

Testimony on HB 2457  
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I am the parent of a 30 yr. old son who has an autism spectrum disorder. He receives services through the Medicaid HCBS waiver and will be impacted by the proposed Medicaid reform. I ask you to support HB 2457.

Last week I attended the Summit on Medicaid and Managed Care arranged by the Kansas Health Consumer Coalition. One of the speakers, Joan Alker, a professor at Georgetown University Health Policy Institute, is an expert on state-specific analyses of Medicaid changes. Although the Brownback administration says Medicaid managed care will save 8 billion dollars, Joan Alker stated that there is no good data to show that Medicaid managed care saves money. She also said she has never seen a state propose to implement the widespread sweeping changes that Gov. Brownback wants. In order to make these enormous changes, the Brownback administration has submitted a concept paper seeking an 1115 Medicaid waiver from the federal government. According to Joan Alker, this is unusual and it doesn't make sense to take bids from insurance companies before waiver approval is obtained. She said the waiver approval process is one of negotiation and insurance companies can't know what they are bidding on until the waiver negotiation process is completed which takes several months. The Brownback administration has submitted the first step in the process, a concept paper which asks for a global waiver administered under a per capita block grant. Per capita means per person and in a block grant there is a set amount of money. This inconsistency needs to be clarified. The Brownback administration sent out and received back proposals from managed care companies without the necessary waiver approval. This seems to me to be putting the cart way out in front of the horse.

Another speaker at the Summit, Jodi Mitchell, spoke about what happened in Kentucky when managed care was implemented. The Brownback administration is using Kentucky as a model. Kentucky's Medicaid managed care does not include HCBS services for the Developmentally Disabled and it should not be included in Kansas. In Kentucky, access to medication has been a problem. Consumers have been switched from medication that is working to lower cost drugs. It is hard to see how taking people off medication that is working improves health outcomes. Medicaid managed care in Kentucky has hurt independent pharmacies. There has been a delay in payments to providers and several small providers have gone out of business. I am very afraid of this happening in Kansas. My son had a wonderful day program that closed due to lack of funding. I fear the one he is in now will also close if Medicaid managed care is implemented for I/DD services.

Medicaid Managed Care as proposed by Gov. Brownback will impose a great burden on guardians. My son will be assigned to one of three managed care companies. I will have to find out if his day and residential providers are contracted with the managed care

company he is assigned to. I will have to study the drug formulary and see if his medication is covered. I'll also have to find out if his physician is contracted with the managed care company. My son's previous physician appeared to be afraid of him and never did anything beyond have the nurse take his blood pressure. The physician he has now is familiar enough with him to be able to do an exam. I don't want to lose that. But the medication issues worry me the most. It took a long time to find a drug that works for my son. A generic version became available several months ago and my son was switched to this. On the generic, he became agitated, uncooperative and hyperactivity increased. We appealed and my son was allowed to go back to the original. There is a difference between the two versions in the time release mechanism which is probably what caused the problem. In Kentucky, the drug choices are extremely limited and only generics are allowed, so I doubt my son would be allowed this medication that has worked well for him for 8 years. If we are forced to find another due to cost, previous experience tells me that finding a new medication can take several months. What happens if the doctor wants to prescribe a medication not on the formulary? What happens if nothing on the formulary works? In Kentucky, one of the managed care companies only pays for the use of one generic medication in a category often used by people with autism. It is a drug that does not work for my son and has excessive weight gain as a side effect and is linked to Type 2 diabetes. How does this improve health care outcomes? I expect that it won't be simple to obtain the necessary information on doctors, service providers and drug formularies for all three companies in the 45 days in which a change from the assigned company to another is allowed. If by some miracle I find what my son needs with one company, it could become a poor choice if the doctor needs to change the medication and the new medication isn't on the formulary.

Both in school and in adult services, my son has sometimes been with individuals whose aggressive behavior makes them a danger to others. Currently my son is in a day program where there are individuals who display aggressive behavior. They are likely to experience forced medication changes too, and I worry that my son will be attacked because he doesn't pick up on social cues that you or I might to stay away from them. I worry that he will see staff attacked which is very upsetting to him also and causes him to have nightmares where he wakes up screaming. The staff are poorly paid for the responsibilities they have, and if the job conditions get worse, I fear even more staff turnover. Staff are my son's friends, and he recites a long litany of staff who were important in his life but who have disappeared from it.

HCBS Medicaid waiver services are not health care services. HCBS services support a person's daily life activities, what they do during the day and where and with whom they live. I think most of us would agree we would not want our health care insurance company making those decisions for us. There are good reasons to carve out DD services from managed care. I ask you to look carefully at all the ramifications of Medicaid managed care on this vulnerable group. Let us learn from other state's mistakes rather than make mistakes in Kansas that damage individuals with developmental disabilities and their families.