

Hi, I'm Kristi and my 20 year old daughter, Tessa, has a severe seizure disorder. I'd like to share a few of the questions & concerns I have regarding including long term care for the I/DD population in KanCare.

Tessa had to go back to the name brand drug for one of the seizure medications she takes. In January I called the pharmacy for a refill, and after a couple days they said it was on hold for pre-authorization. After a couple more days they said it was still on hold. That was a Wednesday night and I knew she would run out over the weekend. Thursday I spent a huge amount of time bouncing between the pharmacy, medical and insurance providers. By afternoon, all parties knew what needed to be done, but I had no assurance this would take place before end of business on Friday. Having a lot of anxiety about that, I called the KanCare Ombudsman and he indicated he would get back with me. By Friday afternoon, I was really sweating it. It's difficult for others to understand the anxiety this creates. I never heard back from anyone so I called the pharmacy and it had been approved. However, I learned it's only approved for 90 days and I don't know what will happen then. Will she have to take the generic again? If so, for how long? How poorly will she have to do before it's considered justified? After eventually going back to the name brand drug, how many months will it take her to get back to where she is now? Why is this in question when it was justified to the State? There was not 'better communication between providers, or care coordination' offered, it's still just us taking care of her. Keep in mind this is the medical care portion that MCO's are experienced at.

This population needs stability. I feel that some decision makers don't understand how hard and long we, as a whole family, have struggled to get any little bit of stability in her life, and therefore in all of our lives. I can't work more than part time, and will have to leave my job this spring as she graduates, as well as her little brother. So we'll be losing what little second income we have, as we need to pay for college for our son. In regard to behavior supports, just a little rock of the boat can make tidal waves, it can create huge regression that is so difficult, and takes a long time to come back from, if they ever can. We've spent years and years and years finding the medications and supports that work for her. Please consider the investment and sacrifices we've made to get this far, what she's been through, trying medication after medication, spending months going up and down on dosages, and all the side effects. How can a pilot project with a few individuals for the next nine months teach inexperienced MCOs even a fraction of what the local people already know?

Finally, where is evidence that this is going to work in the long run, that it's sustainable? How can paying huge administrative costs to these MCOs be justified, when the current I/DD system functions with just 3% administration costs? How will that logic get people off of waiting lists? Decisions about her services being made by inexperienced MCO's, within an unproven system, feels unbelievably careless.

Today I'm asking for your support to permanently carve I/DD long term services out of KanCare. I thank you for your attention.

Social Services Budget,
FEBRUARY 20, 2013

ATTACHMENT #6