

“Speaking Not Shouting: A Community Conversation About Health Care Reform”

“Speaking Not Shouting: A Community Conversation About Health Care Reform” brought together more than 130 people on Dec. 1, 2009, at the A.E. England Building at Civic Space Park in downtown Phoenix. The goal was to create a respectful dialogue and informative discourse on this timely and complex public issue, with an emphasis on process rather than outcome. The format was designed to promote thoughtful conversations and give people the opportunity to voice diverging perspectives, listen and be listened to, and better understand each other’s points of view.

Project Civil Discourse is a special initiative of the Arizona Humanities Council working in collaboration with more than 20 organizations from around the state to provide opportunities for the public to participate in trainings, forums, and special events that share, model, and provide insight on collaborative problem-solving. The program goal is to widely share proven skills that can enhance and improve debate and discussion about important issues that affect our future.

Project Civil Discourse and the following organizations sponsored the event: Arizona Association for Conflict Resolution, Arizona Association of Facilitators, Arizona Chapter of the American Jewish Committee, Arizona Consumers Council, Arizona Foundation for Legal Services & Education, Arizona Humanities Council, Arizona School Board Association, Arizona State University College of Public Programs, Arizona State University Sandra Day O’Connor College of Law and its Lodestar Dispute Resolution Program, Arizona Town Hall, Goldwater Institute, HandsOn Greater Phoenix, International Association for Public Participation, Maricopa Community Colleges Center for Civic Participation, Morrison Institute for Public Policy, and The O’Connor House Project.

Congressional representatives Trent Franks, Gabrielle Giffords, Ann Kirkpatrick, Harry E. Mitchell, and John Shadegg sent letters of support to Project Civil Discourse for “Speaking Not Shouting: A Community Conversation About Health Care Reform.”

Online registration was open to the public on a first-come, first-served basis. Partner organizations sent information to their members, and a large number of registrations were received after the Nov. 25 publication of an *Arizona Republic* editorial about the event. About an equal number of men and women participated, representing Apache Junction, Buckeye, Carefree, Cave Creek, Chandler, Gilbert, Glendale, Gold Canyon, Marana, Mesa, Paradise Valley, Peoria, Phoenix, Scottsdale, Sun City, Sun City West, Sun Lakes, Surprise, Tempe, Tolleson, and Tucson.

The evening began with short, non-partisan presentations about the cost of health care by Kim VanPelt, Associate Director, Arizona Health Futures, St. Luke’s Health Initiatives, and the status of congressional legislative proposals by Prof. James Hodge, Jr., Lincoln Professor of Health Law and Ethics, Sandra Day O’Connor College of Law, Arizona State University.

Participants were randomly assigned to 15 small round tables, with a trained facilitator at each table. The facilitator used a discussion guide to encourage conversation around key issues relating to the health care debate. The facilitator was charged with not only

promoting a robust discussion but also encouraging everyone at the table to participate and voice all perspectives. A trained reporter at each table took notes of key comments and suggestions. Following the discussions, reporters presented a highlight from each table's discussion to the whole group.

Highlights of the Conversations

Expanding Access to Basic Care

Participants expressed a strong consensus that the goals of increasing access to health care, decreasing costs, ensuring high quality, and maintaining innovation are inextricably intertwined and can't be dealt with separately. There was widespread agreement that all U.S. citizens and legal residents should have affordable access to basic, necessary, and high quality health care services. Many felt that health care is a basic human right regardless of citizenship status, while others said it is a privilege, not a right. Those arguing for universal access used words like "humanitarian" and "moral" to justify providing government-subsidized care to everyone. Those who see health care as a privilege emphasized that everyone should pay something toward the cost of care; health care should be affordable but not necessarily free. Some felt that individuals who engaged in illegal activity to enter the U.S. should not have access to subsidized services.

One person said that if the Constitution were written today, the Bill of Rights would include health care. At another table, a participant asked, "Isn't health part of life, liberty, and happiness?" At a third table, a participant said, "Who are we as Americans? What are the inalienable rights in this country? Freedom in the United States includes all sharing in the greater good, and we got here by all pulling together. It is a moral imperative."

Defining "Access" and "Basic Care"

Participants acknowledged challenges in defining "basic" health care. Many felt it includes preventive care, screenings, illnesses, injuries, routine visits with primary care providers (doctors, nurse practitioners, and physician's assistants), necessary drugs, emergency care, maternity, mental health, dental, and vision services for all ages. Coverage of preexisting conditions was widely considered to be part of access to basic care.

Several suggested that a panel of medical professionals and government officials should develop a definition, a number mentioned the value of evidence-based medicine and standardized practices, and a few recommended using Medicare guidelines regarding levels and types of coverage as a framework for defining basic care. There was general agreement that cosmetic procedures and "lifestyle" drugs should not be considered basic.

