fifteen years ago, to set standards for how the departments work with local healthcare delivery services. This process would help drive improvement and could go a long way toward establishing the appropriate role for and credibility of public health.

Re-shaping the role of public health in a new era

Public health leaders can reinvent their mission to better meet the needs of the 21st century. There is a mistaken belief that public health is no longer as necessary or as relevant to Americans' health as it once was because the battle has been won to achieve clean water and good sewage systems. But now our country faces a new set of challenges that underscore that public health still serves a critical function.

During the past two years, public health has assumed a very significant role in national security through its involvement in preparation for bioterrorism and other emerging health threats. Public health, working in concert with the medical community and private health care sector, has taken a leadership role in bioterrorism preparedness. There

are also abundant new resources available to public health to address bioterrorism preparedness. This new area of responsibility has required public health to function in new ways and form new partnerships.

For example, in San Antonio, Texas, public health agencies moved quickly after September 11th, 2001 to come together with local health care providers to form the Regional Emergency Medical Preparedness Steering Committee. [See case study on Preparing for the Threat of Bio-terrorism, p. 117]

This work in San Antonio demonstrates that public health can play a vital role by showing leadership in addressing emerging areas of concern. In addition to bioterrorism preparedness and emerging infectious diseases such as SARS, chronic diseases related to lifestyle are a potential area for greater public health involvement. Clearly, public health has an opportunity to reinvent itself and raise its visibility in the community. On the other hand, these new areas of responsibility should not detract from public health's traditional functions.

There is broad agreement on the essential functions of public health, which have been well articulated by the IoM and others. Some key areas include data gathering and analysis; disease prevention, investigation and tracking; monitoring of community health status; health planning; community outreach and engagement; and mobilizing partnerships. Health disparities are also an important focus in public health. However, the IoM found no consensus when it comes to "translating broad statements into effective action," and no shared sense of what the public can and should expect from public health.

As a result, there is little consistency in the organization or content of services, with accountabilities and relationships driven by political expediency rather than policy objectives and capabilities. While no consistent recommendations can be made with regard to how traditional public health services should be organized, there are several caveats that influence the effectiveness of the services. When health departments are organized under the umbrella of "social and health services," coordination may be easier, especially in smaller states or rural regions. However, public health, which benefits society at large, not just the indigent population, may be misinterpreted as another "welfare" program.

Public health's involvement as part of the safety net cannot be eliminated or marginalized. Confusing public health with safety net services and preventive and primary care, including mental health/chemical dependency, runs the risk of relegating public health to a secondary role. Combining some of these services under one department may be necessary because the same expertise is needed in many cases, but communities should discuss and understand the different roles of the public health system.

Reappraisal of public health must consider the disagreement among public health officials and the public about its role and the distinctions between public health and clinical care and public health and health promotion.

Strengthening public health financing

However public health is organized, its financing remains a significant challenge. As a critical element of community infrastructure, public health's funding and responsibilities should be clearly articulated. Too often, public health is at the mercy of a political process that threatens its dedicated funding streams. It is the position of many community leaders that public health needs more diverse sources of income.

Public health needs to be financed in a way that maintains the best characteristics of public-private partnerships, building on what the private sector can and will do and ensuring that which is carried by the public sector serves an appropriate public good. The way we currently finance private care may undermine public health financing and collaboration, and vice versa. Just as public health and private health care ought to complement and reinforce one another, some suggest that the dollars spent on medical care and on public health programs should both result in some mutual return on investment. The old distinctions between the funding, the activities, and the results of public health programs and medical care are no longer hard and fast. Therefore, rather than look at the system strictly from an individual perspective, we should consider it within an overall public context.

Much of the work of public health is not linked to a provider encounter, so financing mechanisms need to allow for payment for non-transactional services that promote health, such as epidemiology, surveillance, and environmental health activities. In some places, local health departments only focus on services to which a fee is attached – e.g., immunizations, indigent care or septic tank inspection, at the expense of core public health services. Other service requests are referred to the state health department.

There is a strong sentiment that the health care purchasing role of the government, e.g., the funding of indigent care, must be separated from essential public health services. Organizing Medicaid under the department of public health results in a lack of attention to the multiplicity of important public health programs because of a singular focus on the much higher costs of Medicaid.

Cooperation at the local level for optimum public health

The current disconnect between public health and the medical community is clearly "unhealthy" and does patients a disservice. We need to get the medical and public health communities back together if we are to make both as effective as possible. Similarly, we need more interdisciplinary collaboration when it comes to other health-related disciplines, such as the oral health and mental health communities.

There needs to be clear delineation of responsibilities for services where there is the potential for overlap. For example, should immunizations be a part of well-baby checks, or a service performed by health departments? It is inefficient and inconvenient to split these two critical pediatric services.

There are also potential problems with regard to categorical programs. Treatment for sexually transmitted diseases and tuberculosis are usually carved out as responsibilities of the health department. But should screening and treatment be part of the "medical home", with the health department doing contact investigation, tracking, follow-up and outbreak control? Some would argue that when treatment is complicated (as with TB) and follow-up and outreach are critical, public health, which is uniquely good at tracking, should be in control. But collaboration is most effective. There can also be problems in these programs when funding for essential services is combined with patient care dollars. For example, when the price of TB drugs goes up, the health department may feel pressured to reduce nurses.

Some express the view that indigent care is something that should be provided by health departments only until another willing provider can be found. In some cases, however, as cutbacks in other programs are made, there is a potential role for public health in creating a model of care delivery that is on the cusp of public health, population health and individual health management.

Some make a strong argument for a role for public health in chronic disease management. The rationale is that a majority of health care costs are driven by chronic disease, and much of the management of chronic disease goes on outside doctor's office. Possible roles for public health include further development of data registries, with feedback to clinicians; patient education; community support; the development of core indicators for diabetes care; and health tracking, for example, related to asthma. A public health department can play a vital role as a catalyst for change and a convening organization, for example, around chronic care. Public health professionals play a vital role in the continuum of health and health care. They are community-based, can bring communities together, can measure progress and are often viewed as "neutral players". This role also helps ensure that public health will be invited to the table on other issues.

The critical point is not so much which services are deemed appropriate or necessary for a given health department to perform. Rather, dynamics at the local level are problematic and without clarity around roles, a sense of competition, not cooperation, may be created with local hospitals, community and migrant health centers, and private providers.

Moving forward, public health needs much more active engagement from organized medicine.

One place to start would be to put a greater emphasis on public health in medical school curricula. Medical students need to be exposed to public health if they are to understand and appreciate its role.

Data collection and analysis: A role that is distinct from clinical delivery

Clearly, a primary role of the health department must be to monitor disease trends at the local level and provide that information to communities so that they can set goals and priorities. There is strong support for the notion that, if health departments are involved in clinical delivery, there needs to be a firewall with regard to data. Otherwise, if the health department provides prenatal care and infant death rates increase, for example, there could be a perceived bias in data reporting. In the essential functions of public health, public health departments must be perceived as impartial collectors and analyzers of data.

Regionalization

Consideration should be given to regionalizing some public health functions, similar to the notion of regionalizing trauma districts, and some states (e.g., Texas) are doing this. The CDC criteria for the skills needed for full service health departments should be used. This approach can help to create economies of scale in use of resources. The challenge is explaining the role of public health in a "sound bite." For example, everyone understands the concept of trauma care and only wants the best!

Next steps for communities

Highly recommended:
- Survey public health officials regarding the types of data they collect and the sources of that data. Identify gaps in information that is necessary to create a "community health" profile.
- Establish a "national community dialogue" initiative to determine the optimum role of public health in the 21st century. Consider a series of community meetings that would serve to raise awareness of public health's function and provide the opportunity to undertake a methodical process of identifying the most important roles for public health from the perspective of the community. Assure that these community perspectives are reflected in public health and medical care incentives for providers and patients. (The definition of "community" is a local issue. In some cases it may reflect only one region of a large city; in a small, rural, or sparsely populated state, the activity may pull from the entire state.)

Other steps for consideration:
- Begin at the community level to identify public health "best practices", considering the recommendations from the CDC Office of Public Health Practice regarding accreditation. Ensure that criteria are practical and realistic for different practice settings and needs. Catalogue critical success factors embedded in the best practices' work and reflect these in incentives wherever possible. It is suggested that the community find out which states or communities have begun this process and what results are to date.
- Employ the local public health authority as a governmental "convener" of local, health-related leaders. This role can enhance the authority's visibility and help to integrate its services into those provided by private sector and others. This activity may need the support of the governor, mayor, county executive, or other elected officials to give it the clout needed.
- Reevaluate current public and private funding streams and assessment of strength or fragility and look for ways to pay for public health services that do not directly relate to an encounter or physician visit, (e.g., surveillance, epidemiology, environmental health activities).

APPENDIX A: COMMUNITY REPORTS

Salt Lake City, Utah
August 13, 2002

In Utah, the values that rank prominently in health policy discussions are personal responsibility, pluralism, and local decision-making. Other important values include a strong sense of community, cooperation and compassion. The state's health priorities include providing for the needs of children, promoting healthy lifestyle choices, and maintaining a commitment to quality. Utah has earned a reputation for delivering high-quality health care while keeping costs relatively low. In recent years, the state has achieved notable success in improving its child immunization rates and expanding public insurance coverage for children.

Despite these successes, there is deep concern among Utah's health care community about the overall trends in health care. In particular, there is concern that the national, employer-based health insurance system is in jeopardy. "Given that there are 40 million uninsured, I'd argue that the employer-based system is not working," said one physician. Other major concerns are the steep decline in the nation's public health capacity and morale problems in the medical profession.

There is a general consensus among health care leaders that higher spending is not necessarily the solution to these problems. Instead, they say there could be much more effective and efficient use of resources, particularly if patients assert a greater role in their own health care decisions and take more personal responsibility for the cost of their care. However, others cautioned that more consumerism in health care should be coupled with a recognition that many people will continue to need substantial assistance if they are to access health care services. "There needs to be compassion for the less capable, rather than Social Darwinism," said one participant.

Improvements are necessary, but the constraints are real

Health care leaders here agreed on the need for substantial changes in the nation's health care system. The two most pressing issues they cited were expanding access to health care and improving the quality of care. "We need to build into the health care system a capacity for change that improves quality," said one participant. Other issues ranged from improving patient safety to minimizing costly regulations.

These leaders also expressed concern about the administrative burden that is weighing down the health care delivery system. They said that standardizing and simplifying administrative and clinical processes would improve health care quality and efficiency.

They noted that a large number of physicians have become dissatisfied with their role in the health care system. Not only are incomes lower and the paperwork burden greater than many physicians would like,

but they are often not given the proper incentives to do what is best for their patients. For example, physicians could play a greater role in educating patients about how lifestyle choices can affect health status, but they are given little financial incentive or time to do so. Physicians tend to be reimbursed for treating, not educating, their patients. In fact, they are encouraged to maximize the number of patients they see by spending as little time as possible with each patient.

There is concern that some medical specialties, such as primary care and family physicians, are not receiving enough attention and support. There is a great need for primary care physicians, but medical students are often encouraged to pursue more lucrative and prestigious specialties. On the other hand, it was noted that some surgical residencies have gone unfilled this year. Long hours during residency and the high cost of malpractice insurance may be discouraging medical students from pursuing careers as surgeons.

Participants said they felt strongly that these and other issues should be addressed. But they underscored that any policy changes should be made within a context that explicitly acknowledges the financial constraints on the health care system. Currently, there is too little public discussion of health care financing issues, which means that consumers do not fully understand the cost of health care and how it is funded.

As a result, many consumers have developed unrealistic expectations of the health care system. They tend to view themselves as "entitled demanders" of health care and believe they deserve top-quality medical care, without restrictions, and at little or no cost to themselves.

Given the rapidly rising cost of health care, there is widespread agreement that many consumers need to assume more responsibility for their health and the cost of their medical care. Perhaps the most effective strategy for restraining cost growth would be to expose consumers more directly to the economic consequences of their health care decisions and give them clearer choices.

Health care spending: How much is enough?

In Utah, health care leaders disagreed about whether the nation spends too much or too little on health care. One participant said that rapid growth in the over-65 population, expensive new medical treatments and technologies, and ever-increasing liability costs will require increased spending on health care in the future. But the consensus seemed to be that our country already spends an adequate – or more than adequate – percentage of its Gross Domestic Product on health care.

Several participants said the issue is not whether we spend too much on health care, but whether we obtain value for the money. "Right now we're spending on things that are least effective," said one. For example, a great deal of money is spent on end-of-life medical treatment that may have little benefit for

the patient. In such cases, physicians often try to do everything they can, including high-cost procedures, because they are afraid of being sued if they do not, said one participant. If they didn't have the fear of liability hanging over them, "a lot of physicians would do less" in cases where high-cost procedures have little benefit, he said. Several participants spoke strongly in favor of the need for tort reform in order to reduce costs to the health care system.

Government should play a supportive but limited role

There was broad agreement that government's role in health care should be supportive but relatively limited. Participants said that effective partnerships between government and community have done a lot to improve people's health. In Utah, for example, the state's child immunization effort was a public-private partnership that proved highly successful.

But for the most part, government's role should be restricted to subsidizing care for those who are poor and in need and establishing minimal standards for providers, said one participant. Individuals, by and large, should be responsible for their own health status and the economic consequences of their health care, he said. "Financing should be based on responsible individual choice, with a back-stop for the most vulnerable," said another.

Most participants felt strongly that government should not "run" health care and that a single-payer health care system would not be an appropriate solution to current problems. They cited pluralism and local decision-making as important values in health care that would be undermined in a single-payer system. Some participants said they are afraid that, despite the drawbacks, the U.S. will eventually resort to a single-payer system. "If we don't consciously make significant change, we are headed inexorably to a government-controlled system," one warned.

On the other hand, it was noted that a single-payer system doesn't have to be run by the government. It would also be unwise to reject any approach without carefully evaluating it on its own merit, said a public health representative. But there was a general consensus that the needs of our pluralistic society can best be met through multiple models operating simultaneously.

The fear that single-payer health care may be around the corner is fueled by concern that employers will soon decide to pull back from their role as sponsors of health care coverage. "I think the business community is on the cusp of saying, 'we've had enough, we're out," said a participant. There is a general feeling that the employer-based health insurance system is not working well, especially for low-wage workers and those employed by small businesses. The idea of an employer mandate was raised but not discussed in depth.

Building on a record of success

Utah health care leaders said it is important to note that the health care system has done a lot of things right during the past 50 years. As a result, national disability rates have dramatically declined. Community-oriented primary health care has spread throughout the country. In Utah, the state medical society has partnered with public health and the local media to encourage pregnant women on Medicaid to seek prenatal care. These and other ongoing efforts are making a difference in people's lives.

There is a record of successful partnership on which to build. Participants generally agreed that if all of their organizations were to unite behind an action agenda they would have little difficulty moving it forward. "If the people in this room were to take an idea to the legislature, it would sail through," said one. But a key challenge continues to be figuring out a way to make proposals for change more palatable to the general public. "The grassroots level is where things get done," said another.

There appears now to be a window of opportunity for moving forward with changes in the health care system, but that window is likely to close soon, participants said. There is fear that employers will retreat even further from offering health care coverage to their workers and that the number of uninsured will rise just as the baby boomer generation is ready to flood the Medicare program. Participants estimated that in the absence of any significant change during the next few years, the health care system could hit a crisis stage within the next 10 years.

Chicago, Illinois
August 26, 2002

The key values that drive discussion of health care policy in Chicago are trust, respect for patients, and individual choice and responsibility. These values are all related to the underlying objective of moving health care in a patient-centered direction that will better meet patient needs and have some hope of restraining cost growth.

Chicago health care leaders said that earning and maintaining people's trust has to be a fundamental priority. At a time when Americans' confidence in their institutions has been shaken, a number of changes would encourage patients to have greater confidence in the health care system. Their recommendations included providing patients with better information about cost and quality and encouraging patients to develop strong relationships with their physicians.

Consumers are, to a great extent, the key to making changes in the health care system. Consumers' expectations are generally very high: they expect to get top-quality care at little or no personal cost. But

their sense of responsibility for that care tends to be limited. This disconnect is largely the result of patients' removal from the economic equation. Because of the third-party payer system, many patients have been distanced from the true costs of their health care. "The consumer needs to be re-thought as a focal point," said one participant.

Health care leaders here said there is a need to develop a social contract for health care that explicitly states the connection between consumers' rights and responsibilities. The public needs to realize that the health care system depends on shared, limited resources that may require some form of rationing. "There must be a better public-private partnership to educate people on the fact that we can't cover every intervention for everyone," said one participant. However, health care must be fairly distributed and address disparities based on gender, race, ethnicity, culture and socioeconomic status.

It was noted that developing a social contract for health care is likely to be difficult in light of our country's long history of conflict between competing political ideals. Our country has traditionally divided between those who support the ideals of social equality and fairness vs. those who favor libertarian self-determination. "These are two very powerful belief structures that have endured for more than 200 years," said a medical ethicist. Therefore, transforming the health care system will require substantial leadership and a broad-based discussion among all sectors and the public, not just those directly involved in health care.

Government action is necessary, starting with the uninsured

Chicago health care leaders said the most pressing issues in health care are expanding access and maintaining affordable health care coverage. There was a general consensus that everyone in this country should have access to health care. The entire health care and economic system is adversely affected by the burden of uncompensated care. Therefore, government and the private sector must work together to address the problem of more than 40 million uninsured Americans.

Government also needs to make sure there is enough money in the system to cover the costs of patients who rely on the publicly funded health care safety net. Currently, a lot of these costs are shifted inappropriately to the private sector. Leaders cited the impending retirement of the Baby Boomers as an example of the pressing need to ensure that Medicare is adequately financed.

In addition, government must address tort reform. The rapid rise in liability insurance premiums has resulted in physicians leaving their medical practices in some areas of the country, which significantly reduces patients' access to health care providers. Fear of malpractice also drives the practice of "defensive medicine," which contributes to higher health care costs.

Finally, government should play a greater role in educating people about health care. For example, government could put more emphasis on including health education in school curricula and could take further steps to counteract advertising messages that encourage consumers to make unhealthy choices.

Physicians' role as educators is underutilized

If patients are to have trust in the health care system, they must have confidence in their physicians. The patient-physician relationship is at the core of all health care interactions. Patients want the right to choose their own physician and make major decisions in consultation with their physician.

Restoring the patient-physician relationship to its central place in health care also requires recognition that physicians play a key role as health care educators. "The central role of the doctor is to teach," said the medical ethicist. "To fail to take advantage of that is really to miss the central point."

Physicians and other health care professionals must have enough time to communicate fully with their patients about issues such as compliance with prescription medication, treatment options, preventive care, and the importance of healthy lifestyle choices. Given recent data on the epidemic of obesity and its relationship to diabetes and other diseases, there is an urgent need for physicians and other health care professionals to be involved in encouraging patient self-care and preventive care.

Given the enormous benefits of making sure patients are informed, there should be incentives, not penalties, for physicians that educate patients. Physicians should be able to hire the necessary personnel and incorporate office systems that will assist them in educating patients. But the current financial model generally does not reimburse or incentivize physicians for taking extra steps to educate their patients.

While there is a general consensus that strong patient-physician relationships are important, there is also recognition that physicians have a responsibility to keep up with "best practices" and standards of care. Academic medical centers should conduct epidemiological and applied research to define and improve best practices based on evidence, and teach students and residents how to use this information in caring for patients. Physicians should be committed to utilizing evidence-based medicine to best meet their patient's needs. There should be incentives for following best practices and financial consequences for physicians that do not follow evidence-based guidelines.

Finally, coordination of care among various treatment providers is hampered by a lack of health care information systems and a fragmented medical record that adds costs and inhibits efforts to improve quality. It is feared that the situation may be further complicated by HIPAA regulations that may limit the essential exchange of patient information among providers.

Patients need information and incentives

Patients need sources of information other than their own physician if they are to make informed choices about their health care. They need to be able to compare providers on the basis of price and quality, but have few places to turn for reliable data. "There is virtually no transparency in health care," said one participant. It was pointed out that Illinois is the only state that keeps a registry to track cancer treatment outcomes at various hospitals.

Without information, patients face great difficulty navigating the often-confusing health care system and they cannot realistically exercise much choice of treatment or providers. Transparency about cost and quality would allow for a greater degree of consumerism as well as more confidence and choice in health care. "Information technology is not a panacea," said a health insurance executive. "But let's get the electronic pipeline going."

Better information should be augmented by incentives that encourage patients to make good choices. There is broad agreement that increasing consumers' financial stake in their own health care would encourage more prudent decision-making. But certain patient populations, such as immigrants and migrant workers, will need special support in accessing health care because they face hurdles that are financial as well as cultural and linguistic.

Many employers also play an important role in educating workers about health care. Some provide wellness programs or on-site preventive care and disease management, and they may give employees incentive to participate. The American Cancer Society, which is partnering with a number of employers on disease prevention efforts, has seen tremendous uptake by employees when they are given incentives to take part in these programs. It was suggested that employers that need to pass on additional health care costs to their workers might do so through incentives that encourage workers to seek out preventive care, disease management, smoking cessation programs, etc.

There is also support for creating societal changes that would benefit people's health. In an environment where the popular culture and some business interests often encourage unhealthy choices such as smoking, a poor diet and lack of exercise, there must be an increased effort to raise public awareness about the health consequences of these behaviors.

Creating a broader discussion

Chicago health care leaders agreed there is a need to initiate a new national conversation about comprehensive health system change. But there is a sense that any wide-ranging health care reform discussion would be most effective in an environment that makes it safe to talk about these issues.

Following the collapse of the Clinton health care reform effort in the early 1990s, health care leaders have realized that playing the "blame game" is not an effective strategy for moving forward. We are wise to identify what is currently working effectively and find ways to replicate it, rather than "reinvent the wheel."

Government can set the stage for an open discussion. Those with a direct, vested interest in health care would certainly participate, but it is important also to involve people from all sectors of the community. "We need to get to the 'Oprah' level of dialogue," said one participant. Clergy and ethicists could be particularly valuable in fostering a rational, meaningful discussion of the issues. Enlisting prominent figures at the national or local level would have the benefit of raising the discussion's visibility among a broad spectrum of people.

Hanover, New Hampshire
September 26, 2002

Key values that inform health care policy in northern New England are collaboration, partnership, and quality. In this heavily rural area of the country, discussions of health care also revolve around the themes of balance, efficiency, interdependence, and shared decision-making. Health care leaders in Vermont and New Hampshire are acutely aware of the need to bring more balance to the health care system – balance between growing demands for health care and the system's limited resources, between entitlement and personal responsibility, and between interconnectedness and individual autonomy.

The nation's health care system is markedly "out of balance" with regard to how resources are allocated. Over-utilization in some areas of medicine wastes resources that could be directed to health care for the 40 million Americans who are uninsured and others who are medically underserved. New England institutions have been national leaders in pointing out the tremendous variation and inefficiency in health care delivery across the country. There is broad agreement that if resources were better allocated and incentives were correctly aligned, the nation's current level of spending on health care would be more than adequate to provide for everyone's medical needs.

There is also support for fostering among patients a greater sense of personal responsibility for one's own health and greater awareness that one's demands on the system draw on limited resources. Building a community-wide sense of interconnectedness – in other words, creating an understanding that one's own health care choices are linked to the health of the community – is viewed as a key step in this direction. "We do need to get the country to understand that with all rights come responsibilities," said a participant.

Empowering patients, rationalizing utilization and reducing unnecessary costs are the goals that currently drive interest in a new paradigm in northern New England called "shared decision-making," which enables patients to play a greater role in decisions about their own health.

From a global perspective, this community believes that we need articulate leadership at all levels and that all sectors must be part of the solution because we all have a vested interest in the health of our citizens. There is a symbiotic relationship – a true mutual dependency.

Lack of competition means provider commitment to efficiency is key

As a heavily rural area of the country, northern New England lacks the degree of competition among hospitals and health plans that spurs progress toward efficiency and quality improvement in more densely populated areas of the country. Therefore, they have turned to other strategies for rationalizing utilization, reducing medical errors and containing cost growth.

There is a general consensus among participants that hospitals, physicians and others need to be committed to doing what works on behalf of the patient, such as emphasizing preventive care and case management for patients with chronic illnesses, rather than maximizing high-cost procedures. Providers generally recognize the need to not view their role only as taking care of patients one at a time, but rather as contributing to quality improvement in the care of the community.

Health care providers in this area are committed to collaboration and the sharing of information and services as a strategy to improve quality and efficiency. This has been abundantly demonstrated by the Dartmouth Primary Care Cooperative Project, which strives to link primary care physicians in rural settings through a network designed to create intellectual exchange. The Project also created the first primary care research cooperative with a focus on education. This work has been widely published and the model has been emulated in Colorado and Europe.

Similarly, the Dartmouth Hitchcock Alliance, formed in 1993, started by focusing on services that were valued in the community. Its philosophy supports care in the community as a primary tenet. While the limited capacity of smaller hospitals drives a need for alliances, patients are not moved to tertiary care centers unless necessary. Relationships are driven by what is needed in the community – not unilaterally by what the Dartmouth Hitchcock Medical Center thinks is needed.

The success of these regional partnerships is driven by trust, grassroots and "grasstops" involvement, stability of executive leadership, a consistent strategy, and educational collaboration that fosters cooperation in administration and delivery. Common values and philosophy must be there for this model to work in other communities because this is not a return-on-investment strategy.

As a result of these and other initiatives, northern New England has achieved some notable success in keeping utilization and costs lower in New Hampshire and Vermont than they are in many other areas of the country. Much of what is done in northern New England may not be replicable in other geographic settings. However, a number of elements can be instructive to other rural settings where competition is not possible and doesn't make sense.

In addition, leaders here recognized that another problem that must be addressed, common to both urban and rural healthcare delivery, is a lack of infrastructure. This lack of infrastructure makes it difficult to prevent errors of ignorance or omission.

Shared decision-making may be a valuable next step

The emerging concept of shared decision-making, also known as "informed choice", involves both the patient and the physician in choosing among alternative treatment options. It is especially critical in cases where there is no definitive scientific evidence regarding the value of a more aggressive form of treatment over a more conservative approach. The goal is to ensure that whatever course of treatment is determined has been chosen by the patient, who has been fully informed about all of his or her options and their relative risks and benefits.

This paradigm of medical decision-making has growing support in the health care communities of northern New England, where it is currently being tested. Initial results indicate that shared decision-making results in greater patient satisfaction with the course of treatment and has the potential to reduce costs to the health care system. Patients that are fully informed about their options tend to choose the form of treatment that is least risky and least invasive, which also tends to be least expensive.

Shared decision-making also offers the potential to link utilization of services directly to patient preference – a true measure of "patient-centered care." The wide variation in rates of procedures and hospitalizations that now exist could be narrowed significantly.

