An unusual thing happened on the road to health-care reform in Utah: We, the people, have been in on the discussions, given a seat at the table and even a voice.

State lawmakers, as elected officials go, do their best to allow their constituents to weigh in on weighty matters. But in the normal course of making state laws or budgeting, the general public and its opinions are often viewed as potholes in the road to legislative progress — something tolerated but best avoided.

The health-care reform discussion in Utah the past eight months has not been a business-as-usual project. In fact, the task force members in charge of it have a singular, overriding anti-business-as-usual attitude as far as health care in Utah is concerned.

"We couldn't keep it going like it is even if we wanted to, which we don't," said Rep. David Clark, R-Santa Clara, task force co-chairman.

For Clark, the process started more than year before the reformation began in earnest in March with the empaneling of the task force and a unanimous endorsement of a bill calling for changes to the system. Advocates for health-care reform say the state system has become insanely expensive, unbelievably wasteful, slightly above average in quality and wildly indifferent to consumers, who are dropping insurance coverage in record numbers or not buying it at all.

"We're not talking about the ins and outs of a state agency," said Judi Hilman, executive director of the Utah Health Policy Project, research and advocacy group. "We're talking about the one golden opportunity to talk back to the health-care system, which is the fairly monolithic, top-down, doctor's orders institution that people complain about, but now they can help change."

Consumers will be given much more responsibility and more control in the new health-care approach to staying healthy, obtaining insurance, investigating medical service providers' work history and their quality of care quotient.

Under the new system, at least as it's envisioned, consumers will be consultants on medical-care procedure decisions, tests and retests. They will have to be as willing to shop for an insurance plan as they are to investigate the downside of the Wii video game platform.

As far as Hilman is concerned, health care is a problem looking in need of a grass-roots-based solution.

"We can't just leave it up to the providers to make this paradigm shift that we all have to make," she said. "How we view health care and the role it has in our lives will change, and it will be big because most of us have not taken charge of our health. We're demanding more transparency and more authority, but to do that we have to move toward not only more personal involvement but toward a healthier relationship with our own mortality."
The Robert Wood Johnson Foundation, the health-care policy research and survey group, has noticed Hilman's empowerment approach over the years. In October, the foundation named her one of 10 Community Health Leaders nationwide for 2008.

"She exhibits outstanding courage, determination and extraordinary empathy on behalf of individuals and families least able to understand or navigate a system that is Machiavellian in its complexity," said Janice Ford Griffin, national program director for the award.

For UHPP's success in communicating the importance of health-care reform to legislators and the public, the foundation recently announced that Utah will be among six consumer advocate states to push for innovation and health-care reform at a national level.

Bold reforms are needed to expand access and control costs, as well as to improve quality health care, Hilman said. That requires participants to become coalitions, and those coalitions must reach strong consensus.

As co-convener of the Community Workgroup of the state Legislature's Health Reform Task Force, UHPP held satellite meetings in 13 cities and towns around Utah, engaging hundreds of individuals and organizations this past summer.

"True reforms call for significant up-front investments, yet the state is looking at deficits as far as the eye can see," Hilman said. "A fix can't wait until better economic times because good health and access to good care when someone's sick is absolutely vital to the financial stability of Utah families."

Judi Hilman, executive director of the Utah Health Policy Project, is looking for grass-roots support.