

Dear Committee Members:

Thank you for accepting emailed comments regarding the process of privatization of Medicaid in Iowa.

I am writing as the mother of a 27 year old who was diagnosed with developmental delay of unknown etiology when he was a toddler. Due to significant health concerns and our family's inability to keep him medically safe at home in Iowa City he was moved to an ICF/MR 90 miles from us when he was almost nine years old. When he was eleven he moved to a pediatric ICF/MR 120 miles from our home. Over the course of nine years my husband and I drove more than 80,000 miles to visit him. On his eighteenth birthday we were able to move him back to Iowa City through the Home Community Based Waiver; he currently resides in a residence overseen by Systems Unlimited.

Please allow me to give you my experience regarding the process of privatization of Medicaid service in Iowa:

My husband and I were first notified in November of 2014 that rumors were circulating in the professional community that a potential shift in delivery services was being discussed. At that time the professionals in the field of disability services knew nothing other than rumor.

In May of this year we received notice of an informational meeting being held to inform guardians regarding a proposal to privatize Medicaid. The information given at the meeting was of a general nature: an explanation of what an MCO is, many references to the process of privatization in Kansas, and repeated comments along the lines of nobody having details.

During the summer we learned that numerous MCO's were being considered and early fall we learned which four had been chosen.

At a public forum a few days later we heard representatives from the four MCO's give "details" regarding their services. I have written "details" in quotes intentionally. As a parent/guardian of an individual with complex medical needs there were no specific answers to questions; there were no answers as to how needs would be met. The "details" involved assurances that the MCO would walk with us every step of the way, help us with appointments, find specialists, etc. For those of us who are dealing with medically fragile individuals, the simplistic approach verged on insulting.

During the meeting we were encouraged to contact the MCO's directly. I emailed all four of the MCO's within a couple of days. I heard back from one a few days later and was able to communicate directly with their representative. After resending my email two times to the remaining MCO's I heard back from a second one approximately three weeks later. This email response was merely a cut-and-paste answer that assured me that their organization was capable of handling any concern. When I repeated my specific concerns in a follow-up response, the answers continued to be vague.

Throughout the late summer and early fall we were told enrollment packets would be mailed out in the fall. Numerous times between mid October and mid November I called the toll free number to inquire about the date of the mailings. Each time the person I spoke with either had no idea what I was talking about or responded "the enrollment packets will be mailed out sometime in the fall".

Meanwhile, our case manager was trying frantically to get any information from DHS regarding mailing dates for the packets and which medical providers were being signed up. Our case manager has close to thirty years' experience in this field and she continually apologized that her office either did not have access to that information or that information had not been clarified.

Once the online list of providers was available, I logged on to see which providers were enrolled under which MCO's. A notice flashed on the page that there were "technical difficulties; please try again later".

So, this is where we find ourselves as we enter December. We have no enrollment packet, we are unclear as to which MCO has signed up which providers, and we need to make a preference by December 17. Meanwhile, we have learned through the Des Moines Register that three of the four MCO's have varying degrees of court cases either pending or settled, and that three individuals from one of the MCO's are incarcerated due to fraud. We know that a handful of the MCO's who were not chosen are suing the state. We know that one of the four MCO's awarded contracts may or may not be allowed to continue. We also have learned that there is a lawsuit pending from a consortium of hospitals in Iowa. We know that less than half of the current providers accepting Medicaid have signed agreements with one or more of the MCO's and that some providers are being asked to sign contracts that are incomplete.

We know that individuals in rural Iowa potentially face lengthy drives to receive services. We know that individuals who require specialized care from numerous medical specialists may "have to choose the most important medical provider" because not all providers will be signed up with all MCO's.

The state has assured us that things will magically come together by January 1. The state has assured us that Iowa will save 51 million dollars if this plan is passed and if this plan is scrapped the state risks budgetary chaos. Considering that the Iowa City Community School District has budgeted the cost of building Liberty High School at 75 million dollars, it is puzzling that the state budget will be in a freefall over what amounts to the cost of a medium sized high school in a medium sized town. Individuals from other states have weighed in with ample hard evidence that there are no cost savings at all. And yet, Iowa continues to plow on in spite of alarms and red lights flashing from consumers, providers and a significant number of elected officials.

At what point do we take a step back and examine what we are about to do? At what point do we recognize that 20% of Iowa's population is currently experiencing massive confusion regarding the future of their healthcare? At what point do all of our elected officials ask themselves if they personally would want to be experiencing this uncertainty?

Those of us who are personally impacted by this decision find ourselves in the position of being blindfolded, twirled around until we are dizzy, and required to accurately pin the tail on a donkey that may or may not exist.

Sincerely,
Patricia M. Williams
Iowa City

trixiestarr@hotmail.com (I agree to be contacted by legislators or press, please do not include my email on the public viewing area of the web)