But shared decision-making also requires a greater emphasis on educating patients. There is some concern about what form patient education should take. Educating patients about self-care and preventive care can be valuable, but someone who is very sick doesn't necessarily want to be faced with lots of choices and information.

The appropriate role for a patient advocate in these situations is unclear. There is concern that professional advocates may drive over-utilization by insisting that each patient receive the maximum level of care that is available, regardless of whether it is likely to do any good. It was suggested that a better solution is to ensure that health systems themselves are competent enough to address diverse needs.

From "adolescence" to maturity: An evolving social contract for health care

There is widespread support in northern New England for moving the nation's social contract for health care from its current "adolescence" to a stage of maturity. Under an adolescent social contract, Americans are concerned mainly about their ability to make "withdrawals" from the health care system. They want to get their high-quality care on demand at no cost to themselves. But to keep the system functioning, someone has to be making the "deposits," or contributions on which the health care system depends.

A "mature" social contract for health care means individuals expect to contribute to the health care system on which they rely. It means they also understand the importance of not wasting the system's limited resources by overusing services or making choices that are destructive to themselves and others, such as tobacco use. It was noted that in some circumstances, when patients realize they are drawing on a limited source of funds that must be shared, they tend to take only as much as they actually need, which demonstrates that people are willing to consider the needs of others when they make decisions about their own health care.

An additional aspect of a mature social contract is that patients understand they have a responsibility to be connected with a source of payment for their health care, whether that source of payment is private coverage or a public insurance program. In fact, we ought to be prepared to pay not just for the care we need but for the health care system we all need. It was suggested that, although "social contract" is not a notion in most patients' minds, focusing on the concept of self-interest and interdependency could induce people to think beyond "me."

There is a general consensus that everyone should be covered at a basic level, but that tiered health care is inevitable. Variation in patient care is related to a multitude of factors including socioeconomic status and geographic location. There is no consensus on whether tiered health care is appropriate or should be encouraged. It is important to clarify whether or not we are talking about systems that are differentiated on the basis of choice, certain services, and cost rather than on the basis of quality.

It was suggested that services and outcomes that are cost-effective and socially valued should be considered a basic tier to which everyone is entitled. On the other hand, services and outcomes that are personally valued but have little social utility should be an optional tier. However, it was noted that it might be difficult to distinguish between care that is valuable for society and care that is valuable only to the individual.

Government should address the problem of the uninsured and end cost shifting

In northern New England, there is broad agreement that the most acute problems facing the health care system are the high number of Americans who are uninsured and a lack of access to health care. Both

issues require immediate government action, with the support of all healthcare stakeholders. There is a general sense that improving efficiency in the health care system would go a long way toward freeing up resources and making it possible to expand coverage.

There is also agreement that the Medicare and Medicaid programs must adequately reimburse providers for services and end their cost shifting to the private sector. Doing so would solve a lot of health care financing problems and would make it more affordable for employers to sponsor basic health care coverage for workers. Tort reform and other activities that address unnecessary drains on resources should be implemented as a key step toward controlling costs. It was also recommended that government carefully examine legislation, regulations and mandates that drive up the cost of health care without adding value.

Portland, Oregon
October 10, 2002

Health care leaders in Portland said their main concern is the need for a broad public dialogue aimed at developing a national vision for health care. This kind of discussion will require a lot of elements: articulate leadership, candor and integrity, and a willingness to focus attention on where the nation's health care system should be headed. They strongly suggest it has to take place. They predicted that unless this kind of discussion occurs, the country will continue to drift into a deepening health care crisis marked by a growing number of uninsured Americans, steep cost increases, workforce shortages, and diminished access to services.

A public dialogue on health care should begin at the most basic level by addressing fundamental questions such as whether all citizens and residents have a right to health care. Resolving these fundamental issues is critical if the nation is to develop a social contract for health care that clearly defines the public's rights and responsibilities.

A shared public vision is necessary if there is to be any chance of overcoming resistance by special interests, which tend to act as a barrier to health system change. But with articulate and courageous leadership, significant change is possible, as was demonstrated in the 1960s when the Johnson Administration enacted Medicare and Medicaid.

Oregon has also demonstrated that states can achieve health system change by involving the public in strategic planning. In the late 1980s, state and local officials convened town meetings across the state to develop a public consensus that became the constituency that supported the Oregon Health Plan. By

directly involving the public in decisions about how health care resources should be allocated, the process enhanced the community's sense of participation in its health care system.

Similarly, a major opportunity for change now exists at the national level, especially given the severe problems facing health care and the growing number of middle-class voters who are experiencing the loss or curtailment of their insurance coverage. Exercising courage and candor, political leaders can begin talking about the nature of the problem and the pursuit of solutions.

Building a sense of community and the common good

There was a general consensus among participants that the nation needs to talk at a fundamental level about our social contract for health care. Several participants expressed their conviction that health care should be a right that is guaranteed by the U.S. Constitution. Others were not so sure. But it seems that unless Americans reach a consensus that health care is a "common good," there cannot be an effective social contract.

There are hopeful indications that people are willing and able to put aside their self-interested concerns for the good of the whole. An example of this altruism in Oregon occurred during the run-up to the Oregon Health Plan. At that time, the state chapter of AARP indicated that its members did not want to see an increase in their own health care benefits if it meant there would be fewer resources for children's health care.

In another example, cited by a local employer, workers without children objected when the company announced that workers with children would have to pay higher out-of-pocket costs for health care benefits than those without children. In that example, workers without children volunteered to receive a reduced benefit from their employer in order to offset the higher costs incurred by their co-workers with children.

There was a clear consensus among participants that political leaders need to build on the public's willingness to assume community responsibility for health care.

The problem of overcoming each sector's narrow perspective

Participants recognized that more unites the health care sectors than divides them. Despite this, the health care industry has often acted as one of the main obstacles to advancing health system change that would promote the common good. Often health care sectors bring to policy discussions a narrow perspective that protects and promotes their self-interested concerns, rather than advancing the community's interest.

Health sector representatives acknowledged that their jobs require them to take policy positions that will maximize revenue for those they represent – positions that may run counter to the social contract. As a

result, there is vehement disagreement within the health care industry about where the system should be headed. In Oregon, discussions of health care policy sometimes deteriorate into partisan politics, with groups taking adamant positions. Too often, perspective is limited to, "what do I lose if we do this?" Individual silos do not readily promote constructive change.

Recognizing that individual stakeholders are reluctant to change short-term operations, participants believe patients and consumers – not the health care industry – will drive health system reform. For that reason, there is a need to create more mechanisms for consumers to express their voice. Changes that allow consumers more input would also be expected to increase patient's trust and confidence in their health care.

Recognizing that the purpose of health care is health

Impending demographic changes mean that we need to look at ways of changing the current delivery model so that the product is health. Concern about the nation's health care system goes beyond immediate issues of health care delivery and financing and its current inefficiencies and waste to include the full context of successful community enterprise.

We must recognize that the majority of what determines health status does not relate to the health care system, and that a lot of health care is delivered outside the traditional system. We need to create incentives for health and ensure integration of all health-related services. Increasing numbers of Americans are dealing with chronic conditions that are related, at least in part, to their lifestyle. A person's diet and level of exercise, compliance with prescribed treatment, and levels of social support all impact their health status.

It is essential to evaluate lifestyle issues but not with a pejorative attitude. We need to go after these issues in a societal way, with a particular emphasis on children. For example, there should be an effort to look at the nutritional quality of school lunches. Other ideas included giving people a certain amount of time off work each day to exercise. In addition, there should be wellness programs that go beyond just the white-collar, office-based environment and extend further into the community. In fact, some community-based organizations, such as churches, have begun developing wellness programs tailored to the needs of their members.

It is critical for the health care delivery system to put a stronger emphasis on primary and preventive care and create a role for public health that is more relevant and better defined. Currently, the system is devoting more resources to treating end-stage disease, which has the effect of decreasing access to primary care.

An important element of primary care is communicating with patients about their health and helping them navigate the health care system. Patients may bring a lot of information with them into the doctor's office, but they still need consultation with a physician they trust and with whom they have an ongoing relationship. Several participants expressed the view that we need models to envision health care from different perspectives. Innovative experiments can teach patients about different ways of accepting care.

Moving the health care system in the right direction also means developing mechanisms that facilitate transparency of cost and quality information to support good decisions and structures that reward evidence-based approaches. Equally important, it means recognizing that not all patients wish to or can be equally empowered to engage in their own care. Therefore, we must ensure that there is adequate support for those with low health literacy and other special needs.

Beginning a dialogue, developing a message

Oregon health care leaders seem to have little expectation that creative answers to the health care crisis will come from Washington, D.C. Consequently, people in states such as Oregon are discussing these issues among themselves. Despite competing priorities within the health care industry, areas of agreement have been found and community discussion moves forward.

Some participants feel that the first step should be to communicate to the public and to lawmakers that there is, in fact, a crisis facing the health care system. Others are concerned that calling the situation a crisis without offering solutions would only contribute to a political "blame game". They said that perhaps the first step should be developing a positive vision of the community's role in health care while communicating with citizens about community responsibility.

Public discourse needs to emphasize "rational" rather than "rationed" care and to openly acknowledge the necessary trade-offs. Key to this is a consistent message of necessary commitment coupled with a data-driven process that has genuine integrity and transparency. Educating policymakers and creating a role for politicians in health care is essential for parallel engagement of consumers in necessary social and political changes.

San Diego, California
November 20, 2002

Equity, affordability, and consumer engagement are the key principles that drive discussion of health care policy in San Diego. The health care community's main policy concerns are lack of universal coverage,

escalating cost pressures, and consumers' role in taking responsibility for the choices and behavior that impact their health.

The most urgent issue is finding a way to finance universal coverage. Hundreds of thousands of people in San Diego Country are without health insurance, which affects their access to timely and appropriate medical care. A disproportionate share of the uninsured are poor people and people of Non-Anglo ethnicity . There is a need to talk about the concepts of universal coverage and equity and to decide whether these are values we want our society to uphold.

Another pressing issue is affordability. Health care costs are growing at an unsustainable rate from the standpoint of most employers and consumers. Without a better strategy for containing costs, many more employers are likely to drop coverage for their employees. One piece of the strategy for restraining cost growth should be to look more aggressively at consumers' responsibility for their own health. There is tremendous waste in the health care system that could be addressed, in part, by encouraging people to make healthy choices that benefit themselves and reduce their reliance on the health care system.

Clearly, that is easier said than done. There already are a lot of incentives, financial and otherwise, that are meant to encourage people to make healthy choices and to participate in disease management and wellness programs. But many people are not interested in taking advantage of these opportunities, which has frustrated some employers that are offering them and struggling to manage their health care costs. There is a real question as to whether there are sufficient incentives to promote prevention-oriented, healthy choices.

Part of the challenge of increasing consumers' engagement in health care is to solicit their input and ask them what type of support would actually spur them to make healthy choices and take advantage of preventive services. There is a need to better understand how people make health care decisions and why, when given choices, they do not always choose the option that is in their best health care interest.

There are strong societal values that often work against efforts at encouraging people to appreciate how their own choices affect others who rely on the limited resources of the health care system. The emphasis we put on individual responsibility and personal choice, and our ambivalence about government, are key reasons that we have not been able to develop an effective social contract for health care in this country.

Nevertheless, now is the time to begin a public dialogue about the pressing issues that face the health care system. The hope is that we can find some agreement on moving the system forward. Finding solutions will take substantial leadership from Congress and the White House. Incremental steps will not be enough. There is an urgent need to develop a comprehensive national health care policy.

In the absence of a social contract, where can we agree?

Unlike many Western democracies, the United States lacks a coherent social contract that defines people's rights and responsibilities vis-à-vis their health care system. This absence of a social contract is not likely to change, in the view of many participants. One reason is that Americans do not agree on what they should expect from their health care system. Nor do they agree about their responsibilities to the system and to others who depend on it.

Should everyone have a right to health care regardless of insurance status or ability to pay? Do we have a social responsibility not to over-utilize health care so that resources will be available for others? These are questions that have not gotten a clear answer from a majority of the American public or from our political leaders.

In fact, these questions tend to be uncomfortable and divisive in a society that places such great emphasis on individual responsibility, choice, and pluralism. On the other hand, there are many people, including several participants in San Diego, who would like to see the priorities shift more to equity and fairness in health care.

Even without a social contract, there is a widespread desire to find some areas of agreement on moving the health care system forward. In particular, there is a desire to address the question of whether everyone in this country should have a right to health care, and if so, how that will be financed. Several participants noted that they support the notion of universal coverage and universal access to health care.

There is also a need for agreement that the objective of our health care system is to improve and maintain people's health and well-being. This goal requires a commitment from all parties. For example, some employers that sponsor health care coverage for their workers also offer education and wellness programs that are intended to keep workers healthy. In those cases, it is important that employees take advantage of the opportunity to learn about their health and participate in wellness programs that could help them – not only for their own benefit, but also to help minimize the cost of their care.

Putting the emphasis on health

Employers, health plans and providers are frustrated by the number of people who engage in unhealthy behavior and seem to assume that the health care system will always be there when they need help. This attitude leads to avoidable health problems that often require expensive treatment and put unnecessary costs on the health care system.

There is a need for consumers to pay more attention to prevention and to consider the implications of their choices. Towards that end, health plans and employers have invested in education, disease management,

wellness programs, and preventive care for their workers. But they have found a surprising lack of interest, even when employees are given financial incentives to participate.

This frustration has led some employers to consider financial disincentives for those who choose not to take their hypertension medication, for example, or those who pass up smoking cessation programs. If people have "skin in the game," they are more likely to use preventive resources that are available and that can help employers better manage their health care costs. On the other hand, there is concern that taking a punitive approach to issues such as smoking and obesity could be perceived as disproportionately affecting poor people and people of non-Anglo ethnicity .

Other suggestions for improving health and well-being include moving more resources into public health efforts that address lifestyle and behavioral choices. Preventive efforts are often more effective when entire communities are involved in the campaign. There need to be more resources flowing into communities for prevention.

Shoring up and improving the health care infrastructure

The nation's health care infrastructure is under tremendous strain. One issue of deep concern in San Diego is the workforce issue. California, like many other states, is facing an acute shortage of nurses and too few health educators. There will be a rapidly increasing physician shortage in the very near future. Low reimbursement rates, combined with the high cost of living in San Diego, are viewed as the main culprit for the physician and nurse shortage in that community. But physicians are also reporting increased dissatisfaction with the constraints under which they must practice.

There is also a need, particularly in a state as diverse as California, to develop broad-based cultural proficiency among health care providers and to eliminate racism from the system.

How information is handled and disseminated presents another infrastructure challenge. Health care is generally behind other industries in informatics. In San Diego there is frustration that the hospitals all have different information systems. Providers need to be able to share information quickly in emergency situations. Consumers also need access to better information about their options, particularly if the health care system is to move in a more patient-centered direction.

It is not just the traditional components of the health care delivery system that need to be shored up. There is a strong need to better integrate the currently fragmented and piece-meal ancillary health-related services – e.g., mental health, psychological and social services – in order to increase efficiency, reduce cost, and increase access to these types of care.

Finally, several participants also cited the need to improve quality and outcomes.

Looking for leadership

Fundamentally, there is an urgent need for leadership from Congress and the President on all of these issues. Our political leaders have to begin developing a vision for health care that they can communicate to the public. They also need to be willing to talk honestly about difficult issues, such as rationing services. It is time for everyone to step up to the plate and make hard decisions.

One action that must be taken immediately at the federal level is tort reform. The excessive cost of malpractice insurance is a national crisis, particularly in states that do not cap punitive damage awards. The malpractice crisis has raised costs for the overall health care system and, in some areas, has adversely affected physicians' ability to practice. Congress must address this issue quickly.

Government also needs to recognize that its own actions have contributed to many of the problems facing the health care system. Low reimbursements rates set by Medicare and Medicaid programs have meant that federal and state governments are shifting the costs of health care to employers. Government has also increased costs to the system by churning out regulations and un-funded mandates. Government must rein in its tendency to over-regulate health care.

San Antonio, Texas
February 3, 2003

Access, responsibility and a positive outlook are among the key principles that drive discussion of health care policy in San Antonio. Continuing advances in medical science provide good reason for optimism about the future of health care, but there is concern that not everyone will be able to access the new methods of treatment and detection as they become available. Lack of access even to basic preventive and primary health care – not to mention cutting-edge medical technology – continues to be a major problem, especially for low-income workers and their families.

Contributing to the access problem is inadequate funding for certain areas of the health care system – particularly trauma care, public health and mental health care – and the growing workforce shortage among health care professionals. Participants said the shortage is particularly acute in nursing but is increasingly a problem among the allied health professions as well. Squeezed between high malpractice insurance costs and low reimbursement, a growing number of physicians are said to be leaving medicine.

In light of these and other challenges, participants said there is an urgent need for the various sectors involved in health care to "take responsibility" and stop pointing fingers at each other when there are

problems. However, there is also uncertainty and disagreement about each sector's responsibilities. Most notably, participants are divided over the question of whether and to what extent employers should be responsible for their workers' health care coverage. But there appears to be a consensus that consumers can and should begin to take greater responsibility for their own health and health care decisions.

Deciding responsibility within the health care system is a complicated issue – in large part because the country lacks a social contract for health care that is well-articulated and broadly understood. Participants did not agree on whether there actually is a social contract for health care. Some felt that there is an implied social contract, while others said that no contract exists in any meaningful sense. But all felt that there should be a social contract for health care, because without one it will be exceedingly difficult to carry out the comprehensive changes that are needed.

So far, there has not been an effective public dialogue about health care that would lead us in the direction of creating a social contract for health care. It was suggested that a good first step would be to bring health care stakeholders together to find out where they can agree. Despite conflict and tension among stakeholders in health care, they share an interest in trying to find common ground because all are affected by the public's negative perception of the health care system.

Participants emphasized the importance of creating a more positive public image of our nation's health care, which has become the focus of widespread dissatisfaction in recent years. Stakeholders need to do a better job of presenting the health care system in a positive light and emphasizing the value that health care provides to patients, to employers, and to society as a whole. Health care is, after all, a vibrant area of the economy that has dramatically improved Americans' longevity and quality of life.

Problems of funding, reimbursement and personnel

Among the major policy concerns in San Antonio are inadequate funding, low reimbursement, and a growing workforce shortage. These challenges not only undermine the strength of the overall health care system, but also exacerbate the access problems that many residents confront.

Inadequate funding has put San Antonio's public health system in serious jeopardy and is undermining the city's effectiveness as the region's Level 1 trauma care provider. Another key issue is mental health care, which has been chronically under-funded and marginalized. Mental health services are not reimbursed on par with physical health care or well integrated into patients' overall care. It was noted that Texas has more people with severe mental illness in its county jails than it has in state hospitals. More than half of the state's jail population suffers from severe mental illness.

Participants cited the need to continue robust federal funding of biomedical research but also expressed concern that some patients have trouble accessing new drugs and devices as they become available.

Advances in medical science are going to be tremendous, so incorporating them and making them available to everyone will be a considerable challenge. Because of the human genome project, there will soon be the capacity to screen the entire population for certain diseases. But it is unclear whether everyone will have access to screening.

In addition to funding concerns, there is the problem of workforce shortages. The nursing shortage is particularly acute, but there is an increasing shortage in the allied health professions. There is concern that talented people are becoming less interested in pursuing careers in health care. Growing frustration among physicians is causing some to switch to other careers or choose early retirement.

Another workforce issue in San Antonio, where there is a large population of military employees and their dependents, is that the Defense Department has recently deployed many of its health care providers overseas. There is concern about whether enough of the military's health care providers will remain "in the backfield" – that is, on domestic bases such as those in the San Antonio area, to care for those here at home.

Moving toward a social contract for health care

Participants made several references to the need for all stakeholders – including government, employers, and consumers – to start taking responsibility for health care. But in the current environment it is difficult to reach agreement on just who should be responsible for what.

For example, participants could not agree on whether employers should be responsible for providing health care coverage to their employees. Some pointed to the advantages of an employer-sponsored health care system, but others said it is unrealistic to expect that businesses will continue to foot the bill. In San Antonio, about 85% of employers are small employers and simply cannot afford to subsidize their workers' health insurance.

There appeared to be a consensus that consumers should be encouraged to take greater responsibility for their health care, including its costs. Participants also mentioned their hope that government will take responsibility for restraining health care costs by enacting tort reform.

But urging various sectors to take responsibility is complicated by the lack of an explicit social contract for health care. There is disagreement in the health care community over whether a social contract actually exists. Some participants said there is an implied, or de facto, social contract that is supported by mutual self-interest, moral obligation, and tradition. But others insisted that there is no functioning social contract, just a hodge-podge of entitlements and enforcement. For a contract to work, there have to be willing partners. But there is concern that people will leave the health care system if they don't find the terms amenable.

As one participant said, there's certainly no meeting of the minds here about what the contract would look like. But there seemed to be agreement that there should be one. A key first step would be to have a broad-based and community-based public dialogue about people's expectations of the health care system and the trade offs that they would be willing to make in order to achieve such a system.

Creating a positive attitude about health care

There is no question that the health care system is faced with many serious challenges and is falling short in a number of important areas. But it is important to recognize that the news isn't "all bad" when it comes to health care in general and managed care in particular.

The fact is that medical advances and a state-of-the-art health care system have contributed to people living longer and with a better quality of life in this country. That is a message that needs to be better communicated to the public. Stakeholders need to start presenting health care in a positive light and emphasizing the value it provides.

Managed care faces a particularly tough job of changing public perception. It was noted that most Americans are conflicted about managed care: they tend to think it is a good thing unless it's their own care that is being managed. One of the benefits of managed care has been that it provided competition in the insurance market.

Now that consumer-driven health care is an increasing trend, there is an even greater need to communicate a positive vision of health care so that consumers can truly feel empowered. If they are given enough information, consumers can make rational decisions about their own health care and also feel better about the process.

With health care benefits undergoing rapid change, it is important to figure out ways to prevent people from feeling discouraged and alienated from the health care system. Making sure that consumers have full, appropriate and timely information is one way to do that. Reaching out to consumers for their input is another. Several participants said their organizations had succeeded in changing the public's perception of them from negative to positive by giving consumers a greater role in the organization's decision-making.

Albuquerque, New Mexico
February 24, 2003

Coordination, outreach, and inclusion are among the key values that drive discussion of health care policy in New Mexico – a state with a small, diverse population, one of the lowest per-capita income levels in the nation, and a health care system that is heavily reliant on public financing.

There is general agreement among New Mexico health care leaders that better coordination among sectors and an integrative approach to providing services would reduce inefficiencies in the health care delivery system and improve the quality of care that patients receive. There has been a fair amount of collaboration already among the various health sectors in New Mexico, but the delivery system remains highly fragmented.

There is also a need to put more resources into consumer outreach – particularly outreach that is targeted to medically underserved populations and focuses on preventive care and early intervention. Patients often lack basic information about preventing illness. Many patients, particularly those who are poor and those who are elderly, have significant difficulty navigating the health care system. There is also concern that insufficient outreach prevents a large number of children affected by mental health conditions from receiving the early diagnosis and treatment that would help them over the long term. In all of these areas, outreach needs to be a priority and there should be financial incentives associated with it.

Related to outreach is the value of inclusion – that is, the value of bringing more consumers directly into discussions of health care policy and really considering the consumer's point of view. A larger problem is that consumer needs and preferences are generally not the main factor that determines how health care is delivered. Rather, it is various levels of government that shape and direct the health care system.

In New Mexico, where about three-quarters of health care is publicly financed, the health care community is acutely aware of the central role that government plays. But there is also ambivalence about government's impact on the health care system. On one hand, federal and state dollars are critical to maintaining access to health care in underserved areas, such as New Mexico's rural counties, which tend to be poor. On the other hand, there is a sense that government and its role in health care financing have skewed the health care system in ways that are not always in the patient's best interest.

There is a strong consensus among participants that if there is to be real health care reform, consumers should be the starting point and the central focus of reform efforts. The consumer needs to have a voice. This will require a new kind of conversation about health care – one that brings a diverse, grassroots perspective to the table and focuses on the connection between health care and our collective values and principles.

Despite the numerous discussions of health care reform that have taken place, this kind of conversation – one that gets to the heart of what consumers want and are willing to support – has not yet occurred in any meaningful sense.

Finally, participants emphasized that talk is not enough; discussion needs to be translated into action. Participants agreed that, as an action step, some of them would meet with the state's health secretary to discuss a plan for a joint, community project.

Problems of coordination, access, and lack of focus on the consumer

Among the major policy concerns that were identified by participants in New Mexico are inadequate coordination of health care services, barriers to access for poor and underserved communities, and a lack of emphasis on considering the consumer's needs and preferences. All of these challenges prevent patients from receiving optimal care.

The health care delivery system in New Mexico, as in other states, tends to be highly fragmented, which undermines providers' ability to offer patients care that is timely, appropriate and well coordinated. Gaps in the continuum of care affect all patients, but particularly those with chronic conditions who rely heavily on the health care system and often receive little help navigating among providers.

There is a need for more integration and coordination that would enable more providers to offer case management, which is an effective, holistic way of caring for patients and offers huge economies of scale. New Mexico has devoted a lot of resources to providing community-based care, but the next step is to coordinate that care more effectively, participants said.

There is also a need to increase partnerships among health sectors, various agencies and tribal organizations so that services are not duplicated and resources are used efficiently. Currently, there tends to be a "silo mentality" among the various health care sectors that is counterproductive.

Lack of coordination among health care providers contributes to the access problem in New Mexico. Access is especially difficult for low-income patients, patients with mental health needs, elderly people who have trouble navigating the health care system, and people who live in rural areas with few health care providers.

There needs to be a continuum of care that really supports access. It was noted that mental health care is an area where access issues are particularly acute due to a combination of low reimbursement, too few providers, the stigma associated with mental illness, and a lack of resources for outreach to under-served populations. Outreach and early intervention have to become priorities and should be supported with financial incentives.

In New Mexico, mental health care and substance abuse treatment are attracting significant attention from the governor and the legislature, which appear to be interested in devoting more resources to those areas.

Government is one of the strongest driving forces in health care, particularly in a state as heavily dependent on public financing as New Mexico. Although government dollars are critical, there is a growing sense that the government's dominant role in the health care system has diminished the voice of the individual consumer.

There is a need to find new ways of bringing the consumer into health care decision-making so that the health care system can better respond to consumers' needs and preferences rather than to what the government thinks patients need. Unfortunately, in the current system, consumers generally do not have enough information on which to base their decisions, and there has been little serious attempt to engage consumers in thinking about the kind of healthcare system they would prefer to support.

Engaging consumers in health care

There was a general consensus among participants that a greater effort should be made to engage consumers on the subject of health care. There is a need both to engage people about their own health and health care decisions, and to involve consumers more directly in public discussions about health care policy.

