

Lessons from SIM: Advice from Independent Consumer Advocates

Connecticut's State Innovation Model (SIM) project, the latest attempt to reform our health system ended last month. Despite spending \$45 million in federal tax dollars, SIM didn't accomplish much. It was mired in controversy from the beginning and faced criticism from across the state's healthcare landscape. SIM followed many earlier failed attempts to reform Connecticut's health system. We asked independent consumer advocates, many of whom participated in SIM committees and in other past reform efforts, for their best advice to the next reformers.

The question: What advice would you give to future policymakers attempting healthcare reforms in Connecticut based on the SIM experience?

- My quick thoughts from a saddened volunteer who found SIM to be a total waste of my time.

Bring in from the start to the table private payers, providers, high level state officials both elected and executive branch, plus CONSUMERS.
Start by looking at what is working.
Start with an open mind as to what models are to be explored.
Hold public hearings throughout the state.
Have sufficient dedicated staff.

- Involve ALL stakeholders from the beginning, ESPECIALLY those who are most likely to be impacted by whatever it is you're recommending.

Don't try to do something that's already been tried here and failed - what is it they say about doing the same thing over and over again and expecting different results?

You can't only have people who have a vested monetary interest in your project turning out a certain way involved in the planning. You must include independent advocates from the beginning, and not present something that is already a done deal and consider that "stakeholder input"

- "The primary lesson I hope will be learned from the SIM experience is that a project which has a pre-determined method for reaching a pre-determined goal is not a project that lends itself to any meaningful input from genuine consumer interests, and therefore any attempt to get "authentic consumer voices" to the table is inherently self-defeating. Those coming from the place of genuine consumer concern were not listened to but instead a few of their comments

were taken out of context and then shoe-horned into being support for the pre-determined plan. And individuals specifically selected for SIM committees because of their favorable view of the pre-ordained SIM initiative were falsely touted as being representative of the community of consumer advocates. All of this caused further alienation of consumer advocates who were not part of the creation of the SIM plan in the first place.

One of the most transparent illustrations of this was the attempt of the SIM office and its consultants toward the end of the project to convince a few “people with disabilities” to affirmatively support the SIM proposal to capitate primary care providers under Medicaid (called “Primary Care Modernization”), a proposal which presented significant risks of exacerbating access to care for such individuals because of the inherent incentive under capitation for providers to stint on care, particularly for high needs individuals. The approach of SIM representatives seemed to be that, if only the specific proposal was explained well enough, people with disabilities and their advocates would necessarily support the proposal. So when the small group of such individuals selected by SIM expressed concerns with the whole premise of the proposal, despite SIM making unrealistic promises of what would be delivered under capitation, this was not heard. Instead, the SIM staff and consultants cherry-picked a few statements these individuals made at two meetings about needed improvements in access to care for people with disabilities, and then falsely characterized those statements as being support for the basic capitation proposal – when the opposite was intended. The result was alienation of people with disabilities and their advocates, who took the step of writing to SIM stating that they were *not* representative of the community of people with disabilities, that they felt used by the process to serve the SIM staff’s pre-determined result, and that the SIM representatives were not authorized to represent that even this small group supported the proposal. This effort further damaged the credibility of state parties who might seek to get cooperation from consumers and advocates in the future.

Going forward, I would recommend that policy-makers should be interested in hearing broad-based consumer voices FIRST. And the input should be broad enough to ensure reasonably representative consumer voices. It should definitely not be skewed through the selective invitations of individuals known to have a particular perspective. If one wants to really hear authentic consumer voices, then they have to be heard BEFORE the method, and maybe even the goal, of the project is determined. If the broad consumer voices do not support the project, it should either be abandoned or modified to reflect the consumers’ concerns.”

- Leadership needs to be different