Many said that access to hospital emergency rooms does not constitute access to an acceptable level of basic health care. There was consensus that the ER is not a cost effective way to provide care; people need easy access to primary care in clinics and office settings. Several mentioned federally funded Community Health Centers that currently provide services to underserved areas and populations on a sliding fee scale as a model for providing care.

Continuity of care was viewed by most as an important aspect of basic health care. This includes assurance of long-term, ongoing treatment for chronic conditions and being able

to keep the same doctor(s). Continuity of care is currently endangered by factors such as changes in health plan coverage and provider networks, and by loss of insurance due to employment changes.

Controlling Costs

There was general agreement that skyrocketing costs inhibit access and that all players in the system must take responsibility to help control costs. One participant said, “We’ll know that we’ve adopted useful changes to the system if everyone involved squawks.” Most believed that affordable access to care in a timely manner reduces the need for more expensive urgent or critical treatment at a later time, and some observed that affordable access would reduce personal bankruptcies. Many emphasized the need to eliminate Medicaid and Medicare fraud and abuse.

There was widespread agreement that we need “cost transparency,” meaning the ability to understand the true costs of health care, in order to control costs. Transparency would allow consumers to make informed decisions about their health care, and doctors would understand the costs of their recommendations. Many felt that costs should be uniform, but were not sure how to determine cost structure. Some suggested that parameters should be set to identify services that are the most cost effective and then disseminate that information to doctors and the public; the current inability to know the actual costs of care can lead to unnecessary expenses.

Many identified rationing as a “red flag” concept that is being used to create fear about potential changes, when, in fact, rationing is already widespread in the U.S. There was general agreement that insurance companies and employers ration when they design benefits plans through the use of restrictions, exclusions, and copays. One person said, “People who complain about not wanting the government to interfere with health care decisions don’t realize that insurers and employers have a large say in treatment decisions now.” Another said, “Telling the truth reduces fear. Right now, insurance companies can terminate coverage or raise premiums due to age or illness. This constitutes a system of *de facto* health rationing, so it is inaccurate to portray the proposed bills as imposing a system of health care rationing as if that was not already taking place.”

Participants voiced a wide range of perspectives about the appropriate role of government in financing and managing health care. There was no agreement on whether the market or government would be better at controlling costs. The spectrum of opinions ranged from advocating no role for government, to a limited government role, to support for private-sector insurers combined with a public option, to a government-run single payer system that removes the profit incentive from the health care industry. Some expressed strong distrust of insurance companies and the private sector.

Most agreed that the federal government should either provide or mandate access to basic health care coverage; an accessible, affordable health care system should be part of the country’s infrastructure like roads and public schools. Some said the scope of this challenge is larger than any state or single organization; therefore the federal government should be responsible for regulating the industry, capping costs, and mandating coverage. One said, “An advanced country should provide access to health care for everyone.”

A minority felt that health care should be the responsibility of the private sector. Several said that the government does not have a good track record managing costs and therefore should not be involved to any large extent in either prevention programs or defraying health care costs. One person said the proposed plans before Congress would likely lessen or end the role of private business involvement in health care due to the removal of cost caps. Another advocated letting the market control health care costs, and said that government regulations limit competition.

Most participants supported the concept of a public option, saying it is a good way to expand access and would also serve as a balance to the strength of private sector insurance companies. Those opposing a public option said the federal government is not efficient and could not provide efficient health care coverage. A few said that people who choose not to work should not get subsidized health care.

A number of people said high malpractice insurance premiums, high damages awards, and the need for tort reform are issues that should be addressed as part of health care reform. Many said that health care reform legislation should target major cost drivers, especially restrictions placed on Medicare that prohibit competitive pricing for prescription drugs.

Many voiced strong opinions that the influence of lobbyists on politicians has negative consequences for individuals. Comments included, “Legislators should listen to the people who elected them, not to special-interest lobbyists,” and “We need limitations on the lobbyists from pharmaceutical and insurance companies, and should eliminate their donations to politicians. The effect is very wrong for the people of America.”

Paying for Health Care

There was a range of perspectives on paying for health care. Some felt a combination of government financing for basic health care and self-pay for additional care would encourage personal responsibility. Others said that those who can afford the costs should pay for their own care and the government should help those who can’t afford it. Many raised concerns that without a mandate, people who can afford health care may choose not to spend money on it, which could result in higher long-term costs. However, others worried that there are not enough health care providers to meet the demands of expanded access, which could result in longer waiting times and lower quality. One table noted the importance of increasing educational opportunities to train more health care professionals of all types.

Some of those advocating expanded access said we need to pay higher taxes for the public good. One said, “This won’t be free” and another, “It’s appalling that we don’t take care of people on our own soil. Everyone needs to be insured. I’d rather pay money to the government if it guaranteed basic care.” A proponent of private sector responsibility suggested creating tax-free health savings accounts that individuals could elect to give to people in need.