Traditionally, consumers have tended to take a passive role in their own health care, trusting that their doctor will tell them what they need to know. Government and managed care plans have reinforced this attitude to some extent by restricting the type of care they will reimburse and directing consumers to certain providers. According to one participant, the federal government has so dictated the rules of the market that health care today is almost as government-driven as steel making was in the Soviet Union.

But the health care market is gradually evolving toward a system that could provide consumers greater freedom of choice, along with greater responsibility for their choices. Current trends indicate that employers will expect workers to shoulder an increasing share of the financial responsibility for their health care. Consumers need to be prepared for this. Along with greater responsibility, consumers should have access to better information and tools that will help them choose the care that best fits their needs. These tools, which would enable consumers to compare providers based on cost and quality, are generally not yet available.

As the health care system evolves, there is also a need to involve average consumers and other grassroots representatives in discussions about health care policy. Basic questions have never been fully addressed. For example, is health care a public good? To what extent should it be publicly supported? As a result, our

society has no explicit social contract for health care, unlike many advanced industrialized nations that do have an agreed upon social contract that provides a common vision of health care.

There is a general consensus that until there is a broad-based discussion at the community level about health care and our collective values, there will not be a meaningful social contract that can provide a basis for action to improve the health care system.

Translating talk into action

Participants emphasized the importance of public dialogue, but they also noted that discussion – even if it is broad-based and gets to core issues – will not produce meaningful change unless it leads to action. It was noted that the national dialogue on race during the Clinton administration produced a lot of good discussion, but the dialogue didn't go any further or produce meaningful change.

In a state such as New Mexico, where there are a small number of players in the health care arena and they all know each other, there is great potential for stakeholders to come together, decide on a course of action, and carry it forward to implementation. Given a forum, there is an ability to make change. Participants agreed to hold a follow-up meeting, under the auspices of the state health secretary and the state hospital association, to discuss a common agenda for community-based change.

However, there is also a certain amount of fatigue with discussions that have not led to substantial change. The Clinton health care plan of 1993-94 and its failure are still fresh in many minds. Participants said they are interested in finding a new way to have these discussions so that they can lead to meaningful improvement.

It should also be noted that there is some disagreement about the appropriate role of employers in moving the ball forward on health system change. Some participants said they think the business community – as a major payer – should play a leadership role and put pressure on the health care community to make specific improvements. Others said it is the health care community that has the expertise to re-imagine the health care system and should come up with a new model that they can present to the employer sector. But there is agreement that health care is inextricably linked to economic development and that economic development has to be part of the plan for going forward with health care improvements.

Raleigh/Durham, North Carolina
April 10, 2003

Three key objectives emerged in the health policy discussion in North Carolina: to provide equity and universal access to health care, to develop patients' sense of personal responsibility for their health and the cost of their care, and to promote community engagement in health policy issues. But coupled with these ambitious goals is a fair amount of skepticism about the likelihood that reform efforts can overcome major obstacles to change, such as many lawmakers' lack of interest in health care issues, special interest groups' ability to block reform, and the difficulty in getting the public involved in complex and time-consuming public policy issues.

Despite the challenges, participants said there is a need to engage consumers and policymakers on the critical issues facing health care in North Carolina and the nation. Many of the state's providers, especially its public hospitals, are facing financial crisis. The number of uninsured or underinsured Americans is rising. And there continue to be significant disparities in health status and access to health care services.

Equity and universal access are major concerns. There is strong agreement that access to health care services is at least a moral right, if not a legal one. It was suggested that a single-payer system could solve the problems of equity and access to health care, but the idea seemed to have only tepid support among participants. There is also a sense that Medicaid expansion is not the solution.

However, there is strong support for finding a way to equitably distribute health care resources throughout the state and to better link its resource-poor areas to resource-rich areas. There are clearly enough resources in the system, but they need to be better allocated, participants said. It was noted that in North Carolina there are four medical schools, but some poor, rural counties lack even a single doctor.

Participants also think that a "consumer's right" to health care should be linked to a more heightened sense of personal responsibility for one's own health. Currently, a lot of resources are used to treat people whose illness or injury could have been avoided with more responsible health behavior, better health information, and appropriate use of preventive care. For that reason, there needs to be a greater emphasis on health promotion and prevention. Schools could do a better job of incorporating health into the curriculum and there should be more incentives for people to try to stay healthy. It was also noted that "health promotion"— or helping people make appropriate health care decisions – should be emphasized throughout a person's lifespan and in all settings, whether for healthy individuals or those with terminal illness.

In North Carolina there has been some success in engaging communities on health care issues at the local level. With support from the state's Healthy Carolinians program, many communities have been able to

organize and focus on locally determined health care objectives. The Carolinas Center for Hospice & End of Life Care has also been able to engage communities on health care issues related to end-of-life care. Participants said that based on those experiences, they believe communities are often capable of making good decisions if they are given enough information.

The more difficult challenge is to translate those community-level discussions into a broad-based movement that can impact policymaking at the state and national level. Participants expressed support for initiating this type of effort and said that now seems to be the appropriate time to begin to attempt change. But they cautioned that it should be done carefully. To be effective, community discussions should be focused, well timed and leadership-driven. There has to be a well-defined purpose and an appropriate forum for educating participants, talking about issues, and working through differences. Even with these elements in place it will be difficult to achieve change because entrenched special interests are likely to oppose reform proposals that threaten their financial interests. Comprehensive reform is also likely to be very expensive.

The challenge of providing equity and universal access in a "non-system"

The health care community in North Carolina identifies equity and universal access as its two most important objectives. These goals are based on the principle that everyone has at least a moral right to health care, and to some extent a legal one. This "right" exists mainly as a social expectation that a safety net will be provided to those in need. But there is confusion and disagreement about what this right should entail. A health care safety net requires some rationing of services, but only the state of Oregon has held an explicit and public discussion of the rationing issue.

One challenge in trying to spell out the parameters for Americans' right to health care is that the U.S. does not actually have a health care "system," participants said. Health care in this country is too fragmented to be a system. The "non-system" we do have is difficult for consumers to navigate and lacks a consistent financial underpinning.

Coupled with the lack of a health care system is the absence of a health care agenda. "We have random acts of improvement going on, but there is no overall vision," said one person. The social contract for health care has developed in fits and starts. There are the Medicare and Medicaid programs, which are enormously popular, but there are also significant gaps.

In this environment, it is difficult to push forward an agenda of health care equity or a guarantee of universal access. In addition, our society has not yet identified these concepts as goals that everyone will support and be willing to finance. Proposals to subsidize coverage for people who are uninsured routinely run into objections from American voters and special interest groups that don't want to pay for the cost.

In the meantime, we have ended up with a "sick care system" that responds to illness or injury once they have occurred but is generally not designed to keep the population healthy. As a result, said one participant, we're patching up people that didn't need to be sick in the first place.

There is strong support in North Carolina for stepping up efforts to prevent illness and injury. To do that, there needs to be a greater emphasis on health promotion, public health and preventive health care. It was noted that one of the challenges in making preventive care and health education more available is that these activities are often not financially rewarding for providers. Consumers also need to understand the real cost of their care and the value of responsible health behavior. Consumers may need additional incentives to stay healthy.

Obstacles to change

The health care community in North Carolina is under no illusions that reform will be easy to achieve. Participants emphasized that reform efforts face major political obstacles. One of the most daunting is a lack of interest in health care issues among many policymakers at the national, state and local levels. In North Carolina, health care has not gained the level of attention that is consistently paid to issues such as education, roads and economic development. Few state lawmakers are considered knowledgeable about health care and few county commissioners are even interested in health care apart from the burden it places on county budgets.

There is also concern about the level of voter interest in and understanding of health care policy, which is often complex. Most of the public seems to have little knowledge of the issues involved, the problems that need to be addressed, or potential solutions. Health care intimidates many consumers/voters and tends to be left to "the experts." "The Clinton health care plan was dead on arrival because it was so complicated and badly articulated that the public didn't have a chance to understand what it was," said one person. "People can't support what they don't understand."

People also generally oppose ideas that seem to threaten their own interests. If they have a sense that providing more for other people will require them to "give up" something they have, voters and consumers are not likely to back it. People will accept change only if they perceive that the benefits outweigh the risks.

Another challenge is that health care is a major battleground for special interests. Year after year, issue after issue, special interest groups have been able to block changes in health care, said one participant. The obstructionists generally represent those that have become wealthy from the incentives that are provided under the current health care system, such as specialty physicians, academic medical centers, drug manufacturers and insurance companies.

These groups don't want to see their incentives taken away and they are very powerful, particularly in the absence of a strong consumer movement. That is why the key challenge in bringing about health care reform will be to mobilize a level of public support that can counteract the power of special interest groups and motivate policymakers.

Mobilizing public support for change

There are two points of view on whether public support can be mobilized in North Carolina. On the one hand, there is a fierce independent streak among North Carolinians, particularly outside of Raleigh. The mentality is that "we can do it ourselves," even when that does not appear to be the case. There is a distrust of government and the services it provides. Over the years, a number of efforts to bring local players together on health care issues have failed for lack of interest. Recently, a statewide effort to engage people on the issue of mental health reform has proven to be a huge challenge.

On the other hand, the Healthy Carolinians program can point to many communities that have successfully mobilized around health care goals such as establishing dental clinics and school-based health centers. Given the track record of these communities, "North Carolina is perfectly positioned for this kind of discussion," said a participant. Healthy Carolinians, AARP, The Carolinas Center for Hospice & End of Life Care, the North Carolina Division on Aging and the North Carolina Cooperative Extension all have organizational structures to promote community engagement at the grassroots level. It was suggested that there is a need to find additional state organizations that have this capacity in order to set up a statewide coalition/partnership to promote public awareness, education and engagement across the continuum of health care.

There was general agreement that an effort to engage the public would be worthwhile, but only if it is pursued under certain conditions. First, start with an education campaign designed to raise public awareness. It's hard to get people "on the same page" in terms of understanding what the problems are and looking at potential solutions, so there would have to be an effort to educate people. Second, conduct a statewide assessment of the resources for advocacy and education that already exist in communities. Third, if you're going to bring people together for a dialogue, you have to tell them where it's going. Without a well-defined purpose, people will not be interested or know how to respond. Timing is also important. People are more likely to be interested if they have good reason, such as an imminent crisis that will likely affect them.

The process is crucial. There is strong support in the health care community for public dialogue that is open and involves the grassroots. But there also has to be a vehicle for translating these community-level discussions into action at the national level. There has to be a national forum and there has to be dynamic, up-front leadership. As one person put it, "Unless we have someone who is willing to step forward and say very publicly that health care is the agenda, I don't think it's going to take place."

Ft. Lauderdale, Florida
May 7, 2003

The key values that emerged during a discussion of health care policy in Ft. Lauderdale were prevention, education, and taking personal responsibility for one's own health and health care decisions. Each of these values is linked to the need for consumers to become more knowledgeable about what they can and should do to maintain their own health and to be responsible for their health care choices.

At the same time, health care leaders in south Florida said they recognize there is a need for a national vision for health care. "Without a vision, we'll be treading water," said one participant. They said the vision has to be fairly simple and straightforward in order to gain public support.

One place to start would be an effort encouraging consumers to view health as a priority. Not only would it improve people's health status and the quality of their lives, it would also begin to reduce the burden on our mutual health care resources. Many of the problems plaguing the health care system could be significantly reduced or avoided if there were a greater emphasis on prevention and health education. "If you can get people educated before they have pain and see blood, you can go a long ways," said one participant.

It is especially important to target prevention and education efforts to children. There was agreement that health education should be taught in the public schools to a much greater extent than it is now. One suggestion was to put doctors and nurses in the schools to teach kids about health. "We're missing the boat on prevention by not getting kids when they're young," said a participant. It was noted that despite the rising numbers of obese children, physical education classes are often the first item to be cut when schools have budget problems.

There is deep concern about the increasing prevalence in our society of obesity and other chronic conditions that are related to lifestyle. "The numbers are rising and I fear where we're headed," said one participant. There has to be a much greater emphasis on personal responsibility. Individual responsibility is the most important factor that influences each person's ability to maintain his or her health. But there are a lot of consumers who don't know how to take responsibility for their health and health care decisions. They don't have the information and often they are not financially prepared.

There are a lot of consumers facing challenges that prevent them from being able to take more responsibility for their health care. In the case of elderly patients, many are not receiving the help they need to navigate the system, which leaves them confused and unable to access appropriate services. "I don't know how elderly people can navigate by themselves," said one participant. "The average elderly patient needs a PhD to understand billing."

In areas like south Florida there is a large multicultural population that faces significant barriers to accessing care. One participant who works at a community health clinic expressed grave concern about this growing population and providers' inability to reach them. Many of them are uninsured and it ends up costing much more to care for them because they don't understand how "the system" works.

Confronting the access issue: Is health care a right?

The problem of access to health care for the uninsured is one of the most pressing issues facing the country. Like many communities, south Florida has an increasing population of uninsured patients. Safety net providers are finding it difficult to keep up with the growing demand. One of the community health clinics in Broward County was treating 800 patients a month when it first opened a few years ago; now the clinic treats more than 10,000 patients a month.

But while the problem is growing, there does not appear to be a clear solution on which all can agree. Among health care leaders in south Florida, there is strong support but not universal agreement that all residents should be entitled to receive health care.

Several participants said they support universal access to basic services. "We have to recognize that not everyone can have everything, but we all need the basics," said one. "We need to develop universal, basic health care coverage," said another. However, it is difficult to define what is "basic" and what is not. This discussion has occurred in Oregon but few other places.

Nor is there agreement that health care should be defined as a "right." Several participants said they objected to that idea. "How many rights do we already have in our world?" said one. It was suggested that the message should be "health care is a privilege to which everyone should have access."

Certainly there is enough money in the health care system to provide high quality health care to everyone, participants said. But the problem is that a lot of the dollars are wasted or misdirected. "We spend a fortune on health care and yet we have 40 million who are uninsured – unbelievable!" said one participant. Reducing waste would free up resources that could be used to address the access problem.

It would also be helpful if consumers had more realistic expectations of what they can expect from the health care system, participants said. "The whole nation believes they deserve the best care in the world, but how do we pay for it?" asked one.

Low morale and other issues affecting health care professionals

There is a lot of concern in south Florida that the workforce pipeline is dwindling and fewer young people want to go into health care professions. There is also a strong sense that people who currently work in

health care are getting much less satisfaction out of it than they did before. "Provider morale stinks in south Florida," said one participant.

Among physicians, the morale problem is due to many pressures but especially the liability issue. "Medical malpractice is killing us in south Florida and threatening access to specialists," said a physician. "We're punishing the good guys for the sins of the bad guys." There was agreement that tort reform is essential. Without it, more and more physicians will come to view patients as "the enemy."

The liability issue doesn't just affect physician morale. Liability costs put an inordinate burden on health care dollars. "Nursing homes' liability costs are an extreme problem in Florida," said one participant. The liability concern also acts as a barrier to serious attempts to address patient safety. Instead, physicians are practicing a lot of defensive medicine to protect themselves against potential lawsuits.

Several participants also suggested there is a need to re-educate health care professionals so that there is more emphasis on "soft skills" – like the "bedside manner" – that affect a patient's experience. "We need to rekindle our human connection to health care," said one participant. Health care should be "not just high tech, but high touch." There also needs to be an increased level of multicultural competency across the spectrum of health care providers.

Crafting a national health care agenda: Government should step in

Health care leaders in south Florida said the problems that face health care today cry out for attention from our political leaders, but our country still has not begun to craft a national health care agenda. Participants called for a national vision, courageous leadership, and a "gut-level commitment" to the cause of improving the health care system. "We need a national program, similar to the moon landing, to address universal care," said one. "Government has to bring all stakeholders to the table and say that yes, in ten years there will be universal care."

But several participants also said they are skeptical about the role of government in health care. There is considerable confusion about the various levels of government (federal, state, and local) and their various functions (as regulator, provider, and payer) in health care. "Government tends to be reactive rather than proactive," said one person. "Government is responsible for many of the problems in health care today," said another. Nevertheless, most agreed that government is the only entity with the capacity to bring stakeholders together to craft a common vision. "I'm probably as cynical as anyone about the role of government," said one person. "But I'm not sure what other entity can be the catalyst to get it done. I don't think it can come from within the industry because there are too many axes to grind. The grassroots aren't in a position to drive change. Employers have tried to come together, but they are not in a position to address all of the problems."

If political leaders in Washington were to take charge of a national discussion on health care, participants would have several suggestions for them. One is to try to keep it from becoming a partisan issue. Instead, they said, keep health care reform a public health issue.

Second, avoid the lobbying crowd, which tends to act as a significant barrier to reform efforts. "There is so much lobbying in Washington that prevents change," said one person. "Industry groups stand in the way when their interests are challenged." A better route would be to convene a meeting of association heads and CEOs, rather than lobbyists. "You will get more done."

Third, the effort has to directly involve average consumers and local organizations. It cannot be a top-down approach directed from Washington, like the Clinton health care plan. "This effort needs to get out to the grassroots, and it needs to reflect grassroots values or it won't be sustainable," said one participant.

Fourth, whatever the message is, it should use simple, straightforward concepts. "We need a national vision that is simple to understand," said one participant. One of the major challenges is to educate consumers that there really is a crisis in health care that needs to be addressed. Many consumers think that debates about health care financing are just arguments between powerful health care interest groups about money and that they really don't concern them.

Jackson, Mississippi
May 23, 2003

There is deep concern among Mississippi health care leaders about two key issues facing the health care system. One issue is to find a way of providing at least a basic level of coverage to the state's large number of low-income, medically underserved residents. The other issue is figuring out how to align incentives to promote better health status and greater responsibility on the part of consumers. In both cases, the goal is to achieve better health for individuals at a lower cost to the system.

Mississippi has some of the worst health statistics in the United States. "We have bad health indicators, and they're getting worse," said one participant. Lack of access to health care services is a primary reason, particularly in impoverished areas such as the Delta, which has a high number of uninsured patients and too few health care providers. Many low-income families and individuals do not qualify for the state's Medicaid program, which leaves many of them uninsured.

Mississippi health care leaders recognize that lack of coverage not only harms the individual; it often translates into higher costs to administer care in the long run. Uninsured patients suffer worse health outcomes, but they also tend to rely on high-cost settings such as hospital emergency rooms for their care. It

was noted that universal coverage would not only promote human dignity, but would also make good economic sense.

However, there is disagreement over the extent to which government is responsible for ensuring universal coverage. Some cautioned against government playing too great a role in health care, citing concern that it would not work in a market-driven economy. But there seemed to be a consensus of support for ensuring that all residents have access to a basic level of health care services.

There was also agreement that certain areas of health care should receive greater emphasis and support. Health education and prevention were mentioned repeatedly as areas that need more attention. "We invest only 1% of health care dollars in prevention," said one participant. Health education is minimal in Mississippi.

Many consumers, particularly those who are low-income uninsured, have little knowledge of how to maintain their own health. A physician in the Delta said that a lot of care provided in hospital emergency departments is for simple ailments that people could easily treat at home if they had basic medical information. Another area that deserves more attention is the issue of incentives for individuals to maintain their health as well as they can while not misusing resources.

Health care leaders in Mississippi express a sense of urgency about the need to address these issues because of the impact of growing health care costs. "I think the crisis is worse now than it was [in the early 1990s]," said one participant. "We have a sense that every sector is feeling so much pain right now that sectors are more willing to come together," said another. Also, awareness that there are serious problems is spreading from the health care community to the general public. Many people who have insurance find they are paying more for it each year. "It is becoming a middle-class consumer crisis," he continued.

Policymakers need to recognize there is a crisis in health care and start taking action. "If we could declare our health care dilemma as a threat to national security, our country would react as it did in Iraq and act to correct it," said one participant.

Ensuring a "basic" level of coverage

The consensus among participants is that not everyone can have "red-carpet health care." but everyone should have at least a basic level of health care coverage. "Coverage does matter," said one participant. "If people don't have coverage, this system is not going to be successful."

However, defining a "basic" benefits package to which everyone is entitled, is not an easy proposition. One participant said basic coverage should be absolutely minimal. "We don't owe anyone anything above maybe an ambulance when they have a heart attack and immediate, life-saving care. Beyond that, it depends on ability to pay."

Others disagreed. One noted that a more comprehensive benefits package that includes preventive and primary health care could actually reduce overall costs to the system. "Providing [just] ambulance and life-sustaining care is the problem now because it's so expensive to do it that way." Others said there is a moral imperative to provide universal coverage. "We are our brothers' and sisters' keepers."

An insurance company executive pointed out that basic coverage would have to be pretty comprehensive to have a significant impact on the way that uninsured patients use the health care system. "If a basic level of care is not rich enough to prevent the current cost shifting, then it's not worth it," he said. "It has to be both evidence-based and comprehensive coverage."

To design a basic benefits package, the insurance executive suggested setting a target cost per patient and having clinicians rank all of the health care services, along with their price tags, from services that are the most necessary and beneficial to those that are the least. You start working down the list, he said, and when you get to the target price you stop. That would be the cut-off point for the basic benefits package.

Several participants said they would support this kind of explicit rationing process, which has been carried out in Oregon. Under this model, the benefits would also be designed so that cost sharing is related to income and co-payments incentivize healthy behavior. Supplemental coverage would be available to those who want to purchase it.

The concept of a basic benefits package seemed to have majority support among participants, but several pointed out the political challenges. It was noted that a basic benefits package was the centerpiece of the Clinton health care plan. "Back then it was described as the worst thing that could have happened," said one participant who worked on the Clinton plan. "So it's interesting that it's resurfacing now."

On the issue of personal responsibility and a social contract

Although health care leaders in Mississippi tend to support the concept of universal coverage, they also emphasize the need for patients to assume more responsibility for their health and the cost of their care. They would like there to be a social contract for health care that would more clearly link rights to responsibilities, but are uncertain about how to get there.

Participants express some frustration with patients, particularly those who are uninsured; who seem to have high expectations of their health care but little concern for how it's financed. "I see an increasing number of patients who have an almost angry sense of entitlement to health care, and they think it shouldn't have to cost them anything," said a physician who practices in the Delta.

On the other hand, there are many uninsured patients who do not seek out the health care services they need and that are available. "You may see patients in your office that seem entitled," another participant

responded. "My concern is those you don't see in your office because they're too embarrassed or they don't understand the importance of prevention."

The bottom line is that too many patients don't know how to use the health care system appropriately. Moreover, patients' incentives are not aligned so that they will choose to use the health system optimally. As one participant put it, why would poor people spend their money on a health plan when they can use the ER for free? On the other hand, why would a low-income, uninsured patient seek preventive services if they cannot afford the out-of-pocket cost?

So some patients are going to the emergency room for colds and cuts, while others have serious health conditions that go undetected and untreated because they can't access primary and preventive care services. In both cases, the social contract for health care is undermined, to the detriment of patients and the overall health care system.

Enhancing the role of health education

Better health education is certainly one of the keys to improving patient health and making the health care system more effective, participants said. Several noted that health and education are inextricably linked. But many uninsured patients have not been educated to make basic health care decisions. "They don't keep aspirin at home for when they have a headache," said one participant. "They go to the ER for everything."

Participants said that patients have to be better educated about their health and about their rights and responsibilities vis-à-vis the health care system. A good place to start the education process would be with expectant mothers and young children. "A lot of ER care can be done by Mama, like how to treat a cold," said a physician. "We need to educate and we need to start in the schools with sex education and nutrition." However, in Mississippi, health education appears to be minimal. The perception is public schools do not offer sex education and many schools do not have a full-time nurse.

Concerns about how to approach health care reform

Health care leaders in Mississippi seem to agree that health care reform is necessary and urgent. But they said it would also take a great deal of courage and determination to overcome the political obstacles. "Any health care reform will be pulled apart by interests, including business," said one.

Several participants warned against taking on a health care reform agenda that is perceived as too far-reaching because of the opposition it would attract. The Clinton health plan failed because of "the perception that it was too ambitious, and the resistance of insurers," said one. "The opposition was so well-organized it was impossible to break through." Another suggested that in order for reform to be successful, there would have to be a broad-based consumer and provider coalition backing a common vision of basic

health care for all. We need to "sell the vision," and the way to sell it is by having the health care community come together in support.

As for what the vision should be, universal coverage had overwhelming support around the table. But several people cautioned against taking health care reform in the direction of a single-payer or "socialist" system. "This is not socialism," said one. "We have to be personally responsible for our health and our bills." "You have to accept that Russia failed," said another. "Socialism doesn't work." One participant spoke up in favor of a single-payer health care system. But another responded, "Those of us who know physician behavior and know hospital behavior are worried about the consequences of single payer."

APPENDIX B: CASE STUDIES

SHARED DECISION-MAKING IN SPINAL CONDITIONS

DARTMOUTH-HITCHCOCK MEDICAL CENTER
HANOVER/LEBANON, NEW HAMPSHIRE

Dartmouth-Hitchcock Medical Center finds itself in the uncommon position of being a "big city" hospital located in a rural area. As a result of this unique situation, part of their mission is to focus broadly on efforts to improve not only patient care but community health as well.

Some time ago leaders at Dartmouth Medical School's Center for Evaluative Clinical Sciences began asking themselves the question, "What are we going to do to improve delivery of healthcare in our region?" Toward that end, they launched an effort to assist patients and physicians in evaluating treatment options from the perspective of the patient's wishes and values, an approach called "shared decision making." This model is derived from a vision crafted by Drs. Jack Wennberg and Albert Mulley to include patients more actively in decisions relating to their health care. In order to participate in the shared decision process, however, they first need to be well-informed.

Many physicians at first resisted the notion of a formalized process to enhance patient engagement. Most felt, to the extent that it was necessary, shared decision making was already in place in their practices. However, in talking with many patients this did appear to be the case. Many patients indicated they were not aware and had not had the opportunity to discuss different treatment options. Nor were they sure what to expect next when it came to their care or surgery decisions.

Since Dartmouth is involved in numerous clinical outcomes studies, it seemed natural to launch such an initiative as development of an informed choice process for patients. Thus, the Center for Shared Decision-Making was created. Several goals were established for the Center: first, to offer shared decision-making tools and services to patients, clinicians and the public; second, to work with clinicians to integrate shared decision making into clinical practice; third, to initiate and participate in research on the value and impact of shared decision-making tools and processes; and finally, to offer training in decision support as a clinical skill.

The Center does not charge patients for its services. In its prototypical model within the Spine Center at Dartmouth-Hitchcock Medical Center (DHMC), all physicians are required to use the shared decision-making model as part of their clinical trial protocols.

