

February 6, 2018

Testimony for Senate Bill 322 committee hearing February 9, 2018

To whom it may concern:

As Kansas citizens and the parents/guardians of an adult with special needs we would like to provide the committee with an account of our experience with MCO services since the I/DD population was incorporated into the KanCare system. We have three significant concerns to share.

- 1) Inconsistent service coverage between MCOs and poor communication and knowledge of MCO staff about payment for services including persistent misinformation, late payments and refusal to pay for services already provided despite their culpability for billing errors:  
Our son has required physical therapy his entire life to deal with significant weakness and spasticity resulting from a massive stroke at age 2. Physical therapy allows him to remain mobile and navigate his environment more safely despite his physical and visual disabilities. The first MCO we signed up for refused to cover any PT at all and we were forced to pay out of pocket to maintain his therapy for a year until we could change MCOs. When we changed to the current MCO we verified that his therapy would be covered both with his provider and the MCO however the MCO refused to pay for his therapy after his services began. The PT provider spent hours on the phone trying to determine why payment was being denied and was referred to no less than 10 different people to talk to with no one knowing enough to resolve the issue. When the care coordinator finally requested the assistance of an experienced department supervisor it was determined that the issue was simply an obscure change required in coding for adult PT services. This process took weeks to resolve and the MCO refused to pay for therapy provided during that time. We paid out of pocket for those services and of course the 15 hours of the provider's office time dealing with the MCO was uncompensated.
- 2) Care coordination is non-existent:  
Care coordinators are poorly trained, have too many clients and have no knowledge of the complex health and disability issues affecting my adult child. When we changed to the second MCO in an attempt to receive coverage for PT services we were assigned a care coordinator. Over the course of 3 years our son was assigned 5 different care coordinators. They did not know him nor did we know them. We didn't even know a new coordinator had been assigned until the case manager attempted to schedule required meetings for the BASIS and ISP. The coordinators rely on the case manager to essentially do their job and show up to get forms signed. They rely on us as parents to provide a complete medical history and they are totally uninformed about our son's longterm care needs. They

do not know the community resources and which would be the best providers for the services our son requires. We changed MCOs in January 2017 in an attempt to get better coordination of services. Neither the case manager or we as parents/guardians have had any communication with that care coordinator for over 6 months until the case manager received an email last week that our son was being assigned to a new care coordinator 2 weeks before his BASIS evaluation and ISP. The new care coordinator will obviously be present only to fill out forms and get signatures since she has never met our son. The state is wasting money paying for non-existent care coordination. As far as we are concerned their primary function is clerical.

3) MCOs should not be responsible for administering services for the I/DD population:  
MCOs are by definition managed care organizations for health care needs not long term care services. For profit MCOs have a direct conflict of interest in determining the level of services required for children and adults with disabilities. Not only do they lack the experience and knowledge necessary to determine the best services and environment for this vulnerable population but they are rewarded financially for denying services necessary for their health and welfare. Prior to KanCare the I/DD services were being effectively administered by local CDDOS providing much more responsive and efficient coordination in a cost efficient manner. Under the current KanCare system many local providers are being forced to close because of delayed or non-payment by MCOs while at the same time no new licenses are being given to establish new providers. There is now an acute shortage in day service and residential care providers in our area severely limiting the options for appropriate placement for services for persons with I/DD. There is essentially no freedom of choice. Case managers are on the frontlines of accessing available providers and have had longstanding relationships with their clients and their families. They are in the best position to find suitable service providers and can respond quickly to emergencies and changing needs. Our son's case manager has been working with him for over 15 years. We can't even count on the same care coordinator for 12 months. KanCare MCOs have failed to serve the I/DD community fairly and effectively.

Please carve out the long term care services for the I/DD population from KanCare and allow these children and adults to have the best opportunity for safe, effective services so that they can thrive despite their challenges. Every Kansas citizen deserves to be treated with dignity and have the freedom to make choices for their future.

Respectfully submitted,

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