Many stated that health insurance should not be employer-based, saying that employers currently have an incentive to deny coverage to reduce company costs, and consumers have no control over plans available to them. They said reliance on employer-based health insurance is bad for the economy because it discourages people from starting their

own businesses, growing business to add more employees, and changing jobs and careers. This inhibits creative risk-taking, entrepreneurialism, and growth. One said, “Access to affordable coverage would unleash a wave of entrepreneurs,” and another observed, “Now people are tethered to jobs at companies large enough to offer benefits.”

Encouraging Personal Responsibility and Prevention

There was consensus that personal responsibility for one’s own health is essential to control costs. Incentives for healthy lifestyle choices such as reducing obesity and smoking had widespread support. Some supported penalties for those who make unhealthy choices, but there were conflicting opinions on the effectiveness of wellness education and promotion, and some observed that many health issues are beyond personal control. Many said that prevention activities and timely care would improve outcomes and control costs, as would teaching people how to be informed consumers and effectively navigate the health care system. Some said that profit-driven insurance companies don’t promote health; they restrict needed services and don’t provide incentives for prevention and early detection, resulting in worse health outcomes and higher long-term costs. Some speculated that prevention and early detection and treatment might change the statistic that a small percentage of the population is responsible for a large percentage of health care expenditures.

Several people expressed concern with the overuse of emergency room treatment by uninsured and underinsured people. They noted that in many cases, chronic or life-threatening illnesses could be prevented by earlier detection through regular check-ups and vaccinations. One participant said that maintaining a healthy workforce is important, and the inability of people to take time off from work to go to their doctor’s office for a check-up means that many wait until their condition worsens, thereby necessitating ER treatment at a much higher cost.

Some wondered if utilization rates would level off if people get preventive care. Most expected that utilization would eventually decrease, but there would be an initial spike when people currently without coverage get access and are able to get care for untreated conditions for the first time.

Many people voiced concern that doctors are paid not for prevention but for procedures, and some said “perks” from pharmaceutical companies should not influence drug choices made by doctors. Some suggested incentives should be offered to providers for keeping patients healthy. Many said there should be financial incentives for physicians to be primary care providers instead of specialists. Some proposed that all doctors should be salaried, saying that lower costs and higher quality are associated with doctors on salary.

Many people echoed a desire to have doctors who are really interested in them as individuals. Such doctors are in a much better position to make knowledgeable referrals to specialists and manage their overall care in a cost-effective way. One table suggested an independent or government-run oversight committee to ensure that patients get accurate information and are empowered to make informed decisions without the influence of profit-driven “filters.”

Addressing End-of-Life Care

Many expressed concerns about expensive treatments at the end of life and acknowledged that culturally we avoid talking about this issue, which results in expensive and often suboptimal care. There was agreement that we need informed conversations and decisions about end-of-life issues as individuals, as families, and as a society, without inflammatory language like “death panels.”

Supporting Innovation

Many stated that drug company profits and drug costs in the U.S. are far too high, and voiced strong opinions that pharmaceutical advertising should not be allowed. Many do not believe the argument that high profits are needed to support research and development, but some said the current approach leads to innovation and improved outcomes at a lower cost over time. Most said that current health care reform proposals won't inhibit innovation, while others think that profit motives drive innovation. Some felt that innovation is the key to controlling cost, ensuring better access to care, and maintaining a high quality of care.

A number of people mentioned the potential benefits of electronic medical records and a national electronic health information exchange to control costs and improve quality. A few mentioned the Veterans Administration and Mayo Clinic as examples of systems that coordinate records and care, but indicated there is little communication possible among systems at this time. The integrated approach used by the VA and Mayo Clinic was mentioned by several as a way to achieve better quality at a lower cost.

Feedback on the Process

The following represent comments offered by participants at the end of the event:

- “One of the most amazing venues I’ve ever attended. I can hardly wait for the next one!”
- “This was great! Can we do this for the budget problem next?”
- “This is what we used to do as a nation. We need to get back to this as a practice.”
- “The event was educational and beneficial.”
- “I have a greater appreciation for the diversity of opinions on health care reform.”
- “I appreciated opportunity to be heard without fear of ‘booing’ or disrespect.”
- “I would never have the confidence to go up to the microphone at a traditional town hall. I felt safe to talk with a small group.”
- “It’s a good way to discuss difficult issues.”
- “I feel like Congress is not listening to individuals. In this venue, individuals could be heard.”
- “This didn’t change my mind, but it broadened my perspective. I hold a better defined opinion now.”
- “The round tables promote listening – the town hall format promotes persuasion.”
- “I learned valuable information and will share it with other people.”

- “This was an opportunity for moderates to express their opinions. Town halls tend to focus on the more extreme positions, and it’s important for all voices to be heard.”
- Many were happy with the opportunity to express their views and hear a reasoned argument from those with different views.
- Several people expressed frustration about information that they know is not factual disseminated by legislators, the media, and industries. One called this “inflammatory scare tactics.”
- Several suggested that future gatherings include a call to action at the end of the event, and a number asked that future forums be more widely publicized to attract a greater diversity of participants. More documentation and background information before the event would be helpful.

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