

October 2, 2024

TO: Special Committee on Targeted Case Management
Representative Will Carpenter, Chair

FROM: Julie DeMarco
Sister and care provider for Russell (Russ) Richardson, a Kansas resident with IDD

RE: Targeted Case Manager support for my family

Thank you to this committee for your ongoing support and for taking this opportunity to learn about the disabled community in Kansas and how best to support the individuals in it.

My brother, Russ, was born with severe intellectual and physical disabilities in 1972. He has an infectious laugh and loves being around people who know him well and who can good-naturedly tease and be teased by him. Russ can be wonderful to have around.

But Russ can also be very difficult to support. Russ has severe autism and is non-verbal; when he experiences strong emotion, he is unable to express it. A few years ago, he began eloping from his home when angry or upset, putting himself at risk. He has mood-stabilizing medication, but his behaviors are still unique, difficult to predict, and occasionally can be dangerous to himself. Russ needs care providers who through experience understand him, can read his moods and are therefore able to treat him with compassion when he needs it most. His TCM, Corine Preddy, is part of his team that fills that need.

While my brother, Wes, and I grew up, went to college, moved away and had families of our own, my parents oversaw Russ' care, including placing him at Lakemary Center in Olathe for his residential care and until recently, JCDS for his day services. Two years ago, my mother, now aged 80, had a fall that caused a traumatic brain injury. She and my father suddenly could no longer oversee Russ' care. Wes, and I are now his primary family contacts, but with much of Mom's memory now compromised, we have had to lean on his Case Manager and the staff at Lakemary Center for history and continuity of care.

We now interface regularly with Corine and the staff at Lakemary. We have found that the seamlessness of the interaction between the Case Manager and the Lakemary staff is one of the biggest assets we have in understanding Russ' life: his behaviors and the response required when he is in need, his medical care, the sources of his happiness, how he socializes, when he likes to be alone, and what entertainments he likes best. To gather and understand these details in the life of a non-verbal disabled person takes time, compassion, continuity and continued presence. Because Corine is in the building where he has day services and interacts with his residential and day service providers, she understands Russ in a way that a remote TCM simply could not. When there has been an issue, she is on hand to interface with his residential and day services teams to formulate a plan and meet his needs. I hear it in our meetings, and I rely on her experience as I am called to make decisions for him from my home in New Jersey. If we had to change Case Managers, or if his Case Manager saw him and his service provider staff only periodically, we would lose the timely and valuable insights that lead to the well-rounded, compassionate care of my brother that we now have.

It is my hope that Kansas will come up with a solution to the conflict-of-interest concerns raised by the Center for Medicare & Medicaid Services that does not disrupt the intimate, seamless care provided by an embedded TCM in service provider staff locations. Our choices for services have not been limited by the current situation, but the quality of my brother's care very likely would be compromised if we did not have the TCM's daily firsthand experience in his life.