In the beginning physicians were concerned about additional time requirements or the potential for interference with the doctor-patient relationship. It was clear that without implementation leadership, this project could be in jeopardy. Dr. Jim Weinstein not only believed in the vision of Jack Wennberg, he was convinced that physician resistance could be overcome. Since Jim was also a practicing clinician, he understood the concerns of the physician community and appreciated what it would take to bring shared decision-making to life. He was put in charge of implementing this new program at Dartmouth in 1999.

The actual time involved in the process did not prove to be a problem once Spine Center physicians were trained to use shared decision-making tools. Having an independent center for patients and physicians to seek additional assistance and support has become a real asset. Patients can speak with a trained counselor who provides decision support by assessing the degree and sources of decisional conflict, formulating a plan to address information needs, clarifying values and ensuring support from others in making difficult health care decisions. Jim and the team at the Center became advocates for the adoption of shared decision making, or what Jim calls "informed choice".

Measures are underway to track surgical decisions, patient information levels and to link these points to the outcomes of treatment and utilization of resources. While there is now broad support for the Center for Shared Decision Making and the process, it is too early to have all the measurement results. What is clear is that patient

satisfaction levels are up significantly and physicians are realizing the process strengthens, not weakens the entire patient relationship.

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EXCHANGING KNOWLEDGE AND IDEAS AMONG INDEPENDENT CLINICIANS

THE DARTMOUTH/NORTHERN NEW ENGLAND COOP PROJECT
NEW HAMPSHIRE, MAINE AND VERMONT

During a New England blizzard 20 years ago, a heated debate took place among doctors and nurses from the Dartmouth/Northern New England COOP Project. The topic: Do doctors really know what matters to their patients? As a result of the discussion that evening, they carried out a study that was published in The Journal of the American Medical Association in 1983. The findings showed that, in fact, doctors and nurses are frequently unaware of what matters most to their patients.

For more than 30 years, the Dartmouth/Northern New England COOP Project has functioned as a voluntary network of independent primary care clinicians in New Hampshire, Maine and Vermont, which makes it the oldest primary care, practice-based, research network in the country. Clinician members number about 400, with about 60% family practice, 30% internal medicine and 10% pediatric. They meet regularly to advise the COOP staff, prioritize research activities, and determine organizational policies.

Among their most successful efforts has been linking independent clinicians in New England and to provide forums for the exchange of knowledge and ideas. Many of the COOP's members are in small towns and rural areas where there is not a large clinician community or opportunities to discuss clinical innovations and other subjects of interest to physicians and nurses. As a forum for "intellectual exchange," the COOP has enabled clinicians to serve as sources of information for each other, which has even affected clinical practice.

Over the years, the COOP has also successfully competed for millions of dollars from the National Institutes of Health and private foundations, and has published more than 50 peer-reviewed articles. As a result of its study published in JAMA in 1983, the COOP membership elected a governing board of practicing clinicians to provide guidance to the Dartmouth Medical School's Department of Community and Family Medicine. During the past five years, the COOP has also worked closely with the Institute for Health Care Improvement on efforts to improve interactions between patients and clinicians.

The Dartmouth COOP study was also the first to identify the problem of poor communication between patients and clinicians. The study found that 3 out of 10 patients have problems of which their doctors and nurses are unaware. Even when clinicians are aware of certain problems, they may not have the time to provide the level of education and assistance that a patient may need. These problems persist even today, according to Dartmouth COOP research.

It is startling to realize that in today's health care system about 80% of Americans are dissatisfied with the health care they receive and/or don't feel confident they can manage and control their health problems. COOP members decided to develop effective improvements in health care communication because they realized how important it is to boost Americans' satisfaction and confidence in their health care.

Over the years, the COOP developed an approach to improving communication in the clinical setting. They created a template, available at www.howsyourhealth.org, which allows both patients and clinicians to be "on the same page" for improving patients' health.

Numerous organizations have cited the website as an information source for patients, and recently Chicago Mayor Richard M. Daley encouraged local institutions, government agencies and businesses to help citizens improve their interactions with health care providers by consulting the website.

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COMPREHENSIVE HEALTH CARE FOR LOW-INCOME, UNINSURED PATIENTS

HEALTHLINK PROGRAM, LRGHEALTHCARE
LACONIA, NEW HAMPSHIRE

In the early 1990s, not-for-profit Lakes Region General Hospital in Laconia, NH, decided to confront a challenge familiar to many hospitals and health systems. The hospital was looking for a way to better manage uncompensated care so that low-income, uninsured residents would have timely access to comprehensive health care. Expecting these patients to rely on hospital emergency departments and a patchwork of "pro bono" services was not meeting the needs of either patients or the community's health care providers. So in 1993, Lakes Region General Hospital's board of directors established HealthLink, a subsidized health care plan for low-income residents not eligible for the state's Medicaid program.

Using a managed care model, the hospital developed a network that offers HealthLink patients access to the full spectrum of health care services, including affordable prescription drugs. In addition to Lakes Region General Hospital, the HealthLink network includes other community hospitals, group practices of primary care and specialist physicians, home health care and long-term care providers, specialist physicians that do outreach to rural hospitals, and participating pharmacies. Anthem Blue Cross/Blue Shield administers the program.

In addition to using tools typically found among commercial insurance products – such as provider networks and copays – HealthLink assigns each patient a care manager upon enrollment. The care manager performs a health risk assessment and works with the patient to produce a personal care management plan that is then sent to providers before the patient's initial visit. The care manager also educates patients about wellness resources available to them, such as smoking cessation programs. This element of HealthLink has been particularly successful, and the state of New Hampshire is now considering adding care management to its Medicaid program.

Other HealthLink program components include community wellness centers that provide support patients with chronic illness, and a dental resource center that provides dental services to a targeted group of underserved children and adults. HealthLink received a state grant to develop the dental resource center, but the hospital board also spent $700,000 to cover its initial costs.

Lake Regions General Hospital, since renamed LRGHealthcare, has made a substantial financial investment in the HealthLink program since its inception almost a decade ago. The hospital has built a dedicated fund of more than $10 million to ensure the program's continuity and each year devotes millions of dollars to covering program costs. The community's physicians also make a significant "pro bono" contribution to HealthLink that totals approximately $1 million to $1.5 million each year.

As a result of this effort, by the end of 2002, HealthLink was serving approximately 600 patients with incomes at or below 200% of the federal poverty level who would otherwise have had no way to pay for the costs of their healthcare. Through its enrollment outreach efforts, HealthLink also signed up more than 3000 patients for Medicaid and the state's Children's Health Insurance Program. Since the program began in the early 1990s, local hospitals have seen an enormous drop in the number of emergency room visits by HealthLink members.

LRGHealthcare has received national recognition for its HealthLink program for the uninsured, and was named a recipient in 1994 of the American Hospital Association's first NOVA Award. Yet despite the program's success, HealthLink has not yet been replicated by other communities in New Hampshire.

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ENGAGING CITIZENS IN HEALTH CARE POLICY DISCUSSIONS

VERMONT ETHICS NETWORK
MONTPELIER, VERMONT

The Vermont Ethics Network has been working for nearly twenty years to engage the people of Vermont in public dialogue about important health care issues, from health care reform and trust in medicine to terminal illness and end-of-life issues. The network specializes in holding small-group, values-based discussions and has trained hundreds of discussion group leaders throughout the state to frame issues and facilitate dialogue.

VEN's mission is to increase public understanding of the ethical issues, dilemmas and choices in health care, says board chairman Richard Brandenburg. "The goal is not advocacy of any particular position," he says. "The intent is openness, objectivity, and respect for all viewpoints."

The discussions facilitated by VEN have succeeded in raising public awareness of health care issues and increasing appreciation for the complexity of health care. The discussions have provided state government with important feedback from the public on health care policy proposals. Many of Vermont's health care institutions have also turned to the network as a resource.

VEN was created under the auspices of the Vermont Health Policy Council, which was established by the state of Vermont in 1985 to advise the governor, legislature and state agencies on the creation of a Vermont health plan. The council decided to establish a special task force that would solicit the public's thoughts on terminal illness and end-of-life issues. The task force held more than 200 community meetings in churches, schools, community centers and other settings, which led to the publication of a booklet on advanced directives. Out of these discussions also came an agreement to establish the Vermont Ethics Network.

VEN soon branched out from terminal illness issues and began holding quarterly meetings on topics ranging from trust in medicine to health care quality. At the same time, a number of health care institutions, especially hospitals, were becoming interested in setting up ethics committees. Many of them, along with the state medical and bar associations, turned to the network.

Over the years, VEN has worked to engage the public on many of the most important health care policy questions facing Vermont. In 1989, the network initiated a project to explore health care reform proposals and examine "big picture" issues, such as necessary tradeoffs among access, quality and cost. Called the Vermont Health Decisions Project, it involved nearly 3,000 Vermonters and about 125 community forums.

The network became an independent, non-profit organization in 1992. Its major sources of funding are the state's hospitals, grants (both public and private), donations from individuals, and product sales of booklets promoting the use of advance directives.

In 1993, the network organized a project to educate Vermonters about the state's health care reform process. At the time, the legislature was considering two proposals to create universal access. The Vermont Health Care Authority, recognizing the need to inform Vermonters about the proposals and solicit their feedback, contracted with VEN to hold nearly 100 community meetings.

In 1996, VEN revisited end-of-life and terminal illness issues by creating a project called "Journey's End" that gathered information about the needs of dying Vermonters and their family caregivers and educated chaplains, nurses, social workers and others who work with terminally ill patients. This project is ongoing.

Recent initiatives included a project in 2001-2002 to engage the public on the problem of health care access. Several foundations and the state of Vermont gave the network grants to create about 20 "study circles" of 6 to 12 people each. Using a small-group approach and a specially designed workbook for guidance, the study circles produced a major report on health care access.

One of the network's most recent initiatives was to organize a program entitled "Who Wants to Know?" that examines the ethical tensions between the sharing of patients' medical information and a patient's right to privacy. Cosponsored with the Vermont Medical Association, Fletcher-Allen Health Care, and the Vermont Association of Hospitals and Health Systems, the half-day program was offered in 2002 to health care professionals. The network recently offered a workshop for state legislators on the ethical issues and perspectives involved in the physician-assisted suicide debate.

In Vermont, there has been positive recognition among individuals, caregivers, policymakers and communities of the Network's efforts, particularly in the area of advanced directives. Among the lessons that have been learned along the way are the value of opening up public discussion on ethical issues in health policy rather than closing down dialogue, and leveraging knowledge and experience resources through collaborative relationships with other organizations, says Brandenburg. The Vermont Ethics Network is meeting the need for an ongoing process that informs and engages the public in these issues and frames the critical questions about health care values and choices in a neutral environment.

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REACHING OUT TO VICTIMS OF DOMESTIC VIOLENCE

BLUE CROSS BLUE SHIELD OF VERMONT

Blue Cross Blue Shield of Vermont launched an initiative in 2001 aimed at improving health care providers' ability to screen patients for signs of domestic violence, refer domestic abuse victims to confidential support services, and document evidence of abuse.

The project emerged from a growing awareness that health care providers often fail to recognize the signs of domestic violence or intervene appropriately. Only one in ten primary care providers regularly screens their patients for domestic abuse, according to a 1999 study by The Journal of the American Medical Association. Only one in three health maintenance organizations have procedures or materials for screening for domestic violence.

And yet, domestic violence is so prevalent that one in three women report being physically or sexually abused by a husband or boyfriend at some time in their lives, according to a 1998 survey by the Commonwealth Fund. According to the U.S. Department of Justice, 37% of all women seeking emergency room care for violence-related injuries were injured at the hands of a current or former spouse or partner. But victims are often reluctant to share information about the abuse with their health care practitioner, and many providers lack the knowledge and tools for screening, assessment, and intervention.

Blue Cross Blue Shield of Vermont's initiative, called "Reaching Out to Victims of Domestic Violence," is the result of a partnership with the University of Vermont Medical College, the Vermont Network Against Family Violence and Sexual Assault, and Women Helping Battered Women in Burlington, Vermont.

Through this initiative, Blue Cross Blue Shield of Vermont sought to increase providers' knowledge about domestic violence by sending "tool kits" to all of the emergency departments, primary care practices and OB/Gyn practices in the state. The tool kit contained a "physician's guide" that provided facts about domestic violence and recommendations for screening and intervention. It also included a poster with a pocket of "safety cards" outlining safety tips for victims leaving a violent situation and numbers to call for help.

The tool kit has significantly improved physicians' perceived ability to screen patients for domestic violence, document abuse, and refer victims to support services, according to before-and-after surveys conducted by Blue Cross Blue Shield of Vermont.

Before receiving the tool kit, 32% of physicians said their practice was well or extremely well equipped to screen victims of domestic violence. But that percentage increased to 68% after they received the tool kit. Similarly, the percentage of physicians who thought their practices were well or extremely well equipped to document domestic violence rose from 36% to 64%.

The survey also shows a statistically significant improvement in providers' ability to screen patients for abuse. On the other hand, its findings suggest there is an opportunity to do more education. In response to these interim results, the plan is working with the state health department, public agencies, and community-based organizations to develop a strategy to further improve providers' ability to recognize the signs of domestic violence and help abuse victims connect with available resources.

For more information, contact: **http://www.bcbsvt.com/**

COMMUNITY HEALTH ACCESS FOR SENIORS EFFORT (CHASE) PROGRAM

TUFTS HEALTH PLAN, BOSTON, MASSACHUSETTS

While most seniors already qualify for basic health care coverage through the federal Medicare program, immigrant and isolated seniors suffer acutely from preventable illness and premature death due to their inability to access critical health and social services. In 1997, Secure Horizons®, Tufts Health Plan for Seniors, worked with The Medical Foundation, Inc. to conduct extensive primary and secondary research in an effort to identify the needs of Boston's seniors. Based on the findings of this extensive research, Tufts Health Plan collaborated with senior institutions and community-based organizations to identify and reintegrate seniors in need of health and social services, one senior at a time, through sustainable community-based programs.

Tufts Health Plan launched the Community Health Access for Seniors Effort (CHASE) Program in partnership with four community-based collaboratives dedicated to bridging gaps for seniors in accessing health and social services. Since 1998, CHASE has improved the health and social service needs of more than 5,000 ethnically diverse, primarily poor and isolated seniors. Based on their success and replicability, two CHASE partnerships continue to be funded today: the Senior Health Education and Access (SHEA) Project and the Medical ACCESS Project.

The Senior Health Education and Access (SHEA) Project, run by Kit Clark Senior Services Center, connects seniors to highly customized health care services, information and resources through a comprehensive, individualized needs assessment followed by customized counseling, education and information dissemination.

The Medical ACCESS Project, run by MATCH-UP Interfaith Volunteers, delivers comprehensive educational workshops called, "What's Up Doc?" which are designed to break through communication barriers between senior patients and their physicians. The Medical ACCESS Project also incorporates a highly organized volunteer medical escort program free of charge for elders and disabled individuals within greater Boston neighborhoods.

Since 1998, more than 3,100 seniors and senior providers have attended more than 200 "What's Up Doc?" workshops, conducted in five languages. The MATCH-UP ACCESS Medical Escort Project has served more than 1,300 seniors since 1998, representing 2% of Boston's total senior population, and nearly 10% of the isolated senior population. The SHEA Program has identified more than 11,400 senior health and social service needs, including nutrition, basic literacy and social interaction and access to prescription drugs, primary care and life saving immunizations. As a direct result of these assessments and interventions, 915 seniors in the Dorchester area of Boston have reported receiving the important services identified.

For more information, contact: **Tufts Health Plan**
http://www.tufts-health.com/home.php

THE PATIENT NAVIGATOR PROGRAM

HARLEM, NEW YORK CITY & WASHINGTON, DC

Navigating the health care system can be an insurmountable barrier for many people, especially when they are poor and underinsured or uninsured. Helping people stay healthy and gain access to and find their way through the health system is the idea behind the Patient Navigator programs in New York City and Washington, D.C.

Located in the heart of Harlem, NYC and Washington, DC, these programs – which serve mostly underinsured and uninsured Hispanic and African-American women – offer a comprehensive approach to cancer prevention, early detection and treatment. The concept is unique in that they are geared to capture people who have not experienced any symptoms, with the ultimate goal of raising awareness about actions they can take to prevent disease. These programs provide culturally sensitive services tailored to meet the specific needs of the surrounding community, including assistance in obtaining coverage through Medicaid or other sources, together with cancer screening, counseling about disease prevention, and referrals for treatment should an abnormality be detected.

In general, people enter the Ralph Lauren Center for Cancer Prevention and Care of Harlem NYC program through free screening clinics at North General Hospital (in-patient setting) or the Breast Examination Center of Harlem (outpatient setting). Culturally and linguistically sensitive outreach workers promote the services of these clinics at various community hubs, spreading the word about the importance of cancer screening as a means of detecting disease early, when it can be most effectively treated.   As a result of this program, diagnosis of early stage breast cancer in the Harlem community has improved from 1 out of 20 in 1989 to 4 out of 10 women today, and the average length of time between initial breast exams and biopsies has decreased to 10 days, a rate comparable to patients in private care.

At the Washington Hospital Center "Cancer Preventorium" in Washington D.C., healthy people make appointments and pay a $64 fee out-of-pocket (based on the Medicare rate) to have a complete physical exam, including cancer screening tests, and learn in Spanish about what they can and should do to prevent disease.   Word of mouth has made this program very successful in the Hispanic/Latino community, and the clinic is also promoted through radio and television programs created and hosted by the clinic's director.   At the Cancer Preventorium, the impact on patients has been extraordinary, with compliance rates for mammograms and follow-up examinations improving considerably. Over 10,000 people have been seen at the Preventorium since its inception. Sixty percent of those patients had no health insurance, and 85% had no symptoms at the time of visit, with 16 cancers found. Preliminary data indicate that compliance rates for mammograms and follow up examinations have improved considerably.

Under both programs, in addition to the physicians, staff are involved as "Patient Navigators" to identify those patients who may require assistance in obtaining coverage and guidance toward treatment as a result of an abnormal exam. These navigators ensure that patients do not fall through the cracks, receive the guidance and treatment they need, and speak in the patient's language, answering patients' questions and helping to allay their fears about diagnosis, treatment, and coverage.

Patient Navigator programs offer a unique, comforting, neighborhood setting in which health awareness and cancer

prevention services are provided to the surrounding community. They are extraordinary programs that are making a real difference in the lives of people who suffer disproportionately from cancer.

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A HEALTH MINISTRY PROGRAM FOR WOMEN

KEYSTONE MERCY HEALTH PLAN
PHILADELPHIA, PENNSYLVANIA

Keystone Mercy Health Plan, which provides health care services to Medicaid recipients in southeastern Pennsylvania, launched an initiative in 2000 to promote preventive health care and wellness programs among African-American women in the Philadelphia area. Called the "Health Ministry Program for Women," the initiative aims to reach low-income, African-American women with informational workshops about health and health care resources.

Numerous studies have found that low-income women often have difficulty finding out how to obtain support services that would help them address health problems. Moreover, African-American women suffer disproportionately from chronic diseases such as cardiovascular and respiratory diseases, diabetes and arthritis.

In creating the Health Ministry Program for Women, Keystone Mercy Health Plan decided to partner with local church congregations, which promote the program to their members. Keystone Mercy also encourages its Medicaid members, local providers, and the community-at-large to participate.

The program consists of free, interactive workshops and presentations that address the health needs of women. The workshops are offered in a church setting, which provides a welcoming and familiar environment for women and girls to learn about assessing their health and coping with health problems.

Workshop topics include managing stress, controlling diabetes, and breast cancer detection. Presentations are followed by individual health assessments to identify the diseases for which participants may be at risk. The workshops also provide an overview of the preventive steps that women can take to avoid the conditions for which they have been identified as at risk. Health resource directories are provided to all participants.

Keystone Mercy has worked with national advocacy groups such as the American Diabetes Association, the American Lung Association, the American Cancer Society, and the Arthritis Foundation, to design the workshops and train nurses and facilitators in participating congregations. A team of 35 nurses coordinates the program's activities.

In its first two years, the Health Ministry Program for Women served over 1,000 African-American women. The impact of the program is not limited to the workshops. By having nurses who are trained to help women with their health care issues in these participating churches and providing them with a referral guide, the program continues to educate and support women throughout the year.

For more information, contact: **Keystone Mercy Health Plan**
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TRANSFORMING THE SAFETY-NET DELIVERY SYSTEM

COORDINATED CARE NETWORK
PITTSBURGH, PENNSYLVANIA

Jeff Palmer, CEO of the Coordinated Care Network, remembers a day in 1995 when a single mother and her five children walked into the East Liberty Family Health Center in Pittsburgh, where he was then serving as the new executive director. The woman thought she had the flu and said she wanted a prescription for antibiotics so she could go back to work the next day. As it turned out, she was pregnant with her sixth child. She was also HIV-positive. During her visit with the doctor, bruises on her body revealed that she might have been the victim of domestic violence. She also later admitted using drugs to "escape the pain."

While these problems were coming to light in the doctor's office, Palmer was watching the woman's children in the health center's waiting room. He soon discovered that the children all suffered from their own set of challenging health problems. They ranged from asthma to diabetes to, in the case of the youngest infant, failure to thrive due to nutritional deficiency. That day, the health center staff transported the woman and her children to the hospital so she could receive immediate treatment. But it was too late to help her, said Palmer. "Now six children are without their mother."

The day after the woman and her children came to the health center, Palmer called a meeting of the entire staff and asked them: Are there not systems in place to prevent this type of disaster from hitting another family? The answer he got back was "no, not really." Palmer said he was shocked but discovered that that was indeed accurate. No one had put systems in place to ensure that poor people in Pittsburgh were getting the help they needed, "even in the very backyard of one of the premier medical institutions in the world," the University of Pittsburgh Medical Center.

In May 1996 Palmer called a town meeting of the area's safety net agencies to talk about the lack of coordination among providers of health care and social services, which was causing many of the poorest and sickest patients to fall through the cracks of the safety net. Everyone agreed that this was a problem and that it was appalling enough to require some major changes. Palmer then presented a vision of a new system – one that would identify the sickest and most needy patients much earlier in the progression of their illnesses and connect them with a delivery system to receive appropriate care. At the town hall meeting, twenty local agencies stepped forward and said they wanted to participate in making that vision a reality.

Two years later, in March 1998, the Coordinated Care Network became operational as the umbrella organization for coordinating the care of at-risk patients served by twelve member agencies, all of which were faith-based organizations. Initial funding for the network came from two national foundations – The Robert Wood Johnson Foundation and the Pfizer Foundation – and 10 local foundations.

Although heavily reliant on foundation and grant money in the beginning, the Coordinated Care Network quickly sought commercial contracts, which are now its main source of funding. Of the approximately 57,000 patients served by the network, about 7,000 are enrolled in Gateway Health Plan, the region's largest Medicaid health maintenance organization. The network provides outreach and case management for some of Gateway's most hard-to-reach, at-risk patients. The goals, Palmer says, are to reduce the cost of care through early intervention, prevention and aggressive case management; get paid on a gain-sharing basis; and generate earned income for the network to use to subsidize care for its uninsured patients. According to the health plan's preliminary data, the network reduced inpatient bed days by 22% and emergency room visits by 24% over an 18-month period per 1,000 population.

Palmer says the network had to redesign its case management model before finding one that worked. Initially, the network's only function was to identify high-risk patients. The case management was then delegated to its member organizations. But many providers didn't have the capacity to do case management in addition to serving large numbers of patients/clients. Next, the network tried giving its members dedicated resources and additional funds to hire case managers. But the case managers, it turned out, did not have enough authority within their respective agencies to bring about the kind of "system" changes that were needed. So ultimately, the network centralized case management, put case managers on its own payroll, and asked the agencies to just focus on health care delivery. That decision "was clearly one of our critical success factors," says Palmer.

Most recently, the network has added an important component to its services by creating a "prescription discount program" thanks to a grant from the federal Community Access Program. Under the program, the network buys prescription drugs at a dramatically reduced cost through the federal 340B drug discount program, then packages them in common dosages at a centralized pharmacy/mail order facility and stocks them in dispensaries at its Federally Qualified Health Centers. That way, a patient can get a prescription filled right at the health center and can receive refills in the mail.

Since starting the drug discount program in September 2002, the program has been implemented at 6 health center sites and 38 more have contracted with the network. More than 4,000 medications have been dispensed at health center sites and 1,300 have been processed by the central pharmacy/mail order facility. In the first nine months, the program saved $236,087 on drug purchases (as compared to Average Wholesale Price), representing an average discount of 63%. The self-pay (uninsured) patients saved a total of $163,401 on drug purchases (as compared to Average Retail Price), representing an average discount of 91%, or $49 per medication.

The Coordinated Care Network has also recently developed a model to combine its case management for high-risk patients with the 340B drug discount program so that both medical and pharmaceutical costs can be reduced. "We've been told we're the only model in the country to integrate case management with the 340B programs," says Palmer. "Our Medicaid HMO customers, in particular, are interested in how they can reduce drug costs both for themselves and for the state." Palmer says he expects the program to roll out for one Medicaid HMO's high cost pharmacy members in the fall of 2003.

Other states are also expressing interest. New Mexico is the first to begin looking at applying the model to its Medicaid population as well as its state employees and inmate population, but Palmer predicts others will follow.

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HEALTHY YOUTH DEVELOPMENT - A COMMUNITY COLLABORATIVE WITH STAYING POWER

THE "HEALTHY COMMUNITIES INITIATIVE"

The Rose Tree Media School District lies within a suburban community in Delaware County, near Philadelphia, PA and Wilmington, Delaware. During the period 1994-2000, 19 young people of high school age and younger lost their lives through violent death that included suicide, homicide and drug related auto accidents. School officials, parents and the community as a whole gathered to express their dismay, sorrow and deep concern for these events and collectively sought answers to what many perceived to be a school district crisis. In the spring of 2000, the Rose Tree Media School District, Riddle Health Systems, and the Rocky Run YMCA committed their leadership and within a short time 25 additional organizations committed time, money and leadership and created the Healthy Communities Initiative (HCI).

HCI is now a non-profit collaborative that is committed to increasing the community capacity to create and maintain a safe, healthy and nurturing environment that benefits all residents and promotes healthy youth development.

HCI has adopted a model to mobilize the community. The Forty Developmental Assets, developed by the Search Institute in Minneapolis, Minnesota is based on accepted childhood development theory and Search's own research, and focuses on the crucial experiences, relationships, and activities youth need from all facets of a community in order to grow into healthy, responsible adults, adopting positive behaviors and attitudes and avoid risk taking activity.

Through holding a Town Meeting in November, 2001, and a community wide retreat in February, 2002, HCI has established a community framework for moving forward. Structured both organizationally and strategically to drive a grassroots effort, membership continues to grow with representation from businesses, civic and government organizations, social service agencies, faith based organizations, parents, students, and private citizens who have committed human and financial resources to achieve and sustain the necessary changes in behaviors, values and community culture.

