

Senate Public Health and Welfare Committee
Friday, February 9, 2018
Phil & Marilyn Kubler, Parents

We are parents of a 38 year old woman with Down syndrome who has been on the HCBS/IDD waiver since she was 18 years old. Prior to KanCare (four years ago) our services were provided by the State of Kansas and our local Community Developmental Disability Organization (CDDO). If we had concerns or problems we could go directly to our CDDO or targeted case manager who would run interference for us through the state. Issues could be resolved rather quickly and painlessly.

Since KanCare we have an insurance for-profit company to decide her needs through a Needs Assessment and then determine how many hours they will allow each month for support. We have always felt this was a conflict of interest on the part of the insurance company as they hold the funds and the less money they disperse, the more profit they make for their stakeholders. In fact, there is little to no savings for the state in this system and the waiting list continues to be a huge problem as the funds saved do not go to people waiting for services but instead to the insurance companies and their stakeholders.

Last week our daughter had her annual assessment and the care coordinator sent us her individual service plan (ISP) that was full of mistakes. The tier level and the number of hours he determined for her care was incorrect and her day services had to be recalculated in order to rectify the correct number of hours. It looked as if he took last year's ISP and just had us sign it, which we did, but was wrong. Since we didn't get a copy at the meeting we didn't know it was wrong until he mailed it to us several days later. He did correct it, but we had to point out the mistakes to him.

When a care coordinator comes to do an assessment they have a lengthy computer program to go through which is very time consuming and questions relating to health is always involved since they are representing an insurance company. Our case manager develops a thorough person centered support plan (PCSP) that covers all of her health issues and needs but instead of taking the information provided in the PCSP, the care coordinator repeats the questions during the meeting. We do not look on our adult child as a patient and her wellness is taken care of by her family and her providers and her doctors who are documented in the PCSP. My child is not sick. She requires long term care because she has a developmental disability and her diagnosis as a person with Down syndrome will never change.

Since KanCare the Clearing House has been a disaster and it is very difficult to get things righted if someone at the Clearing House hits a wrong key on their computer which happens frequently and kicks them off of Medicaid. This becomes a nightmare when you attempt to resolve it and it takes weeks, if not months to get it fixed. Applications are lost and getting someone, at the Clearing House, to address the problem is very difficult.

For friends of ours who still have their adult children living at home, the assessment conducted by the Managed Care Organization (MCO) requires the parents to document how many minutes it takes for bathing, dressing, washing hair, brushing teeth, toileting, buying food, preparing food if the person is on a separate diet from the family, and transportation. These calculations determine how many minutes/units the MCO will give in support to a family. Unfortunately it doesn't take into consideration that having a disabled child doesn't allow one parent to work, if they cannot find a provider, and the family income is drastically cut. Most families typically receive 18-20 hours a week for paid support at \$9 an hour. Hardly enough for a living wage.

Because of all of these reasons and many more not mentioned we would like to see our individuals carved out of KanCare. The money saved by carving IDD out of KanCare would go a long way in raising rates for providers and funding the wait list.