Aldona Carney 138 N. Gleneagles Wichita Ks 67212 316-722-9094

To: The Bob Bethel Home and Community Based Services and KanCare Oversight Committee

November 18, 2016

Thank you, members of the KanCare Oversight Committee! My name is Aldona Carney and I'm the parent of a young man with severe disabilities who relies upon KDADS programs to make it through each day.

In Secretary Keck's October 24<sup>th</sup> opinion piece in the Wichita Eagle, he indicated the state believes KanCare has been a sweeping success. Some of us believe otherwise.

A mother contacted me because her son with cerebral palsy and seizure disorder was denied his life-saving seizure medication by his MCO. They exhausted all efforts to get it approved, and paid out of pocket for months, but they could no longer afford to do that. I put her in touch with her legislators and it was resolved, but it took legislative intervention.

Secretary Keck states that, "KanCare represents a vast improvement over the previous inhouse administration." This hasn't been realized in practice. The in-house system wasn't perfect, but it functioned as a capable gatekeeper for services and funding. It also ensured that providers got paid.

At the KanCare Forum in Wichita on October 18<sup>th</sup> I heard many heart-wrenching stories. A gentlemen in a wheelchair told of his efforts to reach his MCO for additional help and how he was put on hold for hours. He finally got so fed up that he turned himself in to Adult Protective Services. They finally contacted him and helped him through APS intervention.

Many nursing homes report they are not being compensated for services due to the Medicaid backlog. Between that and declining reimbursement rates, they fear they may not be able to stay open. Adding one more layer of administration with three distinct players has added complexity, aggravation, and expense in communities across the state. Secretary Keck also said that the KanCare contracts provide accountability and pay-for-performance measures to our state system. However, there is no transparency. The public is not aware of progress in meeting the stated performance targets from the original contracts. How many individuals with I/DD have gained employment with help from the MCO's? What has been done to better integrate mental health services for people like my son with a dual diagnosis? Just saying they will do it and offering more training is not an outcome. State leaders and the MCO's need to be held accountable for their stated outcomes. (over)

Lastly, my son receives HCBS services, and we are very grateful for those services, but nothing in his world has changed under KanCare to lesson the chances of an unexpected accident or injury. Suggesting that because my son didn't have to go to the ER during a certain time period, proves that KanCare is a success, is like saying that because I didn't get into a car accident while driving here today proves that my car insurance is a success. I strongly urge this committee to request state administrators make real connections between MCO efforts and stated outcome improvements.

Secretary Keck and I agree on one thing: We all need to work together in caring for citizens with disabilities in Kansas. The administration needs to be willing to listen to those most affected by KanCare. We can do better, and we must do better for the vulnerable populations in Kansas. Thank you!