There are nine Community Action Teams: Schools; Parents and Families; Students and Youth; Businesses and Civic Organizations; Youth Sports Organizations; Congregations; Government Agencies & Law Enforcement; Senior Citizens; Mass Media. Each team creates awareness of HCI and provides groups with support to prioritize their goals and develop an action plan, creating new services and programs or sustaining and improving existing ones. The information collected from these workshops is brought back to HCI staff and volunteers who identify cross functional goals and create networks where there are common goals. The result is an improvement in the utilization of current programs and where there are gaps, an organization that can optimize resources to create new programs and services. The Community Advisory Board, made up of community wide membership, meets to review ongoing activities, provide feedback, and support the continued development of the network and community based activities. Through a partnership with Drexel University School of Public Health, HCI is designing data systems that can capture all gathered information and define the successes of the collaborative. This will include collecting current data on risk taking behaviors, creating measurement tools to track HCI activities and processes, and document outcomes of HCI programs and interventions.

The following programs are currently under development and delivery:
- Series of discussion groups that provide parents with a chance to share child rearing, challenges and discuss ideas in a confidential setting
- A series of lectures on parenting at all ages with a focus on family communication; intergenerational connections; setting boundaries yet encouraging greater responsibility and empowerment; reducing all stressors on family dynamics
- Local arts, theatre, and music organizations using expressive education to teach and develop asset building skills
- Connecting organizational needs with schools and youth resources to promote community service
- "Seniors Teaching Seniors" program where youth work with senior citizens to improve their access to personal computers and their proficiency in using the software, internet, and emails to communicate with their friends and loved ones
- A model for hiring and mentoring youth in local businesses to promote development of a valued and skilled workforce
- A retreat to support community congregations efforts to integrate asset building into their organizations
- Youth run asset building session integrated into clinics delivered to all sports organizations throughout the community in partnership with the school district, sports organizations, community government and civic leaders
- A community driven initiative to support healthy eating and physical activity across all generations and within all sectors of the community to improve lifestyles and limit the development of chronic disease in later years

Since 2000, HCI has become a visible entity among community members and is seen as a resource to bring the community together, harness limited resources and apply them where they count the most.

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STIMULATING COMMUNITIES TO IMPROVE THEIR RESIDENTS' HEALTH

"HEALTHY CAROLINIANS"
NORTH CAROLINA

Since the early 1990s, the state of North Carolina has sought to improve the health status and longevity of its population by encouraging local communities to identify their own health and safety priorities and take action to address them. This initiative, administered by the state's Office of Healthy Carolinians, supports communities in their efforts to assess population health, formulate plans to address health care challenges, and identify resources and funding opportunities.

The effort began in 1991, when the U.S. Dept of Health and Human Services issued its "Healthy People 2000" report, which identified health objectives for the nation to achieve by the year 2000. The report prompted North Carolina's health commissioner and a prominent Duke University physician to launch a similar effort to set health objectives for North Carolina. They began by persuading then-Gov. James G. Martin to establish the Governor's Task Force on Health Objectives for the Year 2000.

The task force, which represented a broad spectrum of the state's health care community, gave North Carolina its first set of statewide health objectives for the year 2000. Its implementation plan called for communities to establish their own health objectives based on locally determined health priorities. The plan also called for North Carolina to set up a statewide network of partnerships to support these local efforts. In 1992, based on the task force's recommendation, the state established the Office of Healthy Carolinians.

Currently, 89 of the 100 counties in the state participate in the Healthy Carolinians program and have established local Healthy Carolinians task forces, says Mary Bobbitt-Cooke, director of the Office of Healthy Carolinians. She notes that this is a remarkable participation rate, because until 1999, these locally based organizations weren't receiving any financial assistance from the state for participating. Instead, communities were asked to rely on local resources and grants to support their health initiatives. Community efforts have been so successful in this area that they have attracted generous funding from local foundations such as the Kate B. Reynolds Charitable Trust and the Duke Endowment.

A measure of the program's success is that it has significantly increased communities' capacity to mobilize and organize around health care goals, says Bobbitt-Cooke. She says that a critical success factor has been the commitment made by three successive governors to believe in local communities' ability to address their own health priorities.

Another critical success factor has been the commitment of the statewide organizations that sit on the Governor's task force, whose latest report is "North Carolina Health Objectives for the Year 2010." These organizations include the state hospital association, the state medical society, and the state nurses association, which all have local chapters that have helped spread the word to their members at the community level. They also include representatives from the state legislature, the NAACP, and the religious community.

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KEEPING OLDER ADULTS HEALTHY AT HOME

THE "JUST FOR US" PROGRAM
DURHAM, NORTH CAROLINA

It is a sad reality that many older adults live with serious chronic conditions that are not treated or monitored. These diseases include not only diabetes, hypertension, asthma and heart conditions, but also mental illnesses.

In the late 1990s, the Department of Community and Family Medicine at Duke University recognized that many of Durham's low-income, chronically ill seniors were unable to access the services that were available. A model was developed which called for creating a multi-disciplinary team of care providers that included a primary care physician, a geriatric nurse practitioner, a psychiatrist, clinical social worker Susan Yaggy, who is Chief of Division of Community Health at Duke, and Dr. Lloyd Michener, Chairman of the Department of Community and Family Medicine at Duke.

The health care community in Durham County recognized that the chronically ill, low-income senior population was growing. There was a need to figure out how to help the fragile elderly in a way that used community resources most effectively, says Evelyn Schmidt, M.D., Medical Director and CEO of Lincoln Community Health Center in Durham.

The Department of Community and Family Medicine convened a working group comprised of the community-based organizations and agencies that serve the elderly in Durham. The group included Lincoln Community Health Center, the Durham Mental Health Agency, Durham County Department of Social Services, Durham Housing Authority, Durham Council for Senior Citizens, and Durham County Department of Health. The program they created, called "Just For Us," received its initial funding from the Fullerton Foundation in 1999 and began to enroll clients living in Durham's public housing facilities for senior citizens in mid-2001.

In the "Just For Us" program, a nurse practitioner provides primary medical care under physician supervision managed by Lincoln Community Health Center. Medical services include physical examinations, treatment and monitoring of medical conditions, and lab testing. A psychiatrist and social worker offer mental health services in the privacy of the patient's home. A social worker helps manage patient care by arranging needed appointments and transportation to see specialists. Initially, Social Services provided an eligibility worker to qualify many of the elderly for Medicaid.

Since the program started, there have been 211 patients enrolled – nearly two-thirds of them women. In addition to chronic medical diseases – primarily diabetes and hypertension – 20% of the patients had a mental health problem, which was addressed by the psychiatrist and/or social worker.

Many of the patients have seen dramatic improvement in their medical conditions. Patients whose diabetes was out of control now have glucose levels in check. Some patients whose lack of mobility had impaired walking are now ambulatory. Nutrition has improved. Some patients who would have been candidates for a nursing home have been able to stay in their apartments with some personal aid.

Recognizing the value of this program for patients who need supervised care at home, doctors in the community are referring many of their patients in need of this service. Generally, patients feel someone really cares. The practitioner is able to spend the time needed to obtain the patient's information and observe the living environment. The social worker is able to deal with the non-medical problems that affect a patient's quality of life at home.

As people age, there is variability in functioning in the population. Some are able to continuing caring for themselves, including their medical needs. Others are less able to deal with the pressures of daily living, including medical and self-care. Communities need to prepare for offering adequate assistance for those who need some level of outside support, including medical care.

"Just For Us" shows one way that communities can provide various kinds of assistance for seniors that need some level of support. The critical success factor to date has been the willingness of the involved agencies to use their present resources collectively to deliver care to this more fragile segment of the elderly community in a new, innovative way. As the program develops further, care providers hope to develop additional strategies for assisting the more needy elderly in the community.

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COMMUNITY PHARMACISTS PLAY KEY ROLE IN DIABETES MANAGEMENT

THE ASHEVILLE PROJECT
ASHEVILLE, NORTH CAROLINA

The Asheville Project, begun in 1997, is one of the few demonstration projects of its kind to examine the long-term effects of pharmaceutical care services (PCS) on diabetic patients' quality of life, clinical outcomes, and direct medical costs. The idea behind the project is that community pharmacists who are trained in diabetic education can play an important role in helping diabetic patients adhere to a regimen that keeps their diabetes under control.

Under the program, the city of Asheville, N.C., began offering its employees a new PCS benefit as part of their health plan. The benefit provides employees and their family members who have diabetes regular consultations – at no cost – with a community-based pharmacist who is specially trained in diabetic education. During consultations with their pharmacist, patients can set and monitor treatment goals, get advice on diet, exercise, stress reduction and medications, and receive home glucose meter training.

Pharmacists – who are reimbursed for these patient care services – also perform physical assessments of patients' feet, skin, blood pressure, and weight. In addition, pharmacists refer patients, as needed, to their physician or to a diabetes education center that employs certified diabetes educators. As an incentive to participate, patients receive a free home blood glucose monitor and a waiver of co-payments for all diabetes-specific drugs and supplies.

In 1999, Mission St. Joseph's Health Care System decided to join the city of Asheville in offering the PCS program to its employees and their family members. By the end of 2001, about 67% of eligible patients covered by the two employers had enrolled.

According to study results published in the March/April 2003 issue of The Journal of the American Pharmaceutical Association, the Asheville Project has had a significant impact. The program has improved patients' Hemoglobin A1c and lipid concentrations, cut patients' work absentee rates, and reduced direct medical costs to their employers.

The 5-year study found that improvement in A1c concentrations persisted over time. At every follow-up, more than 50% of patients experienced improvement over baseline. Moreover, at all follow-ups there was an increase in the number of patients with optimal A1c values. "Since research has established that any improvement in A1c is beneficial, reduces the risks of complications, and prolongs life, all of the improvements noted above were considered clinically important," according to the study.

The other clinical outcomes – LDL cholesterol and HDL cholesterol – also improved, but not substantially. The study notes that, "Because patients with diabetes are at increased risk for cardiovascular disease, future PCS programs should emphasize the importance of improving lipids as well as A1c."

The program's impact on patients' medical costs has been substantial. There was a decrease in total costs that was mostly accounted for by a shift from insurance claims for emergency department, inpatient, and physician office visits to prescription claims. Average insurance claim costs decreased by $2,704 per patient per year in the first follow-up year and by $6,502 per patient per year in the fifth follow-up year. During the same periods, the average prescription cost increased significantly, by $656 to $2,188 per patient per year. But the decrease in overall medical costs far surpassed the increase in prescription costs.

Collaboration between providers and employers was important to the success of this community-based project, the study notes. After physicians were informed that their patients had enrolled in the wellness program, they were asked to share their treatment goals with the patient's pharmacist. This sharing of information enabled the pharmacists to reinforce the physicians' goals during PCS visits. Additionally, the pharmacists provided brief written summaries of their PCS encounters, observations, and recommendations to the physicians.

As a result of the clinical improvements and financial savings associated with the Asheville Project, both the city of Asheville and Mission St. Joseph's Health Care System have made it a permanent part of their health plan benefit. This indicates that from the employers' perspective, the savings have more than offset the costs of the benefit.

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NEIGHBOR HELPING NEIGHBOR TO BECOME HEALTHY

BLADEN HEALTHWATCH
ELIZABETHTOWN, NORTH CAROLINA

In 1992, a health care needs assessment in rural Bladen County, NC, revealed that many of the area's residents did not know how to access local health care services. At the same time, there was growing concern in the county about the high rates of chronic disease, particularly heart disease and diabetes, which affected nearly every family. Together,

these two factors served as a wake-up call to local agencies that people in their county were facing serious health problems with little information about where they could go for help. So in March 1993, Bladen County Hospital hired a full-time coordinator to begin figuring out how to better connect local residents with the health care resources that were available to them.

The health needs assessment had revealed that one of the most serious health problems facing county residents was the prevalence of diabetes among African-Americans. The new coordinator began her outreach effort by visiting a group of African-American women in the tiny town of East Arcadia, population about 200. These women were the town's matriarchs and members of a quilting club that met once a week in the town's community center. When the coordinator visited them, she asked if they had any ideas on how local agencies could better serve diabetic patients in their community.

As it turned out, all of the women in the quilting club – and most of their family members – suffered from diabetes themselves but said they didn't know how to manage their symptoms or access services. The coordinator immediately arranged for a hospital nurse to go to East Arcadia to test the women's blood glucose levels. A hospital pharmacist came to check the medications they were taking and a nutritionist came to talk to them about diet and exercise. Most of the women were not in the habit of exercising and so the parks and recreation board brought out exercise equipment for them to use. After a while, the women began to feel better.

But there is more to the story, said Leo Petit, CEO of Bladen County Hospital. The women in the quilting club became concerned about the health of other people in their community. They asked if kids were getting immunized and pregnant women had prenatal care, if women were getting mammograms and men were being screened for prostate cancer. They fed the information back to local service agencies. Health fairs were started. The hospital sent out a bus to do mammograms and other cancer screenings. But the women didn't limit their interests to health care.

The quilters, by going around the community, realized that a lot of kids were not graduating from high school. So they asked the local community college to establish a Graduation Equivalency Degree (GED) program in their town, which the college did. This led them to apply for a grant to construct a building where young people are taught literacy and other skills, such as carpentry. Local business owners got involved by setting up a walking program that gave participants incentives in their stores for walking a certain distance several times a week.

Soon the quilting club, with the collaboration of local partnering agencies, turned itself into "Bladen HealthWatch," a community-based health education and outreach organization that now serves the entire county. The organization capitalizes on a key strength of small communities, which is that people tend to watch out for each other. "In a small community, everybody's a busy body," says Joy Grady, executive director of Bladen HealthWatch. "Instead of fighting it, we decided to work with it." All of the organization's health initiatives originate from people in the community.

Bladen Healthwatch is a grants-based program that does not receive federal or state money. Initially, the organization relied almost entirely on funding from the Duke Endowment and the Kate B. Reynolds Charitable Trust, and on "in kind" contributions from the Bladen County Hospital. The grants have become a little more diversified, but raising money has always been a challenge, says Grady. In the beginning, "we had very few resources so we had to be resourceful ourselves."

Over the 10 years of its existence, the organization has grown from a staff of one to a staff of six, who work out of the Bladen Healthwatch Resource Center in Elizabethtown. The resource center is located in the Healthy Lifestyle Center, which is owned by Bladen County Hospital and offers a consumer library of medical and health books and other resources. It is also the site where the diabetes support group meets and health fairs and screenings are held.

Healthwatch carries out much of its work through churches and schools, which are the main institutions in most small towns. The organization holds Diabetes Depots at local churches and other locations every three months, which gives diabetic patients the opportunity to have their glucose levels screened and their health concerns addressed by a nurse practitioner on a regular basis.

Healthwatch has also established a "Healthwatchers at School" program to educate kids local schools about physical activity, tobacco use and nutrition. Recognizing that obesity is a significant problem in Bladen County, the program recently set up an 8-week walking campaign that encouraged students to walk during the day at their school, home or church. Fourteen participating schools set up designated walking trails, and both students and their teachers were

given incentives to participate. The campaign "was a huge success," says Grady. The program's next initiative will target nutrition.

Grady credits the organization's success to it being "a true partnership of people truly working together." Support and involvement from the community has been a key factor. So have the support of the local health department and the leadership of Bladen County Hospital CEO Leo Petit, who hired the program's first coordinator. It was her visit to East Arcadia ten years ago that led to the creation of Healthwatch.

Petit, who will retire from the hospital this year, was recently honored at Healthwatch's 10th anniversary celebration. In addition to words of gratitude, Petit received a special quilt sewn by the ladies of East Arcadia.

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IMPROVING PRENATAL CARE FOR LOW-INCOME WOMEN

LINCOLN COMMUNITY HEALTH CENTER
DURHAM COUNTY, NORTH CAROLINA

When Lincoln Community Health Center was founded in 1971, the Durham County Health Department decided to collaborate with the new health center on prenatal care. The county health department transferred the prenatal clinic and well-baby clinic that had operated at Lincoln Hospital to Lincoln Community Health Center. The catalyst for this change was the then-director of nursing at the county health department, who also served on the health center's board of directors.

The department also made Lincoln Community Health Center the only site in the county that offered prenatal services to low-income women regardless of race. This was a sharp break with the county's segregated past, when prenatal services were offered through three different locations based on race: Lincoln Hospital for African-Americans, Watts Hospital for whites, and Duke Hospital, where most patients were white but there was a ward designated for African-American patients.

With the new arrangement, the health department could ensure that women would have ready access to medical care after pregnancy as well as during pregnancy. The transfer of its clinics to the community health center also enabled the county health department to use its limited resources more effectively. Funding that had been used for the well baby clinic at Lincoln Hospital could be transferred to another needy area now that well baby care was provided at the community health center.

When patients enroll with the prenatal clinic they are registered as health center patients, which entitles them to the sliding fee scale. Services include medical care as well as transportation, lab testing, x-rays, and pharmacy services. The prenatal clinic coordinates with local hospitals so that patients with high-risk pregnancies are delivered at Duke Hospital and those who have no untoward risk are delivered at Durham Regional Hospital. The prenatal clinic is also a resident training site for the Duke Medical Center's obstetrics department.

During the past 30 years the prenatal program has thrived, says Dr. Evelyn Schmidt, Medical Director and CEO of Lincoln Community Health Center. As a long-time collaboration between a community health center and a county

health department, the prenatal program is fairly unique in the country. The center and the county health department continue to look at available resources collaboratively to serve the population in need.

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DELIVERING FREE HEALTH CARE TO THE POOREST UNINSURED POPULATION

"COMMUNICARE"
SOUTH CAROLINA

In 1993, multiple health care stakeholders in South Carolina created Communicare, a program that provides free health care services for the working poor whose low-paying jobs do not offer health insurance. The program provides free doctor visits and donated prescription medication to adults who do not have any other form of health insurance, including Medicaid, Medicare and Veterans Health Benefits. In addition, an enrolled family must fall within 125% of the federal poverty level.

The State of South Carolina provides the primary administrative funding for Communicare. Additionally, pharmaceutical companies, hospitals, physicians, pharmacists, labs and other health care providers donate their resources and time.

To launch the program, Charleston neurosurgeon and, at that time, South Carolina Medical Association president Dr. Bart Barone recruited 125 physicians. Blue Cross Blue Shield of South Carolina and the Samuel Freeman Charitable Trust provided start-up funding. Pfizer and Johnson & Johnson agreed to provide their products at no charge.

In 1997, Communicare established itself as a stand-alone nonprofit organization. Dr. Barone became the first chairman of Communicare's board of directors until September 2002. Since 1997, Communicare has grown rapidly, with 2000 volunteers and seven pharmaceutical manufacturers serving thousands of patients. Communicare has also created new programs to meet needs in pediatric dental care and reduce emergency room use.

In 2000, Communicare was named one of five national "Models That Work" by the U.S. Department of Health and Human Services, and Blue Cross Blue Shield made the lead gift to establish the Communicate endowment. Also, two new pharmaceutical sponsors were added to the program. Two million dollars worth of prescriptions per year are now donated to the population the program serves.

During 2002, the South Carolina Budget and Control Board conducted a study that found a significant reduction in the frequency of emergency department visits by Communicare patients during 1998, 1999 and 2000. This drop in emergency department usage translated into a public spending savings of $167,915. By providing these patients with primary health care and pharmaceutical benefits, the state believes it has saved at least $1.5 million in emergency room visits over the entire period that Communicare has been in operation.

In the future, the project hopes to continue expanding its network of providers and cooperating partners, including pharmaceutical manufacturers.

For more information, contact: **http://www.commun-i-care.org/**

PHARMACEUTICAL ASSISTANCE FOR SENIOR CITIZENS

THE GEORGIACARES PROGRAM

The GeorgiaCares Program, implemented between September 2002 and March 2003 serves seniors on Medicare with incomes of less than $18,000 annually ($24,000 for couples), with no other prescription drug coverage. It also serves senior citizens who are eligible for HICARE, the Georgia state health insurance program for Medicare beneficiaries, and the Senior Medicare Patrol Program.

The purpose of GeorgiaCares, a public-private partnership of state agencies and private organizations, is to assist these eligible senior citizens with the application processes for manufacturer patient assistance programs (PAPs) and other pharmaceutical assistance programs. The program also provides a number of other valuable services to these individuals. Help with sorting and filing medical claims, analyzing the Medicare Summary Notices, and understanding Medicare beneficiary rights are all offered. GeorgiaCares provides information regarding health insurance, managed care, long term care insurances, Medigap, and Medicare savings programs. The program also coordinates the private manufacturer PAPs with the efforts of HICARE.

While the state is considering developing its own computer software, the program uses existing internet-based applications to access manufacturers' programs. Georgia's 12 Area Agencies on Aging (AAA) administer the program using over 300 existing staff and volunteers. The centers provide facilities to process applications with on-site computers. GeorgiaCares partners with pharmaceutical companies, pharmacies, physicians, hospitals, and state universities. Many of the partners provide facilities in addition to financial support.

In order to jumpstart GeorgiaCares, donations were obtained from the private sector, including pharmaceutical manufacturers. Funding has also been obtained through the State, the Centers for Medicare and Medicaid Services (CMS), and a new 3-year 100% federal Administration on Aging grant for the Senior Medicare Patrol Program.

GeorgiaCares is still in its early stages and currently deals mostly with prescription drug assistance. There is an expected phase-in over approximately 6-months. It has a toll free phone number (800-669-8287) for citizens to find out about the program in their area.

For more information, contact: **http://www.northwestga-aaa.org/georgiacares.htm**

DEVELOPING COMMUNITY STRATEGIES TO SUPPORT HEALTHY, POSITIVE AGING

THE CENTER ON AGING, FLORIDA INTERNATIONAL UNIVERSITY
MIAMI-DADE COUNTY, FLORIDA

With the Baby Boomer generation headed toward retirement age, the over-65 population is set to increase dramatically in most areas of the country, including Miami-Dade County in Florida. As a result, communities are starting to look at new ways of providing and coordinating services to support healthy, positive aging.

In Miami-Dade County, diverse stakeholders came together in June 2002 to form a Leadership Council whose goal was to develop a strategic, collaborative approach to improving the local environment for older adults. The Council was convened by The Center on Aging of Florida International University, which wrote the proposal for this community-based partnership with the Area Agency on Aging and secured funding for the project from a local foundation.

About 35 member organizations hold a seat on the Council. They include funders and a broad spectrum of hospitals, in-home providers, mental health providers, community advocates, managed care organizations, and city, county and state agencies, including housing and transit agencies.

Getting funders involved in the Leadership Council was the catalyst for other organizations to become involved, says Max Rothman, J.D., LL.M., Executive Director of The Center on Aging. "We also held out to them the possibility that this collaborative planning could result in a funding proposal to improve the system of long-term care to The Robert Wood Johnson Foundation," says Rothman. "So providers had good reason to be at the table."

In September 2002, the Council developed values and guiding principles that focused on the issues of access, continuity of services, making providers more consumer-friendly and culturally accepting, quality assurance, and the cost of creating services. The Council also identified areas for research such as surveying providers on various issues and mapping the elder population by neighborhood using census data.

Extensive research by The Center on Aging found that levels of funding were inadequate to meet the cost of delivering services; consumer information is not readily available or is confusing; there are long waiting lists in areas of high density of elders living alone and aged 85 and older; and needs differ by race and ethnicity.

Provider surveys found that one-third of providers "don't know" if older people who need services are able to obtain information about those services, and well over one-third of providers don't know if persons who need services are appropriately referred or receive follow-up.

In June 2003, the Council narrowed its priorities to three key issues: access, continuity of services and collaboration among providers, and linkages between hospitals and other providers of long-term care services, including residential facilities, other care providers, and social services organizations. These top priorities reflect a recognition among stakeholders that acute needs, chronic medical needs and chronic social needs are all interrelated and need to be addressed on that basis.

The Council plans to complete a report and proposed strategic action plan by October 2003. "Then we can take all of that and move forward with additional community initiatives and proposals," says Rothman.

The toughest challenge during this process has been getting all of the stakeholders to the table and willing to work together on this agenda, says Rothman. Some participants "were concerned about changes to existing systems and processes and challenged whatever came along," he says. "But we moved beyond that."

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THE MIDWEST BUSINESS GROUP ON HEALTH'S DIABETES COLLABORATIVE

CHICAGO, ILLINOIS

In 1999, in response to newly released reports on the lack of appropriate care for patients with diabetes, the Midwest Business Group on Health, a coalition of large and small employers covering 10 Midwestern states, decided it was time for action.

Upon reviewing results presented in the Dartmouth Atlas of Healthcare for diabetes, it was clear that there was a serious need for better knowledge and education on the appropriate care for diabetic patients. Member companies were experiencing the effects of the lack of appropriate care as evidenced by an increase in the number of diabetic employees requiring emergency room care.

The Metropolitan Twenty/Twenty Initiative in Chicago, focused on improving the business climate in the Chicago area, included healthcare among its metrics. This initiative was the actual catalyst for the Midwest Business Group on Health and Institutes of Medicine of Chicago to partner together and secure a grant from the Robert Wood Johnson Foundation to study the effects of training local clinicians using the Chronic Care Model developed by Dr. Ed Wagner.

Twenty-one teams of medical practitioners were assembled from a diverse group of regional facilities. Trauma and community hospitals, as well as Indian Health Service facilities, participated in the teams. Over an eight month period, three two-day learning sessions were conducted. Using a Plan-Do-Study-Act model of learning, the teams were trained in various aspects of diabetes management including creations of patient registries, aspects of chronic illness care, patient self-management and clinical decision support. By conducting the training on a regional basis scheduling of the sessions was much easier and participants were able to stay connected on an ongoing basis.

Each of the teams chose their performance measures from a group of required and elective items. The required measures focused on such things as a reduction of hemoglobin A1C levels of at least 8%, having hypertensive patients on appropriate medications, ensuring routine monitoring of cholesterol levels, retinal eye and foot exams. By reinforcing routine care with ongoing measurement, local facilities are seeing appropriate diabetes care become imbedded in practice. Member companies of the Midwest Business Group on Health are also seeing a reduction in the number of costly emergency room visits for diabetics.

In May of 2003 a Regional Congress was held with the community at large to celebrate the success of the first teams. Team members shared success stories and reinforced the need for ongoing training with future groups. It was clear that the local focus enhanced the commitment of the teams enabling them to build on shared experience and helping the community reach a "tipping point" for change. Coupled with the active involvement of the faculty who are committed to the effort, the results are beginning to be evident.

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USING A COMMUNITY HEALTH ALLIANCE TO IMPROVE POPULATION HEALTH

"HOW'S YOUR HEALTH, CHICAGO?"
CHICAGO, ILLINOIS

In 2003 the Chicagoland Chamber of Commerce developed a vision of better health for its members' employees, who comprise about 1 million of the 8 million persons living in the Chicago metropolitan area. The vision was to improve health care by providing local information about what needs to be done, support change at the practice level to meet these needs, and initiate community-wide approaches to manage prevalent and important health care needs without requiring direct involvement of health professionals.

