

To: Rep. Will Carpenter, Special Committee on Targeted Case Management

From: Courtney DeBok, Shared Home Living Provider

Re: Targeted Case Management Challenges for Individuals Served

I would first like to thank the members of the committee for their previous support for the Kansans with IDD. My husband and I are Shared Living Providers and have been for the past two years. Before that, we were Children's Residential Providers for 10 years. The individuals in our home (Zach and Iris) became adults, which is why we decided to change our license to Shared Living. Zach has been in our home 12 years, and Iris was in our home almost 5 years. During the past 8 years, Anna Perkins has been the Targeted Case Manager serving Zach, and also serving Iris since she joined us 5 years ago.

Anna is an exceptional individual. Over the past 8 years she has been one consistent force in advocating for the welfare of Zach and Iris. She has taken the time to get to know Zach and Iris, knowing their behaviors and their joys. She has built a relationship with them and they enjoy getting to see her when she visits. They know instinctively that she is for them, and not against them. Her demeanor in our home is a happy one, regularly making everyone smile. We have come to trust our TCM, and trust is a value that we cherish.

She has built a relationship with my husband and I and our family. She has wisely balanced the needs of our family with the needs of the individuals and has provided sound advice when in conflict. Anna has great communication skills and has handled complex issues between the day service provider and us with the ability to help us all understand each other better and work together to reach a common goal.

Before Anna, we had 4 different case managers within 4 years. This was difficult on our family and I believe that the care and advocacy Zach received during that time was diminished and even non-existent at times. Because relationship takes time to build over successive visits, these case managers never got to know Zach well enough to really know him. The difference between having changing case managers frequently to having a long-term case manager has been tremendous.

When we were told that the Final Rule included changes in case management due to conflict of interest, we were alarmed. Of course, we want the overall goal to be for the individuals served to be served well with their needs at the forefront and not a business's agenda. We agree in that, however, the major challenge presented would be that we would lose our long-term case manager who HAS served our individuals well, and it would be detrimental to them to lose a long-term relationship and someone who cares about them and knows them well enough to be able to advocate well for them.

I believe the loss of our case manager, Anna, could be a really big deal for Zach and Iris. I believe they would experience emotional distress and grief to lose someone in their lives that has been a positive consistent presence and advocate. Individuals in foster care shouldn't have

to experience more emotional trauma on top of the trauma already unfairly laid on their shoulders. They would lose someone they trust and they would lose a friend.

I ask that policy-makers would collaborate with Kansas service providers in finding a commonsense solution that addresses the concerns of unique situations like ours. If the needs of the individual are claimed to be of the highest priority, then it would be a dis-service to our individuals to remove their case managers in favor of giving them new ones that first don't know them, and second, may not work with us long enough to get to know them and their needs.