To: Special Committee on Health and Social Services

From: Julie DeMarco. To present in person.

Re: Targeted Case Management

Thank you to committee members who have been so supportive of the IDD population in Kansas. I appreciate your time and attention today.

I strongly believe in the existing structure of Targeted Case Management (TCM) in Kansas today and am alarmed at the changes that KDADS is proposing that would force service providers to divest of TCMs. I would like to share my experience with you so that you see real life situations where a TCM within a service provider delivers vastly superior care that any outside TCM would be able to provide. The proposed changes would reduce our choice of TCM, and would weaken TCM delivery of essential services.

My brother, Russell, is 53 years old and has received residential and day services in Johnson County by Lakemary Center for more than 30 years. His TCM is employed by Lakemary. Russ has severe autism and is close to non-verbal. He cannot self-advocate, nor explain cause when he is frustrated. He likes routine and for people to treat him in certain ways. To understand him takes years of exposure. Today I have two recent examples of embedded TCM superiority.

At the heart of the first example is continuity of care. Our parents had been responsible for Russ' care, but they are aging, and two years ago I suddenly had to take over. The transition from parent to sister was stressful for both Russ and me. His TCM provided a vital link of stability and knowledge of all facets of his life. She provided me with details of his care provision and informed staff of the transition so both he and I were surrounded by support. Because she is present daily in his life, she can describe his quirks, his non-verbal tells, and the standards of care that he prefers. She knows his team of direct support staff and can talk to them in real time when situations arise. This knowledge does not come from reports gathered twice a year from a remote TCM; it is from daily observation and frequent engagement. He trusts her, as do I.

My second example is current and illustrates that embedded TCMs provide better care in a crisis for a severely disabled individual. Russ sometimes expresses frustration by leaving his home and going for a walk on his own. A staff member has to follow. In the last month, these episodes have increased, and the police have intervened to keep him safe near intersections. They called me, and I called his TCM. She has experienced his "elopements" and knows the staff who surrounds him. She is gathering his Lakemary team to inform them and to brainstorm solutions. She is present for Russ, advises staff, and can adjust his environment. Her interventions have kept him calmer, enabled him to have more positive interactions with people, and kept his medications to a minimum. A TCM who is not embedded would not have firsthand, in-depth knowledge of him, nor be able to work with his support staff as colleagues in an emergency.

KDADS proposals break this essential link and would force us to choose a TCM who is in a separate location. A remote TCM will not be able to respond to Russ's needs in real time, with the intimacy of knowledge and ability to gather resources that our embedded TCM has. I am aware of conflict-of-interest concerns, but I want the option to waive them. Much the same as someone seeking legal services or tax preparation work can waive conflict-of-interest, I would like to provide informed consent to keep my TCM embedded at his service provider. It should be our choice. Safeguards against abuse of the embedded TCM have been in place in Kansas, and I believe they will work to protect individuals, and at low cost to KDADS. The option in not on the table today, but it should be.