The Chicagoland Chamber called its vision, "How's Your Health, Chicago?" To carry out the project, the Chamber formed a Community Health Alliance, which is defined as an active collaboration between patients, providers, health systems, and their communities to improve personal and population health. A Community Health Alliance can focus divergent interests within a community – not just interests directly involved in health care – on meeting health goals. Because it is broad-based and led by respected organizations, this type of alliance is also in a strong position to present health needs and concerns to the traditional medical care systems.

Implementation of "How's Your Health, Chicago?" was divided into two phases. The first phase used a web-based approach to do community assessment. Chicago residents were invited to use a web site called www.howsyourhealth.org to receive a self-assessment of their health care needs. The web site tailors education based on the self-assessment and provides a summary that can be taken to an office practice to improve care. Most importantly, the website collects information that is then available in aggregate form for the community to assess its needs and the care that is received. This web-based approach to community assessment has been tested previously in Long Beach, California, Mobile Alabama, and several smaller regions.

Offering the web-based service to all residents of the Chicago area was so inexpensive and the information gathered was so valuable, that the Chamber was quickly able to obtain "buy-in" on the project from stakeholders such as the Chicago Department of Public Health, the Chicago Medical Society, and several large health systems and employers.

However, the Chamber also made clear that it was "not in the health business" and wanted to make sure there would be a new structure that could take on the long-term task of ensuring better health and health care for all Chicagoans. For this purpose, during the second phase of the project, the Chamber and its partners formed a goal-oriented Community Action Committee.

By using the "How's Your Health" technology, the committee was able to quickly identify important community issues and make a connection between personal and population health. This information identified the work that needed to be done to improve the overall quality of care and to help members of the population self-manage their own health.

Now the focus of Phase Two in Chicago is to improve medical care and patient/population self-management. The Committee Action Committee prepares specific reports for regional health systems that give the "front-line" information that is actionable. The idea is that office practices can use the information to better plan services so that they meet the needs of patients, and to better plan care so that the services are individualized for particular patients as their clinical needs, self-management skills, and desires change over time.

As a member of the Community Action Committee, the Chicago Medical Society offers a free, web-based, continuing education program for front-line office practices about planning care and planning service. The program is based on work by the Institute for Health Care Improvement, the McColl Institute for Chronic Disease Management, and Dartmouth Medical School. It helps practices incorporate well-tested methods to improve practice effectiveness and efficiency, planned care, and planned service. Patients who visit these practices receive better care and become more confident in self-management.

The Chicago Community Action Committee is continuing to promote and use "howsyourhealth.org" to identify issues of concern in different populations and monitor the progress of participating health systems and practices. For example, outreach to population groups underrepresented during Phase One is being explored with the AARP, the public schools, faith-based organizations, and the Spanish language media.

The Community Action Committee can also stimulate solutions to community health problems that may be beyond the scope of a specific health system or office practice. For example, in Chicago, about 15% of adults aged 19-69 have a combination of pain and psychosocial problems. But less than 50% of persons with pain and 20% with bothersome emotional problems currently report receiving good education from doctors and nurses. For this reason, the Community Action Committee is exploring a pain-impact reduction effort, called "Pain is a Pain", that offers people with bothersome pain a phone resource center to receive non-clinical coaching for better self-management of pain. This approach is inexpensive and likely to be effective even though it will not provide evaluation or pharmacological treatment.

States such as Montana and New Jersey, and other large communities are now adapting this "Chicago Story" for their own use.

This case study is based on a yet-to-be-published study titled, "Community Health Alliances: A Chicago Story," authored by John Wasson, Dartmouth Medical School, with support from The Commonwealth Fund.

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OFFERING INTEGRATED CARE FOR HIGH-RISK, OLDER ADULT PATIENTS

PARTNERS IN CARE, CARLE CLINIC ASSOCIATION, PC
MAHOMET, ILLINOIS

The Carle Clinic Association recognized as early as the 1980s that the combination of an aging patient population and decreasing Medicare payments meant that the multi-specialty, physician-owned practice needed to adopt a more coordinated and comprehensive system of care for its older patients. So the practice started a case management model in 1986 to address the needs of this patient population.

Over time, the model has evolved into the "Partners in Care" program, an integrated approach to patient care that links primary care physicians, nurses who function in an expanded role called nurse partners, and resources across the continuum of care. The program focuses mainly on older adult patients residing in rural areas who are at high risk for mortality or functional decline.
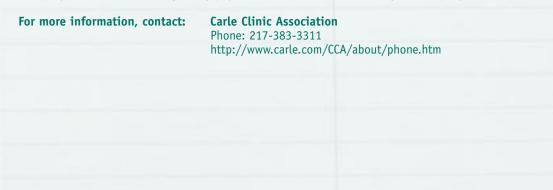
There were a number of steps along the way in the development of the case management model into the Partners in Care program. First, the practice received a grant to be in the Medicare Alzheimer's Disease Demonstration – a 5-year project (1989-1994) that introduced many precursors of the tools used in Partners in Care. Another precursor was the Generalist Physician Initiative, a 3-year project (1992-1995) in which the nurse worked in partnership with the patient and primary care physician. It was during this project that the name "Partners in Care" was introduced and dedicated funding for nurse partners was instituted on the basis that an expanded role for nurses would improve patient care.

The integration of nurse partners into the case management structure is one of the key components of Partners in Care. In developing the case management model, the practice had become aware that nurses were not playing an integral role. This was a key concern because older adult patients from rural areas are often more willing to describe accurately how well they are functioning and express their concerns to a nurse than to a physician. So the practice decided to use what it calls "nurse partners" in the Partners in Care program to work with the primary care physician, the patient, and the patient's family in developing and implementing a comprehensive health care plan for the patient.

The program emphasizes a collaborative team approach. The primary care physician provides skilled geriatric care and serves as team leader. The nurse partner combines the role of the office nurse with that of a community-based home health care provider. Each nurse partner builds the initial assessment and care plan for the patient, and facilitates communication between the patient and the physician. The nurse partner also bridges the gap between health care settings by seeing patients when they are in the hospital and working with discharge planners, home care nurses, and payers to ensure the most appropriate level of care after discharge. A third member of the team is the case assistant, who takes calls from patients with problems, tracks patients' activity and coordinates appointments. Patients and their families are at the center of the program. Their role is to provide accurate information, prioritize problems, and decide on the best interventions with help from the nurse partners and physicians.

By actively involving the patient, primary care physicians and nurse partners in the patient's plan of care, the Partners in Care program has been able to reduce hospitalizations, shorten lengths of stay, and reduce the cost of care. According to results published in 2000, patients enrolled in Partners in Care had about half the number of annual hospitalizations as similar non-program, high-risk patients. Program patients had more physician visits, but their total per member per month billed changes were less than half those of similar non-program patients. Most important, patient care was improved by reducing gaps and duplications in service and by educating both the patient and family so they could make better health care decisions.

One of the major lessons learned from instituting Partners in Care is the critical role of the nurse partner in delivering appropriate and cost-efficient care. Another key success factor was that the practice's medical leader, who played a crucial role in gaining physician acceptance and funding for the program.

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COORDINATING PRENATAL CARE FOR PREGNANT WOMEN AT RISK

DEAN HEALTH SYSTEM, INC.
MADISON, WISCONSIN

Pregnant women who don't receive early and regular prenatal care are more likely to have poor birth outcomes, particularly low birth weight, neonatal death, and post-partum complications. In Dane County, WI, there was a substantial increase by the mid-1990s in the number of pregnant women who were at risk of not receiving appropriate prenatal care, and these patients had become more difficult to reach.

Recognizing the need to ensure that pregnant women receive appropriate prenatal care, Dean Health System, Inc., in 1995 developed the Prenatal Care Coordination Program, which identifies at-risk pregnant women and partners with local human services organizations to see that these patients' needs are met.

Since it began operating in Dane County, the program has been successful in reducing the incidence of low-weight births and number of premature births and decreasing the gestational age at first prenatal visit. Outcomes for these measures are better for women who enroll in the Prenatal Care Coordination Program than for other women in Dane County who are eligible but choose not to participate. In addition, there are lower hospital charges for infants and their mothers.

Before launching the program, Dean Health System established a planning team to consider development of a prenatal care program. The multi-disciplinary team consisted of a clinical obstetrical nursing supervisor, the director of community services and director of advocacy, a perinatologist, a family practitioner, and the vice president of reimbursement. Because the multi-specialty, physician-owned practice had a history of involvement in community advocacy, the planning team received strong support throughout the organization and immediate physician acceptance.

The planning team estimated that about 300 pregnant women in the health system would benefit from being assessed for the program and that one third of those women would benefit from comprehensive case management throughout the course of their pregnancy. Once the board approved the program, the organization established an implementation team that consisted of the planning team members plus 3 members of the outcomes staff and a newly hired registered nurse case manager dedicated to the Prenatal Care Coordination Program.

No initial cost analysis was performed to justify the expense of hiring the nurse case manager; however, the members of the practice felt strongly that the birth outcomes and the hospital cost savings would justify the expense. The case manager reports to both the manager of community services and the obstetrical nursing supervisor – a management structure that helps ensure a wide variety of resources, information, and support is available to the program.

The program was set up so that patient referrals could come from a physician or from other medical professionals, social workers, public health professionals, or school officials. Once a patient is referred, the nurse case manager contacts her to discuss the program and offer services. If the patient agrees to enroll, the nurse schedules a meeting with the patient to complete a 6-page questionnaire to determine whether the patient is "at-risk" to the extent that she qualifies for the program.

If the patient qualifies, the nurse meets with her for an initial evaluation to determine the patient's knowledge about preterm labor, community resources, nutrition, prenatal care, and well-baby visits. Referrals are made to necessary services. During the remainder of the pregnancy, the nurse case manager meets with the patient at least every 30 days to address her needs with regards to housing, Medicaid, food, parenting resources, and psychological counseling. Each patient receives at least 1 home visit prior to delivery to help ensure that her needs are met. Throughout the woman's pregnancy, the nurse case manager confers with the physician about the patient's progress.

Following the birth, the nurse case manager contacts the patient by phone 7 to 10 days after delivery for a postpartum assessment. This phone call is followed by a home visit during which the patient completes out a patient satisfaction survey. The survey data are entered into the program database. The data on birth outcomes are collected from the hospital through chart reviews. The patient is discharged from the program 60 days postpartum.

A comparison study published in 2000 indicates that although the program's patients had considerably higher risk factors, their birth outcomes approximated, and in some cases were better than, those of the benchmark population represented in a 1990-1995 study of neonatal health by Consortium Research on Indicators of System Performance (CRISP). Despite higher risk factors for program patients, the percentage of low birth weights was 5.2%, compared to 9.65 among the benchmark population. The percentage of premature births was also lower: 6.9% for program patients vs. 7.6% for the benchmark population.

In another analysis, the internal hospital data indicated that, on average, program patients had lower total hospital charges and shorter lengths of stay for both themselves and their infants than patients who were eligible for the program but chose not to participate. The differences may not be significant because of small sample size, but they suggest an average decrease in hospital charges of $1160 per program patient. As of 2000, the program was serving about 225 clients annually.

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FINDING WAYS TO BETTER INTEGRATE MEDICAL AND BEHAVIORAL HEALTH CARE

BLUECROSS AND BLUESHIELD OF TENNESSEE AND MAGELLAN BEHAVIORAL HEALTH TENNESSEE

A growing body of literature on the mind-body connection has prompted insurers like BlueCross and BlueShield plans to recognize the importance of integrating behavioral health consultations and treatment with physical medicine care management and treatment. Not only does integrating and coordinating care for medical and behavioral health lead to better patient care, it also provides more cost-effective results.

Medical patient populations with chronic medical conditions such as diabetes, asthma and heart disease, are particularly affected by concomitant behavioral health disorders. These members are known to experience an even higher proportion of behavioral disorders than the general population. For payers like BCBS plans, this quality of care problem is a costly one. Better integration of medical and behavioral treatment through health plan leadership is essential.

With that in mind, the BlueCross and BlueShield of Tennessee, Inc. (BCBST) organization decided to partner with its behavioral health vendor, Magellan Behavioral Health, to implement a Medical-Behavioral Coordination Committee, with oversight over all medical/behavioral health interfaces. The goal was to achieve result-oriented initiatives and to address this important quality of care issue.

The Committee has implemented and overseen numerous innovations designed to help improve services and differentiate BCBST as an organization focused on quality of care in the area of medical/behavioral health integration. One innovation is the development and integration of practitioner-oriented behavioral health information, resources and links within the BCBST web site. This was instituted in January 2002.

The Committee also integrated BCBST and Magellan's utilization review and case-management units for collaborative care of patients with concomitant physical and behavioral health disorders. This was done to ensure that behavioral health consultations occur on medical units, behavioral health needs are addressed in the medical unit's aftercare plans, physical medicine needs are addressed in the behavioral health unit's aftercare plans, and consultations assistance for physicians is available. As a result of this initiative, quarterly reporting of referrals by both organizations shows a significant increase each year since 2000.

In addition, the Committee has developed a continuing professional development and training program for both BCBST and Magellan staff. Training events have been held quarterly as planned, and evaluations of the training have been

very positive. The Committee has developed and reviewed medical policies affecting medical and behavioral patient populations and providers. Six policies have been developed.

The Committee has also developed Depression Treatment Guidelines for physicians in primary care who may be doing as much as 60% of the treating of depression for BCBST members. Magellan and BCBST developed a treatment guideline in 2000. In 2001 the decision was made to adopt the Colorado Clinical Guidelines Collaborative's "Major Depression in Adults" guidelines.

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TRANSFORMING A VACANT SHOPPING MALL INTO A COMPREHENSIVE HEALTH CARE FACILITY

THE JACKSON MEDICAL MALL THAD COCHRAN CENTER
JACKSON, MISSISSIPPI

Jackson's first shopping mall, built in 1969, was for years the largest mall within 400 miles of the metropolitan area, drawing customers to its stores from throughout the state of Mississippi. But as newer malls sprang up in Jackson, the original mall gradually lost much of its business and was forced to close in the mid-1980s. The once-vibrant neighborhood surrounding the mall also fell into decline. Within a decade, the vacant mall became a crime-ridden eyesore and its neighborhood was economically depressed.

At the time, most of the people living in the neighborhood had low incomes, ere dependent on public transportation, and had limited health care services available in their area. Many residents had enormous difficulty accessing high-quality, comprehensive health care.

In 1995, Jackson physician Aaron Shirley, MD, was walking through the empty corridors of the former mall when he had an idea. Dr. Shirley was then project director of the Jackson Hinds Comprehensive Health Center, the largest community health center in Mississippi. Dr. Shirley's idea was to turn the dilapidated shopping mall into a comprehensive, multidisciplinary health care complex serving the low-income residents of Jackson. He envisioned the new health care facility as a community-based venture that would not only improve people's health, but also revitalize the surrounding neighborhood.

Dr. Shirley's vision has become what is now the Jackson Medical Mall – a one-stop, comprehensive health care facility that also offers human services and economic development. The Medical Mall's health care and human service providers serve about 170,000 people each year, drawing patients from throughout central Mississippi.

When Dr. Shirley first conceived of the idea of turning the mall into a health care complex, he mentioned it to his friend Reuben V. Anderson, an attorney and former Mississippi Supreme Court justice. Together, they presented the idea to Dr. Wallace Conerly, vice-chancellor of the University of Mississippi Medical Center (UMC). UMC was at that time, and remains the state's only comprehensive medical school and research center.

At the time, the Medical Center's teaching clinics had outgrown their space on the Medical Center campus, but it seemed too expensive to build a new, freestanding ambulatory care center on campus. Presented with the idea of transforming the old Jackson mall into a health care facility, the Medical Center moved quickly to help create the Jackson Medical Mall Foundation, which purchased the mall in 1995 for $2.7 million with loans from three prominent banking institutions. Its teaching clinics now occupy what was once a large department store and has since been completely renovated.

Other partners in the Medical Mall include Tougaloo College and Jackson State University, which were added to the team to develop and offer educational opportunities at the mall. Together, all of these partners became the board of directors of the Jackson Medical Mall Foundation, which is chaired by Dr. Shirley.

The mall re-opened as a health care facility in 1996, the year after it was purchased. Since then, both the Medical Center and the Hinds County Health Department have operated primary care centers at the mall where patients can gain access to the system without physician referral. Using case management procedures, these clinics coordinate patient care with the Medical Center's outpatient specialty clinics and other health care providers in the mall.

In addition to delivering health care and human services, the Medical Mall is putting increased emphasis on the third part of its mission: economic revitalization in the community. Throughout the construction and renovation process, the Mall Foundation awarded millions of dollars in contracts to small and disadvantaged contractors. The mall has also hired dozens of minority-owned firms as subcontractors and vendors. Now the mall has started to bring in tenants that can help neighborhood residents find employment and earn their Graduate Equivalent Degree (GED).

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SUPPORTING A NETWORK OF COMMUNITY HEALTH WORKERS

CENTER FOR SUSTAINABLE HEALTH OUTREACH
HATTIESBURG, MISSISSIPPI, AND WASHINGTON, DC

In an increasing number of communities nationwide, community health workers (CHWs) play an essential role in providing effective outreach to families who are least likely to receive appropriate health care. These families are often at the greatest health risk, but because of language barriers, financial barriers, cultural beliefs, or mistrust of the system, they may not receive health care and preventive services.

CHWs provide a vital link between these medically underserved families and health care providers. As members of the communities they serve, CHWs provide outreach that is culturally and linguistically appropriate, and that reflects the value systems of the community. They educate individuals, families and communities about health-related issues and facilitate access to services. They also educate providers and health care systems about being more responsive to the communities being served.

The Center for Sustainable Health Outreach (CSHO) was formed in 1999 to provide support and technical assistance to CHWs and CHW programs. The Center is a collaboration between The University of Southern Mississippi in Hattiesburg and the Harrison Institute for Public Law at Georgetown University Law Center in Washington, D.C. It provides assistance to CHWs in the areas of program development, funding and sustainability; public policy development and strategic planning; program evaluation; and education and training. CSHO also assists CHWs and CHW programs by facilitating partnerships with potential funders, policy makers, health systems, and community organizations.

The Center's USM-based co-director, Agnes Hinton, DrPH, began working with CHW programs in 1987. In 1993 she was named director of the Community Health Advisor Network (CHAN), then based in Jackson, MS, which promotes and supports community health advisor (CHA) programs. A CHA is a specific kind of volunteer CHW, defined as a trusted person in a community who is trained to help others with health-related issues. CHAN began its work in the Mississippi Delta and expanded to Alabama, Arkansas, and Georgia. When Hinton joined the USM faculty in 1996, she brought CHAN with her. From USM, CHA programs were established in Texas; Delaware; Alabama; Georgia; Chicago, Illinois; and a number of other sites.

By this time, the Harrison Institute had been working for several years on policy development and technical assistance in support of community health advisors. The Institute was looking for a partner that could complement its work by providing CHAs with training and evaluation. So in 1998, Hinton and Jason Newman from the Harrison Institute began discussing their universities partnering to support CHWs.

With the help of a grant from the Health Resources and Services Administration, Office of Rural Health Policy, USM and the Harrison Institute created CSHO in 1999. The Center's responsibilities are divided between the two locations. The USM staff of CSHO is responsible for education, training and evaluation. Other functions include promoting its two model programs – CHAN and the Maternal/Infant Health Outreach Worker Program (MIHOW), a peer home visitation program for pregnant women and mothers of children birth to three years – in Mississippi, Arkansas, Tennessee, and Louisiana. Another model CSHO program is the Deep South Network for Cancer Control, which utilizes an adaptation of the CHA model to focus on cancer awareness and control in Mississippi and Alabama.

CSHO-Georgetown is responsible for policy development and sustainability information. Building on a request for technical assistance from programs in Virginia, CSHO-Georgetown was able to help a coalition of programs obtain funding for a state center based at the Blue Ridge Area Health Education Center for Health Outreach. The new center, named the Virginia Center for Health Outreach (VCHO), provides statewide support to CHW programs and is the first of its kind on the state level. CSHO-Georgetown is currently researching issues of CHW liability, incorporating a state CHW coalition, and past legislative initiatives that may assist in CHW policy development in Virginia.

CSHO conducts an annual training/networking Unity Conference in the spring and produces a quarterly newsletter, Connections, available free to anyone interested in CHWs. CSHO is currently gathering information for a national inventory of programs involving CHWs, including their evaluation methods. An annotated bibliography of articles describing CHW programs is also being produced.

Visit www.csho.net for the latest information.

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PREPARING FOR THE THREAT OF BIO-TERRORISM

REGIONAL EMERGENCY MEDICAL PREPAREDNESS STEERING COMMITTEE
SOUTH CENTRAL TEXAS

The September 11 terrorist attacks not only affected Americans' sense of personal safety, they also changed – immediately and dramatically – the way health care providers view disaster preparedness in their communities. Suddenly, in addition to the usual hurricanes and school bus accidents, providers had to start thinking about how they would respond in the event of a terrorist attack. In most communities they knew they were not well prepared.

In San Antonio and the surrounding region of south central Texas, the health care leadership moved quickly. A group came together, dedicated to improving and expanding bio-terrorism preparedness planning on a regional basis. Approximately 50 organizations throughout the region coalesced to form the Regional Emergency Medical Preparedness Steering Committee (REMPSC).

Within a month after the terrorist attacks, REMPSC held its first formal meeting and laid out both a 60-day work plan and a long-term, "ideal" plan that required additional time and funding to develop and implement.

REMPSC members represent the broad array of health care services in the region, including public health, military medical emergency planning, EMS, acute care and trauma care. They were well aware of the need for immediate action, says Harry Smith, REMPSC's chair and vice president of the Greater San Antonio Hospital Council. "[Our country] had just been attacked," he says. "Nobody knew what was next, but this group recognized and acted on the need for a 'quick and dirty' plan."

Within 60 days of its first meeting in October 2001, the committee staged a "tabletop exercise" to simulate how health care providers would respond, using available assets, in the event of a bio-terrorist attack. The purpose was to identify gaps in the health system's ability to respond to this type of emergency and to communicate among providers, law enforcement, and other responders.

The exercise involved a broad spectrum of organizations throughout the south central Texas region, which covers 27 counties and 22,000 square miles. They ranged from the public health system, hospitals, trauma health systems and pharmacists to the San Antonio Emergency Operations Center, fire departments, and the U.S. military's Joint Forces Command.

Following the exercise, REMPSC performed a gap analysis. The results were encouraging, says Smith. There were definitely gaps to be filled, "but with the strong relationships in place between the various organizations, the communications capabilities were realized as a critical component in addressing the gaps."

One reason that REMPSC was able to move quickly to organize and develop a work plan was that most of its members were already accustomed to working together on emergency preparedness. Many of the organizations involved in REMPSC were already involved in a well-established working relationship, called the Joint Emergency Management Committee, which was formed by combining separate committees that had been in place at the Greater San Antonio Hospital Council and Bexar County Medical Society. Having in place this long-standing dialogue between local military planners, trauma organizations, hospitals and EMS allowed for smoother and more rapid communication and coordination in addressing bio-terrorism planning issues, says Smith.

Another key to the REMPSC's success has been the local and regional public health agencies' role on the committee. The public health authority is historically geared toward surveillance and other traditional 'public health' concerns, says Smith. So the transition to a role in coordinating pre- and post-acute health care issues has been somewhat new territory for the agency. Nonetheless, public health has taken a leadership role on the REMPSC.

An initial challenge for the committee was its size. "The inclusive nature of the REMPSC forum led to broad, diverse discussions at the meetings," says Smith. The committee addressed this by establishing a "coordination workgroup" that is made up of the key stakeholder's senior decision-makers, who provide overall guidance to the REMPSC process. Currently, there are seven specified work groups addressing prioritized issues.

Recently, the state of Texas dispensed federal money to each region to support their bio-terrorism preparedness planning efforts. The REMPSC work group on EMS/Hospital Disaster planning (EHDG) was designated by the region's hospital CEOs to administer the nearly $700,000 specified for hospitals.

That funding is a significant first step for hospitals, says Smith. But he points out that the committee did not wait for the money before taking steps to plan and prepare. Instead, they took action immediately, under the direction of the Southwest Texas Regional Advisory Council for Trauma, with Eric Epley as Executive Director, to identify the initial priority areas of need for the region's hospitals and to drill down into hospital-specific implementation programs

Among the 22 regions that make up the state of Texas, the Greater San Antonio area is recognized as being in the forefront of bio-terrorism preparedness planning. The Texas Department of Health is working to use a REMPSC-type model as a template for other regions in Texas.

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A COMMUNITY-BASED JAIL DIVERSION PROGRAM FOR PERSONS WITH MENTAL ILLNESS

THE CENTER FOR HEALTH CARE SERVICES
SAN ANTONIO, TEXAS

The Center for Health Care Services (CHCS) in San Antonio, Texas, was nearly bankrupt when Leon Evans became its executive director in April, 2000. As the mental health and mental retardation authority for Bexar County, the Center was not only failing financially, it was failing almost all of its performance agreements with the Texas Department of Mental Health and Mental Retardation. The Center also lacked the trust and confidence of the community.

Now, less than 4 years later, the Center is financially viable once again and met all of its targets in its most recent performance review of state-mandated targets – a first for any mental health authority in a major metropolitan area in Texas. In addition to its improvements in quality and performance, the Center has made a major effort to invite community participation in its decision-making process by creating community advisory groups that meet on a regular basis and actively advise the Center's board of trustees. Comprised of mental health care consumers and family members, advocates, and interested community members, the community advisory groups have had "a phenomenal impact" on the Center's policymaking, says Evans.

Among the groups' areas of involvement is the Center's new Jail Diversion Program, which is designed to reduce the number of people with mental illness who are jailed in Bexar County as a result of behavior that is caused, at least in part, by their mental illness. Typically, people with severe mental illness end up on the streets or behind bars because they lack treatment options. "The fact is that our criminal justice system is a major provider of mental health services," says Evans.

Creating a jail diversion program was originally the idea of Bexar County Judge Nelson Wolff, who recognized that the criminal justice system was not the appropriate setting for dealing with people with severe mental illness. His concern was not only that the county jail system does not offer appropriate mental health treatment, but also that there are fewer spaces to incarcerate violent criminals when jails are overloaded with mentally ill, nonviolent offenders who would be better served in other settings. In some cases, a person may need to be hospitalized for a period of time, but in the majority of cases, other settings are much more appropriate and significantly less expensive.

In 2001, the Center created a multi-stakeholder committee aimed at creating a "jail diversion model" that would provide people with severe mental illness treatment and other services. Committee members included a number of representatives from law enforcement and the court system such as the local police chief, the sheriff, probate judges and county clerks, as well as mental health care consumers and their family members.

One of the jail diversion program's first actions was to hire four deputies from the sheriff's office and train them to deal with people who have severe mental illness. Now, when a phone call comes into law enforcement about a mentally ill person causing problems with their behavior, the Center can send out a specially trained "mental health deputy" to respond. These deputies have proven to be so beneficial that an additional two full-time deputies and one part-time deputy were added to the team in September 2003. The Center has trained an additional 40 officers to assess a person's mental state when they are called to the scene of a disturbance and to use gentle "talk-down" techniques with people who are psychotic.

The program has also been involved in the public policy arena, through educational efforts aimed at changing state law to remove obstacles to jail diversion and to change parts of the "total judicial and mental health system" so that a more coordinated public safety and public health system is created for this population.

As a result of these initiatives, "we've diverted a lot of people from jail and psychiatric emergency rooms," says Evans. "I think we've got a good model because people won't be going to jail and using services inappropriately."

To provide more comprehensive care and reduce overall costs, the program has partnered with the local hospital district, the University Health System, to provide access for its clients to primary care and dental services. The program also gets many of its medications through the University Health System's 340(b) drug purchasing discount program, which results in enormous cost savings.

In May 2003 the Center received a three-year grant from the U.S. Department of Health and Human Services' Substance Abuse and Mental Health Services Agency (SAMHSA). The grant will provide $300,000 each year for the Center's jail diversion program and includes a strong research component to measure outcomes and perform a cost-benefit analysis of the program.

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TAKING ON DIABETES WITH COMMUNITY GUIDELINES FOR CLINICAL CARE

BLUE CROSS BLUE SHIELD/ HMO OF NEW MEXICO AND OTHERS
ALBUQUERQUE, NEW MEXICO

When diabetes became the seventh leading cause of death in New Mexico, a group of the state's health plans, including Blue Cross Blue Shield/HMO of New Mexico, decided to create an initiative aimed at improving clinical care and health outcomes for diabetes patients.

Begun in 1999, the "New Mexico Health Care Takes on Diabetes" initiative now involves a total of 22 health care organizations, including all health plans in the state, the New Mexico peer review organization, the New Mexico Department of Health, local chapters of national medical societies, the local and national American Diabetes Association, and others.

These organizations came together because they recognized there was a need for community-wide guidelines on clinical practice care for diabetes. The group agreed to use and disseminate one comprehensive clinical practice guideline, using the ADA's clinical recommendations as its foundation.

The guideline was released at a press conference in November 2000 and then distributed to more than 5,000 practitioners, including all primary care physicians, specialists, nurse practitioners, physician assistants, and certified diabetes educators in the Albuquerque area.

The group also developed an "Office Tool Kit" for the staff in physicians' offices who often play a key role in coordinating and organizing care for patients with diabetes. The tool kit, which complements the practice guidelines for physicians, contains foot care posters to hang in the providers' office and chart makers that can be placed in the patients' medical records to remind practitioners of the appropriate guidelines for diabetic care.

The initiative expanded in 2001 when three group practices piloted an electronic patient registry designed to increase efficiency and effectiveness in diabetes management. Known as the Diabetes Electronic Monitoring System (DEMS-Lite), the patient registry was used for a three-month pilot and results were excellent. Among the 616 diabetes patients registered in the database, there was a demonstrated increase in the number of A1C tests and lipid profiles performed.

All three group practices reported that they would continue to use the electronic patient registry because it has helped them improve their consistency in monitoring patients and identifying patients that need more rigorous outreach.

Overall, the initiative has achieved significant success in improving care and health outcomes for patients with diabetes. Using HEDIS diabetes measures to evaluate the outcomes of the initiative, results from data in 2002 reveal dramatic increases in A1C testing, eye exams, lipid profile, lipid control and monitoring of diabetic retinopathy. In addition, the percentage of patients with poor A1C control dropped from 63.57% in 2001 to 45.47% in 2002 revealing that fewer patients will suffer complications associated with high levels of A1C.

As this collaborative initiative continues to expand, over 100,000 New Mexicans with diabetes stand to benefit from improved care delivery.

For more information, contact: http://www.bcbsnm.com/Members/hp/hmoBlue/hmo_index.htm

REVIVAL OF A SMALL, RURAL HOSPITAL

SIERRA VISTA HOSPITAL
TRUTH OR CONSEQUENCES, NEW MEXICO

If you drive south from Albuquerque on the main highway to Las Cruces, you'll pass Truth or Consequences, a laidback town of about 7,000 residents, many of them retirees living on modest incomes who moved to the area for its warm weather and low cost of living. Truth or Consequences is a pleasant place to live, but it is also relatively isolated and has little industry aside from a bit of tourism during the summer months.

The town is also home to Sierra County's only hospital, Sierra Vista. The hospital has had a rocky history and came close to shutting down at least a couple of times. But in the last few years, Sierra Vista has staged a dramatic reversal of its fortunes by pulling itself out of debt, regaining its accreditation, and restoring its image in the community.

Founded by Catholic nuns as a mission hospital, Sierra Vista was sold to Adventist Health System in 1981 and within a decade lost its accreditation. By 1994, when Adventist Health System announced plans to close Sierra Vista, the hospital was losing in excess of $1 million per year; several physicians had lost their licenses; and the hospital had lost much of its reputation.

To prevent the hospital from closing, the City of Truth or Consequences, the County of Sierra, and the Village of Williamsburg formed a Joint Powers Commission that began leasing the hospital from Adventist, and it appointed a governing board. The board, in turn, recruited one of the hospital's former administrators, Domenica Rush, to become its new CEO. A registered nurse who grew up in Truth or Consequences, Rush had left Sierra Vista Hospital in the 1980s for a position in Albuquerque. But she accepted the offer to return in 1995, as a contracted Administrator from Presbyterian Healthcare Services in Albuquerque.

When Rush took over the hospital's management, the outlook was grim. Sierra Vista had only one physician left on staff, a decrepit facility, and no money in the bank. Rush says that when she walked into her new office on the first day she found a pile of more than 200 patient complaints sitting on her desk. "No one thought the hospital could make it," she recalls. "If an outside company couldn't make a go of it, how could we as a local community?"

As a first step, Rush began an all-out effort at physician recruitment. She started a rural health clinic as a recruiting vehicle and began searching for new physicians through the J-1 visa program. The city gave the hospital $200,000 and the state contributed $100,000. Both expected the hospital to pay the money back.

From the beginning, Rush took a "hands-on" approach to running the hospital, which she credits as one of the key reasons Sierra Vista was able to turn around and become successful. Rush personally addresses all patient complaints and has implemented an aggressive performance improvement program. She has also developed a leadership team that is politically active and visible in the community.

In 1997 the JPC bought the hospital for $1.5 million and put about $800,000 into improving its infrastructure. But Sierra Vista continued to struggle. Rush says that by 1998 she had become "desperate" about the hospital's chances of long-term success. In 1998 the hospital was given the opportunity to become a "critical access hospital," which meant it would start receiving cost-based reimbursement from Medicare instead of the 31% reimbursement rate it had been getting, and which was just not enough. The hospital received an additional boost to its bottom line when it was designated a "sole provider," which gives the hospital an enhanced federal match for indigent care. About 20% of Sierra County residents are uninsured.

By 2000 the hospital had restored its image in the community and was successfully recruiting new physicians. The staff now number about 150 full- and part-time workers, including seven physicians. Rush says the hospital is fortunate in having a staff that understands the value of working at a small, rural hospital even if they don't earn as much as in they would in a city.

Sierra Vista has expanded its multi-specialty practice and provides services such as home health, outreach, and health promotion. The hospital recently opened a mental health center and plans to add an OB/pediatric practice this year. Rush says business has more than doubled in the last 3 years and the hospital actually turned a profit in fiscal year 2002. This year, the hospital expects to add close to $500,000 to its bottom line.

The hospital's successful turn-around has not gone unnoticed. Austin-based Blackhawk Healthcare made an offer to purchase the hospital that the JPC accepted earlier this year. The contract calls for Blackhawk to build a new hospital facility in Truth or Consequences within 5 years of the purchase. Rush, who supports the sale, says the hospital badly needs the new facility but that local politicians did not think the community could support the additional public funding it would require.

But Rush predicts that maintaining Sierra Vista's success and growth won't be a cakewalk. Her advice to the new owners? Keep a hands-on, community-based approach to managing the hospital. "If they don't," she cautions, "they're going to lose it."

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COLLABORATIVE EFFORTS TO ACHIEVE MENTAL HEALTH PARITY IN UTAH

THE UTAH PSYCHOLOGICAL ASSOCIATION

State-based efforts to bring an end to the arbitrary, one-size-fits-all limits on mental health benefits continue to gain momentum. In the past decade 37 states have enacted "parity legislation" which requires comparable coverage for mental health treatment. Among the large number of legislative victories at the state level to eliminate discrimination against coverage for mental illness, many of them were extremely hard fought, including a four-year campaign in Utah.

What truly made the parity effort in Utah unique was the creative approach that its advocates took in crafting a bill that would ultimately unite a broad coalition of mental health professionals, consumer advocates, consultants from state and national mental health associations, state mental health PAC organizations, actuaries, small business advocates, state-based private, non-profit health care networks, lobbyists, and legislators. The result was the 2000 Catastrophic Coverage of Mental Health Conditions Act.

When the legislative effort began in Utah there was tension between mental health groups over whether they should advocate for a comprehensive parity bill that would address the needs of individuals suffering from all mental health disorders or whether they should support parity legislation that was limited only to diagnoses relating to "serious mental illnesses" (SMI) (defined as schizophrenia, schizo affective disorder, delusional disorder, bipolar affective disorders, major depression, obsessive compulsive disorders and anxiety and panic disorders). Coordinated by the Utah Association for the Mentally Ill (UAMI) and the Utah Mental Health Association (UMHA), the 1997 and 1998 bills restricted parity coverage to "seriously mentally ill" (SMI) diagnoses. While strongly supporting the concept of parity, several professional organizations, including the Utah Psychological Association (UPA), as well as children's advocacy groups and disability groups were uncomfortable with a diagnosis-based bill which would offer relief to only a small percentage of persons with mental health disorders. Meanwhile, the opposition, primarily business and insurance groups, was united and effectively pressed the message that "Parity is too expensive and will result in increasing the ranks of the uninsured. Parity is a mandate; we oppose all mandates." As a result, neither the 1997 bill nor the 1998 bill passed either chamber of the Utah Legislature.

Before the start of the 1999 legislative session, mental health advocates, spearheaded by the Utah Psychological Association, agreed to meet regularly to craft parity legislation acceptable to all of the bills proponents. As a result, a comprehensive parity bill, including coverage for substance abuse, was generated within the coalition with the consultative assistance of the American Psychological Association (APA). Introduced by Representative Judy Ann Buffmire with the unified support of mental health and consumer protection advocates, the 1999 parity bill passed in the House. But, the opposition maintained its tight coalition and continued to assert that parity was too expensive, which ultimately prevented the bill from reaching the Senate floor.

With parity legislation beginning to make progress in the Utah Legislature, advocates called for interim meetings with parity opponents to forge a bill that would be acceptable to all parties. The meetings were held under the direction of the Salt Lake Chamber of Commerce, an outspoken opponent of any parity legislation. It was at this point that the mental health coalition, led by UPA, and in consultation with an actuary from PriceWaterhouseCoopers working with the APA, proposed the catastrophic mental health coverage approach to parity. Like its predecessor, this legislation extends to all mental disorders and requires insurers to set dollar limits, outpatient session and inpatient day limits equal to those imposed on medical coverage within the plan. At the same time, it added a new piece that includes mental health costs in the annual maximum out-of-pocket (OOP) limit. After out-of-pocket spending on mental or physical health care exceeds the plan's OOP limit (typically $1500-$2000 per year), all further medical and mental health care is covered 100% by insurance. This feature protects individuals from the financial ravages of a catastrophic cost where even a generous 20% coinsurance paid by the patient can threaten a family's financial resources. This catastrophic parity option is less costly than other parity options; it uses cost control mechanisms common in the health insurance marketplace (e.g., deductibles, copayment and coinsurance); it does not discriminate against children or make artificial distinctions between types of mental disorders; and it eliminates the need for insurers to develop a complex tracking system by diagnosis.

By addressing much of the opposition's concerns, the "catastrophic" approach to parity gained significant momentum. In fact, this compromise proposal added new small business allies to the bill's camp of supporters. A new and powerful advocate, the President of the Senate, Senator Lane Beattie also began to press for passage of parity — further evidence of the coalition-building efforts by the bill's proponents who were now more united than ever before. The mental health coalition also hired a lobbyist, with assistance from the APA and UPA-PAC funds, to help with the final push for the bill's passage.

The work of the mental health parity advocates in building a broad-based coalition over time and the good faith efforts responding to opposition arguments with a compromise bill were clearly recognized by both chambers of the Utah Legislature. The 2000 Utah Catastrophic Mental Health Parity Act overwhelmingly passed both the House and the Senate and went into effect on January 1, 2001.

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PAYER-PROVIDER COOPERATION HELPS REDUCE BILLING ERRORS AND COSTS

UTAH HEALTH INFORMATION NETWORK
SALT LAKE CITY, UTAH

In the early 1990s, Utah health care insurers and providers began to recognize the need for greater efficiency in health care data processing. They knew that the fields of business, banking, and transportation had been using electronic transactions processing for more than two decades, and they felt it was an appropriate time to bring its efficiencies to the health care industry.

A broad-based coalition of Utah health insurers, providers, and other interested parties, including state government, came together in 1992. Their goal was to reduce billing errors and administrative costs for the state's health care

payers and providers by offering a standardized system of processing health care data transactions electronically. The group soon incorporated as a non-profit organization that it called the Utah Health Information Network (UHIN).

To develop seed capital, the coalition agreed that anyone who wanted a seat on UHIN's board of directors would have to contribute $25,000. Virtually everyone did, said Michael Stapley, chairman of UHIN's board of directors and president and CEO of Deseret Mutual. Provider organizations such as the Utah Hospital Association and the Utah Medical Association joined the board, as did all but one insurer who does business in the state and even the state's Medicaid program.

The coalition also identified ex-officio members, including the state insurance department, a large employer group, the state's chief information officer, and Utah Health Insight, which does quality assurance for the state's Medicaid and Medicare providers. Stapley credits this very broad-based coalition as a key factor in UHIN's success. Other states started with very narrow coalitions and found they had a hard time getting investment, he says.

The first step for the network was to set up a subcommittee to develop electronic data standards. They identified billing experts to sit on the subcommittee, which proved to be an invaluable decision, says Stapley, "because we had people who knew the details of how the standards would affect their work on a day-to-day basis." Another subcommittee was set up to deal with technology and was comprised of information systems experts. The two subcommittees worked in parallel for an 18-month period.

Once the data standards and technology were in place, UHIN was ready in 1994 to begin operating as the hub for the centralized data transaction system, which is now used by health care payers and providers throughout the state. In describing how UHIN functions, Stapley compares the network to the postal system. Like a postal system, the network moves "mail". It operates as a centralized, secure clearinghouse through which health care transactions pass in Utah. Every time an insured person receives health care the provider writes up a paper claim and sends it via the network to the insurance company. The payer determines what they'll pay and sends back a written statement showing what was paid and why.

In this way, UHIN eliminates the paper in both transactions and "mails" all of the information electronically. Transactions are sent directly between the computers of the provider and the payer. Network users can send and receive UHIN "mail" directly in their office any time of the day or night, any day of the year.

In developing the UHIN model, the network struggled with the concept of a statewide data repository and ultimately decided, for legal reasons, not to become a data warehouse. UHIN took the position that if the state of Utah wanted to use UHIN as a source for their statewide database, the network would require the state to mandate submission of UHIN transaction data, which it did, under the provisions of the Utah Health Data Authority Act. UHIN believes this will protect the network from disclosure-related liability, says Stapley. But UHIN will have to revisit the issue as it considers the network's role in developing a statewide clinical database.

When UHIN developed its data standards for electronic transactions, its members knew that eventually there would be national standards with which they would have to comply. "Our fear was that the national standards would be significantly different from our standards and we'd be in a world of hurt," says Stapley. So UHIN became actively involved in developing national standards.

In 1996, Congress passed HIPAA, which directed the U.S. Dept. of Health and Human Services to issue national standards for electronic health care data transactions. Those standards go into effect in October 2003. Thanks to UHIN's early input, the standards adopted by HIPAA are almost identical to the standards that UHIN has already implemented. As a result, UHIN is confident that Utah insurers and providers "are in an excellent position" to become HIPAA compliant, although there could be a few glitches along the way, says Stapley.

As a not-for-profit company, UHIN charges for its services, but only enough to cover the costs of running the network. Most payers and providers that use the network have found its services well worth the money. Not only are they ready for the HIPAA standards, UHIN has also reduced their overhead costs.

Use of a standardized data format has resulted in tremendous cost savings for both payers and providers in Utah. For payers, the primary savings come in receiving claims in a known format. This has allowed payers to directly place the information in their electronic claims payment systems and, in many cases, adjudicate the claim the same day it was

received without any human intervention. Payers that have exploited this system to its full potential have virtually eliminated their mail handling and data entry staff. Deseret Mutual, for example, has been able to reduce its claims department staff by 25%, says Stapley.

In addition, a standardized format has encouraged providers to submit electronic claims to all UHIN payers, not just one or two. Even payers who accepted electronic claims prior to UHIN have benefited from a marked increase in the percentage of claims received electronically.

For providers, standardized remittance enables them to automatically post to their accounts from all e-payers, which allows them to reduced posting staff, place them in collections, and focus on collections of small bills. Many providers routinely write off claims of less than a certain amount because it is too costly to collect. With the staff savings that come from auto-posting, providers can significantly increase their income through a more effective collection process.

Stapley says the vision for UHIN is to keep moving forward in incremental steps. Next, they would like to develop standards for processing pharmacy and lab orders electronically. Adopting electronic clinical standards could significantly reduce the potential for errors and has "enormous quality implications."

It is rare for payers and providers to work together as effectively as they have in developing UHIN, but Stapley says the network's philosophy is one of "cooperative competition." You cooperate where it makes sense to cooperate, and you compete where it makes sense to compete. "It did not make sense for us to compete on this, so we decided to cooperate," he says.

For more information, contact: **Utah Health Information Network**
www.uhin.com.

DEVELOPING A RANGE OF PROGRAMS TO ADDRESS ADOLESCENTS' NEEDS

GROUP HEALTH COOPERATIVE
SEATTLE, WASHINGTON

A review of care received by Group Health Cooperative's (GHC) teen members in the early 1990s showed patterns consistent with national trends. Teens over-utilized certain services, such as emergency care, while they under-utilized other services, such as preventive care. Since that time, Group Health Cooperative has developed several initiatives that focus on teens, their parents, and their health care practitioners: a school-based health program; a special teen magazine; and an Adolescent Consultation Team (ACT).

These initiatives are available to all teen members, including Medicaid beneficiaries; participants in Washington State's subsidized program for low-income populations; and commercial members. The programs are designed to mitigate barriers in access to care, such as concerns about confidentiality, convenience, and availability of social support networks. These barriers, often more acute among teen Medicaid members, place them at higher risk for poor health outcomes.

School-Based Health Centers

Approximately four years ago, GHC entered a partnership with King County to manage and provide clinical support to its school-based health centers (SBHCs), which are funded through grants. Each SBHC has a multi-disciplinary staff that includes a nurse practitioner, a mental health counselor, a services coordinator, and the school nurse. Currently, GHC supports three of Seattle's ten SBHCs, providing nurse practitioner staff; physician preceptors; budget oversight; and in-kind laboratory and pharmacy services.

In addition to serving Medicaid-eligible students, the SBHCs serve a large number of uninsured teens. The centers' goals include increasing adolescents' access to high-quality, comprehensive and confidential health and counseling services; supporting students' potential for academic achievement by enhancing their health; and helping students develop the skills to appropriately utilize the health care services at the SBHCs and in the community.

The "Totally Teen" Magazine

Fear of embarrassment and concern about confidentiality often inhibit teens from asking questions or talking about sensitive topics such as puberty, mental health, and drug abuse. To help teens gain information on their own terms, GHC traditionally had prepared written materials for teens on a variety of topics. In 2000, GHC's Teen Health Services and Department of Health Improvement Programs enhanced their ongoing efforts by developing "Totally Teen" a colorful, magazine-style publication. From social issues to healthy eating to sexual behavior, the publication offers information and advice with "plain talk." It communicates health care information geared to teens, and it connects readers with other resources. "Totally Teen"—which is sent to parents of all 13-year-old members—recently received recognition for its content and layout from the American Public Health Association.

The Adolescent Consultation Team

To assist primary care providers (PCPs) in coordinating a teen's care, GHC formed the Adolescent Consultation Team, which includes an adolescent medicine physician, psychologist, psychiatrist, social worker, team nurse, and program assistant. The ACT, established ten years ago, meets twice a month to review utilization information and providers' referrals to help identify high-risk teens. The ACT reviews information on teens who in the previous six months have had three or more visits with health care practitioners in three or more specialties. After this review, the team considers factors such as the teen's diagnoses and the PCP's involvement with his or her care. Upon identifying a high-risk teen, the team's nurse provides chart summaries, which the team and the PCP use to develop the teen's care plan.

Results

GHC's array of programs reflects the fundamental fact about adolescent health—it is influenced by numerous factors. Each program has specific goals and outcome measures, including participation, improved care coordination, and satisfaction. A King County analysis found that more than 3,000 students made 15,000 visits to the eight high-school-based SBHCs during the 1999-2000 school year. The ACT also has experienced positive results. In one case, the team worked with a teen patient who, in the previous six months, had multiple visits with numerous health care practitioners. By developing a care plan, the ACT helped the PCP to better coordinate the teen's care. Of equal importance, the teen had dramatically improved school attendance and was doing better academically.

Response from the 8,000 parents who received "Totally Teen" signals a strong appreciation for the publication. Ninety-two percent of parents who responded to a survey reported being very satisfied or satisfied with "Totally Teen." Parents' comments ranged from a simple "thank you" to "very easy to read... covered things that they [teens] want answers to but don't want to ask."

For more information, contact: **Group Health Cooperative**
http://www.group-health.com/
Phone: 888-203-7770

IMPROVING CARE THROUGH THE END OF LIFE

FRANCISCAN HEALTH SYSTEM
TACOMA, WASHINGTON

The leadership at Franciscan Health System realized in the mid-1990s that for patients nearing the end of life, the systems of care were often inadequate. Recognizing the need for quality end-of-life care, the integrated health care delivery network in Tacoma, WA, implemented a system-wide approach to improving care for this patient population.

The system-wide program, called "Improving Care Through the End of Life," was created to raise the standard of care for patients with a life expectancy of 12 months or less. The goal was to relieve suffering, control symptoms, and maintain functional capacity in a context that would be sensitive to patients' personal, cultural, and religious values, beliefs, and practices.

The program began in 1997 as a pilot project that was part of a nationwide initiative sponsored by the Institute of Healthcare Improvement to improve end-of-life care. Franciscan Health System's CEO, the vice president of mission and ethics, and members of the Ethics Committee had reviewed the network's existing system of referral for end-of-life care, conducted a cost analysis of patient care within the acute-care setting, and carried out a survey of people facing life-threatening illness to ascertain their needs.

The findings were sobering. For end-of-life patients, the costs of acute care and repeated hospital visits were high, hospice was underutilized, and dying patients' needs were going unrecognized and unmet. Most patients wanted to remain at home but needed the support of community services. These findings and the results of the pilot project were the impetus for creating the Improving Care Through the End of Life Program.

Under the program, Franciscan Health System now refers patients to end-of-life care through its community-based clinics. First, a primary care physician refers a patient with terminal illness to a registered nurse specifically hired for the End-of-Life program. The nurse arranges a meeting with the patient, family, caregivers, and physician to assess the patient and family's needs in an advance care planning session. During the session, all areas of a patient's situation are assessed in a culturally sensitive framework, including the patient's spiritual and psychosocial needs.

The nurse then collaborates with the physician on a plan of care, implements supportive services and connects the patient and family to community resources, such as Meals on Wheels, transportation services, medical equipment, prescription delivery, support groups, respite care, and home health services. Volunteers who have been through a hospice-training model to work with end-of-life patients make phones calls once a month to speak with the patient, caregiver, and/or family member.

Throughout a patient's involvement in the program, the staff responds to patient calls about concerns or problems. The nurse triages the patient's needs and communicates requests to the primary care physician. Also, weekly debriefing meetings are held with the volunteers, coordinating nurse, and chaplain to review specific patient needs. A hospital-certified chaplain also makes home visits.

According to survey results from 1997 through 1999, the Improving Care Through the End of Life program has had a dramatic impact on end-of-life patients' quality of life. The program has produced an increase in patient satisfaction during involvement in the program; an increase in physician satisfaction; greater use of supportive, community services by end-of-life patients; more referrals to hospice, which is the gold standard of end-of-life care; and fewer hospitalizations for acute episodes in the last year of life.

Patient and family satisfaction with the program increased dramatically each month the patient participated in the program – rising from 28% during the patient's first month to 80% to 90% after 6 to 12 months. In addition, there were significantly fewer hospitalizations for acute episodes in the last year of life among program participants (14 hospitalizations) than among patients in a control group (37 hospitalizations). Use of supportive services was also higher among program patients (92%) compared with those in a control group (31%).

A key factor in the program's creation and success has been the health system's leadership, who championed the program in the planning stage and helped to gain system-wide support for the initiative. There was a particularly strong effort to make physicians in the network aware of the end-of-life program and to work with the local medical association to gain support for the program.

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END-OF-LIFE PLANNING FOR PATIENTS IN FAILING HEALTH: THE "PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT" FORM

CENTER FOR ETHICS IN HEALTH CARE
PORTLAND, OREGON

Too often, dying patients in nursing homes, hospices and similar facilities are revived against their will because caregivers don't know that they want to die peacefully and without extraordinary measures to prolong their lives.

In 1991, the Center for Ethics in Health Care in Portland, OR, decided to address this problem by convening the Physicians Order for Life Sustaining Treatments (POLST) task force, which included physicians, nurses, nursing home representatives and ethicists from across the state. The task force came together to develop a mechanism for ensuring that patients' life-sustaining treatment wishes were known and honored by caregivers, even in cases when patients were unable to speak for themselves.

The task force created the POLST – a short, easy-to-recognize medical form that details a patient's life-sustaining health care wishes and is signed by his or her physician. The form is designed for patients with serious or life-threatening illnesses who are in long-term care, the hospital, hospice or home health care and who want to decide how aggressively caregivers can intervene if they go into decline. The patient's physician may use the form, which is kept in the patient's medical file, to write orders that indicate what types of life-sustaining treatment that the patient does or does not want. The current version of the form clearly spells out directions for resuscitation, medical interventions, antibiotics and artificial feeding.

Importantly, the POLST form is different from an advanced directive, which is a multi-page statement in which adults describe the medical care they would want if they became incapacitated. Unlike the POLST, an advanced directive is not signed by the patient's doctor and therefore is not a doctor's order that can stop a paramedic from reviving a patient.

POLST was first implemented in 1995 in a select number of long-term care facilities in the Portland area, in Bend and in the coastal community of Coos Bay. Since that time, the POLST program has spread. Although voluntary, the POLST has been widely accepted throughout Oregon. By 2001, the form had been ordered by providers in almost every community with more than 5,000 residents statewide. An estimated 400,000 POLST forms were distributed around the state between 1995 and 2001.

Research results indicate that the POLST is highly successful in ensuring that nursing home residents' treatment preferences are honored at the end of life. After pilot testing and the initial implementation, research was conducted at eight nursing homes across the state to measure the effectiveness of the POLST form. Of 180 nursing home residents who requested comfort measures only, transfer to hospital only if comfort measures fail, and do not resuscitate, 2% were hospitalized to extend their lives, but none were resuscitated against their wishes.

In a more recent study of 58 older adults enrolled in an all-inclusive care program, the medical treatments administered matched the POLST instructions for CPR, antibiotics, IV fluids and feeding tubes more consistently than previously reported for advance directive forms. This data suggests that the POLST form is more effective than other methods in honoring patient care preferences.

The success of the POLST has attracted interest from health care organizations around the country. There have been requests for informational POLST packets from individuals in at least 40 different states and abroad. In Wisconsin, The Gunderson Lutheran Medical Foundation has developed a POLST form that closely resembles Oregon's form. The

form has been distributed in a four-county area in western Wisconsin. The states of West Virginia and New Mexico have also looked to Oregon for developing forms to use in their own states.

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BRINGING HEALTH TO THE HOME – "SALUD EN SU CASA"

BLUE CROSS OF CALIFORNIA
KERN AND TULARE COUNTIES, CENTRAL CALIFORNIA

In Kern and Tulare counties in central California, many residents face significant barriers to health care. The counties are mostly rural, with a population density of just 75 people per square mile; one quarter of the population lives below the poverty level; and many of the uninsured are migrant and seasonal farm workers who receive little or no public assistance. According to the U.S. Department of Health and Human Services, nearly 59% of the population in Tulare County, and 55% in Kern County, are medically underserved.

Blue Cross of California serves the residents in these counties who are covered by Medicaid and the State Children's Health Insurance Program. Sixty percent are Hispanic and Spanish is their primary language. Therefore, there is an urgent need to provide health education programs that are culturally appropriate and designed for Spanish speakers.

To meet this need, Blue Cross of California created the "Salud en Su Casa" program ("Health to Home" in Spanish), which is a health education program that serves primarily seasonal, Hispanic migrant farm workers. By bringing health education to the member's home, the program overcomes barriers such as lack of transportation, lack of knowledge of resources, mistrust of the educational system and lack of resources in the small cities and remote areas of these two counties.

The population served by the "Salud en Su Casa" program needs ongoing health education. Diabetes is the leading chronic illness reported among patients served by migrant health centers. This population also shows a high occurrence of respiratory ailments such as chronic asthma, valley fever, chronic bronchitis and pneumonia – conditions that are exacerbated and provoked by high volumes of pollution, dust and pesticides in areas where farm workers live and work.

Diabetes and asthma both require daily health management to maintain quality of life and prevent unnecessary hospitalizations. Unfortunately, health care providers are often too busy to spend the time necessary to provide disease management education during a routine office visit. In addition, transportation, language and cultural barriers often prevent this population from attending the health education classes available at local hospitals or clinics. "Salud en Su Casa" is designed to bridge that gap.

The program began operating in 2000. Initially, the Kern County BCC approached Catholic Healthcare West, the county's largest health care provider, with a proposal to provide in-home health education programs for diabetes and asthma. The state of California had just announced the availability of grants administered by health plans to expand services in underserved geographic areas or for special populations. BCC was able to obtain a grant for CHW to fund culturally appropriate, bilingual in-home and small group health education outreach programs. Together, they created the Salud en Su Casa program.

Under the program, patient referrals come from a variety of sources including primary care providers, S-CHIP health plans, participating CHW clinics and community-based organizations such as Kern County Economic Opportunity

Corporation, Mercy Outreach Center and Mercy Learning Center. Any individual, regardless of his or her participation in a health plan, is eligible to participate.

Once a patient is referred, a Health to Home educator schedules appointments with the patient for in-home visits during which the health educator teaches disease management in either English or Spanish to both the member and his or her family. Education topics include preventive health care issues as well as how to discuss a treatment plan with providers. Health educators also provide members with a self-assessment tool to monitor their own progress each month and report any significant changes.

Salud en Su Casa has been recognized as an excellent example of a strong health plan partnering with a strong local provider to create an innovative health management program.

For more information, contact: http://bccinsurance.com/

HEALTH-RELATED ORGANIZATIONS COLLABORATE TO ADDRESS LOCAL NEEDS

COMMUNITY HEALTH IMPROVEMENT PARTNERS
SAN DIEGO COUNTY, CALIFORNIA

In 1994, California's governor signed into law a new mandate that every private, not-for-profit hospital in the state prepare a health needs assessment of its community every three years and a community benefit plan every year. This new law, which only affected hospitals, became a catalyst for collaboration among a broad spectrum of health-related organizations in San Diego County, which has long been a highly competitive health care environment.

In response to the new mandate, representatives from 25 health-related organizations – most of which were not affected by the new requirement – met for the first time in June 1995. They came together at the invitation of three "neutral" organizations – the Hospital Council of San Diego and Imperial Counties (now called the Healthcare Association); the County of San Diego Department of Health Services (now called the Health and Human Services Agency); and the Graduate School of Public Health at San Diego State University.

The purpose of the meeting was to discuss the benefits of collaborating to complete the health needs assessment requirement of the 1994 legislation. By the end of the meeting, it was agreed that collective action would produce a better document, and one with more widespread application, than if each hospital were to work separately. To carry out this effort at a collaborative health needs assessment, participants decided to form a coalition called Community Health Improvement Partners (CHIP).

The countywide needs assessment was a tangible, short-term goal that provided the impetus for CHIP, and it is considered a key factor in the coalition's development. All coalition members contributed to the final document, called Charting the Course: A San Diego County Health Needs Assessment, which was produced in less than nine months. The success of that effort produced enough momentum that the coalition decided to collectively address the highest priority needs identified and developed a strategic plan with specific objectives and implementation strategies.

Through working collaboratively on the needs assessment, coalition members have developed a sense of trust in each other and a common mission and purpose. "We have such a collaborative spirit that when people come here they're surprised by how quickly we can get things done," says Kristin Garrett, CHIP's executive director.

Today, 8 years after it was founded, the CHIP coalition includes 30 members, representative of hospitals, health systems, health plans, community clinics, physicians, universities, community-based organizations and the County of San Diego Health and Human Services Agency. The partnership has become a model of what voluntary, public-private collaboration can achieve in a challenging environment such as San Diego, which has a very diverse population, inadequate public funding for health care, and a substantial number of uninsured.

Early on, the coalition developed a loose, three-tiered structure comprised of executive partners, a steering committee, and self-managed work teams. The executive partners, which include the coalition members' CEOs, meet three times a year to set policy direction for the coalition. The steering committee is composed of executive partners' designates and meets monthly to oversee CHIP projects. The work teams perform the coalition's actual projects and activities and were formed based on individual interests and high-priority health needs. CHIP also has three paid staff. Last year, CHIP became a 501(c)(3) organization and the executive partners now function as the CHIP Board of Directors.

One of the work teams, which began meeting in July 1996, was the Access to Care Work Team. The team recognized that the severity of the access problem in San Diego County required more than an incremental approach. In fact, the coalition's top priority since the beginning has been to improve access to health care, particularly for the region's large Latino population, which is disproportionately uninsured and medically underserved, says Garrett.

In 1997, the work team received a $60,000 planning grant from the Healthcare Association to draft a report, Safe Harbor: Increasing Access to Health Care in San Diego, which described the problem of the uninsured and barriers to health care along with strategies to remove some of those barriers. For example, one of the action items in the report is to ensure that those who are eligible for Medicaid enroll. The strategy suggested in the report is that the health care community work with community-based organizations, schools, and community health workers to identify adults and children who may be eligible for Medicaid but have not applied. It also called for training individuals to assist potential applicants with the application process.

The Access to Care Work Team's initiatives include developing a resource center for community health workers – many of whom work in Latino communities. CHIP has identified 35 programs in San Diego County that use community health workers to encourage healthy behavior. "We provide them with trainings, such as in helping people enroll in and retain their health insurance, so that they get a broader scope of knowledge," says Garrett. CHIP is also working with community colleges to develop a certification process for community health workers.

CHIP is involved in carrying out a number of other initiatives as well, including Project Dulce, a community diabetes care program in medical underserved areas of San Diego County – now housed at the Scripps Whittier Institute for Diabetes. The decision to focus on diabetes was driven by American Diabetes Association data showing that Latinos are more likely to be diagnosed with diabetes, more likely to delay care, more likely to suffer complications, and less likely to be insured or have access to preventive care for their chronic conditions. Project Dulce ("sweet" in Spanish) combines state-of-the-art clinical interventions and behavior modification program tailored to meet the needs of underserved Latino populations.

CHIP has become increasingly involved in advocacy as well, says Garrett. The coalition initially took the position that it would not become involved in advocacy, but members changed their policy when $945 million of the state's tobacco settlement funds became available to San Diego County. The coalition decided that collectively they would insist that all of those funds be directed to health care, and their effort was successful.

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HRSA'S HEALTH DISPARITY COLLABORATIVE ON CANCER

Background

Twelve experienced health center teams are participating in a Cancer pilot geared to improve communication with patients and among providers, screening rates, coordination of follow-up for diagnosis, and documentation of treatment. The Pilot began in June 2002 and is supported by a national team of cancer and primary care experts with knowledge about breast, colorectal, and cervical cancer as well as practice interventions. The Collaborative Chairman for the Cancer Pilot is Stephen Taplin, MD, MPH, Associate Director, Preventive Care Research at Group Health Cooperative in Seattle, WA.

Clinical Issue

The Cancer Pilot targets breast, cervical, and colorectal cancers, which affect 338,000 people and account for 105,800 deaths in the United States each year. A disproportionate share of this cancer burden is borne by minority and medically underserved populations, largely because these groups have limited or no access to cancer screening services or follow-up care. Under the current system, primary care providers often receive only limited communication concerning the progress of patients they have referred to specialists for care. Recognizing these issues, the collaborative initiative is designed to drive organizational change within health center practices to help ensure provision of timely, coordinated cancer screening and follow-up care.

Aim, Measure, Process

(1) Several issues will be addressed during the pilot phase of this project, including:
Use of a Care Model for improving the care of people with cancer. The essential elements of this model are the following:

Patient Self-management
- People learn about their disease and how to prevent problems. They set goals for themselves, and the clinical team supports them in attaining these goals.

Decision Support
- Clinicians use evidence-based practice guidelines and protocols, applying the most current knowledge to help their patients.

Clinical Information System
- Health centers create a "registry" database of the entire population with the chronic condition, and the care team uses it to guide the course of treatment, anticipate problems, and track progress.

Delivery System Design
- Clinicians plan visits well in advance, based on the patient's needs and self-management goals. "Planned visits" allow patients to meet with primary care providers and specialists, and "group visits" allow them to see their clinician and meet with others with similar health problems.

Organization of Health Care
- Health centers commit to improving clinical outcomes and make organizational goals for chronic illnesses part of their business strategy. Senior leaders and clinician champions offer strong support.

Community
- Health centers reach out to form partnerships with state programs, local agencies, schools, faith organizations, businesses, and clubs.

(2) Development of change concepts to improve and accelerate efficient cancer screening and patient care coordination. To do this, health center teams respond to three basic questions in the following ways:

What are we trying to accomplish? Teams specify aims, focus on measurable actions to be accomplished within a specified time, and select patients and providers who will participate.

How will we know that a change is an improvement? Teams specify the desired improvement and data needed to determine whether it has been made.

What changes can we make that will result in any improvement?
Teams plan a change, try it out on a small scale, observe the results, and refine the change as necessary. This "Plan, Do, Study, and Act" (PDSA) cycle enables teams to test changes quickly to see how they work.

(3) Identification of appropriate aims and measures of progress. Measurement is essential to ensure that changes made in clinical practice are leading to desired improvements. All health center teams use national measures determined by a panel of clinical experts. In addition, each team selects at least one additional measure to use in assessing

clinical outcomes. An electronic registry is used to collect data; schedule office visits, labs and education sessions; and generates reminders and guidance for patient care. Health centers are expected to track and report monthly on the core measures used by all Collaborative participants, as well as the additional measure(s) they have selected.

(4) Identification of elements or refinements needed for the current information system

At the end of 12 months, through the work of the pilot health centers, the expert panel, and faculty, a cancer collaborative will be included in the HRSA Health Disparities National Collaborative.

Key Partners

Key partners with HRSA's Bureau of Primary Health Care Pilot currently include the Institute for Healthcare Improvement (IHI), the National Cancer Institute (NCI) Division of Cancer Control and Population Sciences (DCCPS), the Centers for Disease Control and Prevention (CDC), The American Cancer Society, and The Patient Advocate Foundation.

Time Line/Key Dates

Prototype development and Planning Group meeting (Spring. 2002); Learning Session #1 (June 17-18, 2002, Denver. CO.): PECS training and Learning Session #2 (September 25-27. Reston, VA.); Learning Session #3 and harvesting session to aggregate key change concepts and ideas (February 3-5. 2003. Washington, DC); Kickoff for the HRSA Health Disparities National Collaborative 2003-2004 (July 23-27, 2003. Orlando).

Results

Aggregate data are unavailable at this time; however, there are preliminary data from individual health centers that reveal a screening baseline at 54% for mammograms, 74% for PAP smears, and 56% for colorectal cancer screening. Changes have been tested and are beginning to be implemented in each of the components of the Care Model. Trends include: development of reminder systems and registry of patients, education and self management support materials in multiple languages and various literacy levels, education for providers and staff; development of relationships to provide discounted services for screening and follow-up needs, and community programs (including faith based, community health workers, and linkages with state based programs and The Susan B. Komen Foundation).

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INNOVATIVE TRANSFORMATION OF HEALTH CARE DATA INTO ACTIONABLE KNOWLEDGE

ANCETA, LLC AND AMERICAN MEDICAL GROUP ASSOCIATION

Anceta, LLC, is a new and novel endeavor spawned by the American Medical Group Association (AMGA) to enhance the context and delivery of health care by transforming comprehensive health care information into actionable knowledge and accountable, evidenced-based practice. As a subsidiary of the AMGA, Anceta is collaborating with the AMGA to leverage its access to the vast store of patient data available from the nearly 300 AMGA member medical groups that serve over 50 million patients per year, representing some 70,000 physicians in 41 states. The AMGA represents large, multi-specialty medical groups throughout the U.S.

Anceta, AMGA and participating AMGA medical groups are engaged in the development and utilization of a national data warehouse comprised of comprehensive, longitudinal patient health care information. The Anceta Data Warehouse will provide the AMGA medical groups with access to comparative data among participants of similar size and structure and key benchmarks for practice management, clinical performance, product performance, health outcomes, economics and quality of care. Additionally, the Warehouse and its proprietary health informatics tools will assist providers, policymakers and purchasers (including employers and employees) in making better decisions regarding health care choices.

Anceta is accessing electronic health information from select medical groups that have information technology infrastructures currently more advanced than that typically found throughout the nation's general health care system. Since these multi-specialty group practices "own" a greater portion of a patient's complete health care picture, usually with common patient identifiers among ambulatory care and hospital information systems, data can be more easily collected and integrated for data warehousing. The design of Anceta's data warehouse, and all of the data collection and scrubbing operations, conform to all HIPAA and other relevant privacy requirements.

The proprietary informatics tools and analyses of the Warehouse will allow Anceta to provide patient-level, de-identified health and health care data (from patient records rather than solely from claims data) to various health care product and service providers throughout the industry. These offerings, including customized analyses and reports and access to customized data marts and data sets, will address the ongoing needs of pharmaceutical, biotechnology and medical device companies, as well as contract research organizations and health care information providers who serve these industries. Anceta's products and services (covering areas such as clinical development, product effectiveness/outcomes, quality of care and cost/utilization) will benefit various corporate departments including clinical development, outcomes research, health economics, regulatory affairs, marketing and sales, managed care/reimbursement, market research and business development.

The Anceta Data Warehouse also is unique in the depth and scope of data it will collect and analyze. Most of AMGA's multi-specialty medical groups from which Anceta will source its data have in-house laboratories and radiology departments. In addition, over 60 of AMGA's largest medical groups support in-house retail pharmacies, and about 70 of the groups have an inpatient facility. Many other clinical systems are maintained for the purpose of providing support to a wide range of in-house therapies and advanced procedures. Given the multi-specialty nature of the groups and their prestigious reputations in their communities, their patients receive a full scope of care over long periods of time irrespective of changes in their insurance coverage. The resulting patient data that is collected and maintained by the groups provide the single best and largest source of longitudinal patient information in the country.

A major milestone attained by Anceta is a recently completed Data Warehouse pilot program involving the aggregation of data from three of the larger AMGA medical groups. Anceta's primary operational components, which were successfully tested in the pilot, included: data extraction and normalization to a standard data schema; database development; data integration; formation of longitudinal patient records and data sets; and preliminary analysis and reporting tools. These three medical groups alone provide care for 1.2 million patients. Over the next three years, Anceta is planning to grow the Data Warehouse to a database of 8-10 additional medical groups representing some 7 to 10 million longitudinal patient records.

In sum, Anceta's Data Warehouse, as the largest repository of longitudinal patient information in the U.S., will be a unique source of health care information, with the capacity to assess and compare multiple points of care, physician practices and administrative variables among participating AMGA member groups.

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THE AMERICAN CANCER SOCIETY QUITLINE

Preliminary studies released at the 2002 annual National Conference on Tobacco or Health found that the American Cancer Society's new telephone-based cessation counseling capability, QuitlineSM, nearly doubles a smoker's chances of quitting successfully compared to the use of self-help materials alone. Dr. Harmon Eyre, MD, Chief Medical Officer for the Society said that "there is one major obstacle to counseling; having to make several trips to a doctor's office or classroom." ACS's QuitlineSM virtually eliminates this obstacle by allowing anyone the flexibility to receive cessation counseling services by phone. The ACS telephone call center currently provides call center operations and clinical telephone counseling for state-financed Quitlines in 10 states.

Demonstrated Success: Quitline Use Among 18-25 Year Olds

The18 to25 age group has been perceived as a particularly difficult segment of the population to reach. Recognizing this, in observance of the 2002 ACS "Great American Smoke Out," MTV ran an ad sharing the life of Pam Laffin, a woman from Massachusetts who began smoking at the age of 10. At 21 she contracted bronchitis and at 24 was diagnosed with emphysema. A public service announcement following the documentary encouraged young smokers to call the ACS toll free number for assistance in quitting smoking.

The response to this ad from 18 – 25 year old callers contacting ACS was overwhelming, and confirmed that the availability of counseling has a large part to play in ensuring successful quit rates in this and other age groups. Results from a study of ACS QuitlineSM callers aged 18 to 25 found that the quit rate was more than double (15%) among callers receiving counseling as compared to the quit rate (6.5%) of their counterparts who received self-help materials only. In general, the 18-25 year old age group reported less frequent daily use and slightly fewer previous quit attempts as compared to other participants. While they were less likely to use nicotine replacement therapy, their success rate was higher when using patches, sprays, and gum in comparison to older adult counterparts

For detailed information on ACS Quitline services and QuitlineSM studies, contact:
    Ron Todd, National Home Office
    Interim Director
    ACS Quitline, 404-329-7652 or
    Angela Geiger, National Home Office,
    Population Strategy Managing Director,
    Health Promotions, 404-327-6414.

COMMUNITY PHARMACISTS IMPROVE DYSLIPIDEMIA THERAPY COMPLIANCE

PROJECT IMPACT: HYPERLIPIDEMIA
26 COMMUNITY PHARMACIES IN 12 STATES

Dyslipidemia (also known as hyperlipidemia) is a major risk factor for developing coronary artery disease (CAD) – the leading cause of death in the United States and a condition that accounts for $100 billion in annual health care expenditures. Dyslipidemia can be treated effectively with the persistent use of lipid-lowering medications and lifestyle modifications. But recent studies on the treatment of CAD indicate that the majority of patients who are eligible for dyslipidemia management go untreated.

In 1996, community pharmacies initiated Project ImPACT: Hyperlipidemia to demonstrate that pharmacists can play a valuable role in improving patients' persistence and compliance with dyslipidemia therapy, with the goal of improving patients' cholesterol levels over time. ImPACT is an acronym for Improve Persistence And Compliance with Therapy.

According to a paper on the project published in the March/April 2000 issue of The Journal of the American Pharmaceutical Association, "dyslipidemia was considered an ideal area in which to demonstrate the value that pharmacists can add to the patient care process for several reasons." Not only is dyslipidemia a major health problem in this county, which makes it an important area of focus, pharmacists are well-placed to assist patients in managing their lipid levels.

Pharmacists are accessible to patients and physicians, and evidence suggests that pharmacists can increase patient compliance and improve treatment outcomes if they provide disease management services. In addition, there is a point-of-care testing device for measuring lipid levels, the Cholestech LDX Analyzer, which is available to pharmacists and other health care providers. As a result, pharmacists can obtain reliable patient lipid profile results within 5 minutes of obtaining a blood sample by fingerstick.

The project was initiated in March 1996 and completed in October 1999. A total of 574 patients were enrolled at the 26 sites before July 1, 1997. Of those, 397 patients completed the entire two-year study. The patients were either newly diagnosed with dyslipidemia or they were already receiving lipid-lowering medications but were not yet at target lipid level. Patients were identified through referrals from local physicians or other local health care providers, by the project pharmacists, or by patient self-referral.

Twenty-six pharmacy practice sites across 12 states completed the project. Pharmacy selection was based on criteria that addressed the readiness of the pharmacy to provide basic pharmaceutical care services. For example, the pharmacies that were chosen had to have a private or semi-private area for patient consultation, technician support, a documentation system for tracking patient care interventions, experience with patient-focused disease management programs, demonstrated communication skills, and the ability to implement point-of-case testing technologies.

Patients provided the necessary personal and general health information that the pharmacist used to assess their CAD risk. A fingerstick blood sample was taken and results were logged into a clinical activity record at each project visit. Patients were asked to make follow-up visits every month for the first 3 months and every 3 months thereafter. Patients as well as their physicians were kept informed about their clinical progress in the areas of cholesterol test results, condition, CAD risk, and National Cholesterol Education Program goal achievement.

Of the 397 patients who completed the study, 345 (86.9%) patients were treated with lipid-lowering medications and lifestyle modifications, while 52 (13.1%) continued with lifestyle modifications focused on diet and exercise in an effort to reach target cholesterol goals. Of the 345 patients started on medication, 323 continued with drug therapy – a patient medication persistence rate of 93.6%. By contrast, recent studies on the treatment of CAD indicate that only 40% of patients who are treated remain on their lipid-lowering medication therapy after 12 months.

Literature from primary care settings indicates that successful treatment-to-goal results range from 8% to 33%. However, outcomes from Project ImPACT: Hyperlipidemia "present a dramatically different picture," the study notes. "In

the project, pharmacists demonstrated that they can, in collaboration with patients and physicians, effectively identify patients with lipid disorders who require treatment and support them in their efforts to improve persistence, compliance, and treatment to goal."

In fact, the project was so successful that the results, if compared with the existing health care delivery system, represent a twofold to fourfold improvement. Patients enrolled in the project achieved medication persistence and compliance rates significantly higher than those previously found in the literature from similar ambulatory care settings. As a result, mean reductions in both total cholesterol and LDL-C exceeded 30 points for the diverse patient population enrolled in Project ImPACT: Hyperlipidemia.

For further information contact: **National Association of Chain Drug Stores**
413 N. Lee Street
Alexandria, VA 22313-1480
Phone: 703-549-3001

5 A DAY FOR BETTER HEALTH

The 5 A Day for Better Health program is the nation's largest public-private nutrition education initiative with 5 A Day coordinators in each state, territory, and the military. The program is guided by the collaborative efforts of members of the National 5 A Day Partnership with the goal of increasing fruit and vegetable consumption to 5 A Day for 75 percent of Americans by 2010.

In the Beginning

The prototype for the 5 A Day program originated in the California Department of Health Services in 1988 with a National Cancer Institute (NCI) capacity-building grant for the purpose of conducting cancer prevention and cancer control programs. With the grant, California built a well-recognized fruit and vegetable promotion program through the media and retail supermarkets. As support of the program flourished among industry partners and coverage by the trade press and presentations at professional meetings generated a growing interest in the program outside California, industry members and California staff approached NCI with the idea of a national 5 A Day campaign.

In May 1991, the nonprofit Produce for Better Health Foundation was formed to work with NCI to oversee industry participation, and in October the national 5 A Day for Better Health program was launched to the industry at the Produce Marketing Association annual convention in Boston.

For its first 10 years the program was co-sponsored by Produce for Better Health Foundation and the National Cancer Institute. In November 2000, the program went under review by the National Cancer Institute. The resulting 5 A Day for Better Health Program Evaluation Report found the program to be a great success despite limited resources and thus called for the 5 A Day program's expansion.

A New Decade

The National 5 A Day Partnership was established in January 2001 in response to the Evaluation Report's recommendations and formed to guide the 5 A Day program into the future with an expanded base of health-oriented government agencies, businesses, and non-profits willing to commit significant resources to the 5 A Day effort. Also designed to mobilize organizations and agencies from federal, state, and community levels, the Partnership works to increase fruit and vegetable consumption by capitalizing on the vast local volunteer networks, enhanced advocacy capabilities, and targeted research of its partners.

The Partnership's steering committee is chaired by Produce for Better Health Foundation President Elizabeth Pivonka and is comprised of representatives from:
    National Cancer Institute
    United States Department of Agriculture
    Centers for Disease Control and Prevention

American Cancer Society
Produce Marketing Association
United Fresh Fruit and Vegetable Association
National Alliance for Nutrition and Activity
Association of State and Territorial Directors of Health Promotion and Public Health Education
Five sub-committees complete the Partnership structure and include Communications; Research/Evaluation; State, Regional, and Community Organizations; Industry; and Policy.

For further information contact: **CDC, Division of Nutrition and Physical Activity**
National Center for Chronic Disease Prevention and Health Promotion
Phone: 770-488-5820
Fax:770-488-5473

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