

October 2, 2024

TO: Representative Will Carpenter, Chair, Special Committee on Targeted Case Management
FR: Sandra McCurdy
RE: TCM in the State of Kansas

My name is Sandy McCurdy, and I write to you today as the mother of Scott, my 38-year-old son who was diagnosed at birth with Cornelia de Lange Syndrome. Scott's primary CdLS symptom is profound intellectual disability that leaves him functioning at the developmental level of about twelve months. He also has joint constrictions and feet malformations that prevent him from walking. Scott requires full-time supervision and care.

I now don't remember how it all happened, but we were blessed to find Lois, Scott's first case manager. Lois had access to resources we were desperately seeking for his immediate needs, as well as knowledge that helped us begin thinking about long-term care, such as residential and day services. Over the years, as Lois learned all she could about Scott, she was also able to recommend additional programs she thought would benefit him. After a ten-year wait, Scott's name rose to the top of the State's IDD residential waiting list. As he moved into a group home and began day services, Lois was key in making that difficult transition a success for both Scott and his family.

When Lois moved into a managerial role, we lost her as Scott's case manager. Fortunately for us, Lois recommended Marlo, who also was a wonderful case manager. Unfortunately, the agency that was caring for Scott at that time had significant and serious issues at its top management level. As the issues grew in severity, and just before the State closed the agency, Marlo helped us navigate the problems and then was instrumental in helping us find another agency for residential and day services.

In April 2023, after a dozen years on Lakemary Center's waiting list, Scott was offered day and residential services in Paola! We eagerly accepted the invitation, even though we knew we would need to select a new case manager who was from Miami County. We were disappointed to learn there are relatively few case managers in Miami County and were quickly faced with the decision to use someone from the Lakemary organization or to find an independent case manager. We chose Steva, a Lakemary case manager, and have been so very pleased with that decision. There has been no conflict of interest. In fact, I can think of two specific instances where a unit of the agency made a recommendation for Scott, and Steva immediately identified reasons not to follow the recommendation. The potential "conflict of interest" did not exist, as, in both of those situations, she clearly put Scott's interest before the agency's interest. Generally speaking, I believe the interests of the case manager and the agency are aligned in their goal of providing excellent services for Scott. Further, we have found that Scott has benefited from the extensive knowledge Steva has of the agency and its opportunities.

I hope I have shared with you the critical role Lois, Marlo, and Steva have played in helping us navigate what are often very confusing and difficult systems and processes. Also, it's been our experience that a case manager from the same agency that is also providing other services can provide strong additional benefits to that consumer; it is my belief those benefits outweigh the potential for a conflict of interest. If the State should determine case management should not be provided through the same agency from which other services are being received, I hope such changes will be for future consumer/case manager relationships, allowing all current consumers in that situation to continue with their current case managers. And, that brings me to my final concern.

Scott is lucky to have parents who work with his case managers to determine the best care providers and directions for his future. If we hadn't had those expert case managers, I don't know what our situation would be today, other than we would likely be struggling every step of the way. Over the last 13 years, Scott has had many housemates who have no one, except their case managers. It absolutely breaks my heart to imagine what their lives would be without the dedication of those case managers. We are so very grateful to the State of Kansas for the IDD funding that supports Scott and our ever-growing family of Scott's housemates/friends. Please continue to explore every avenue to increase the funding that will retain our targeted case management system and also will expand resources to the thousands of Kansans with IDD who desperately need targeted case management, day services, residential services, and other support programs. Thank you for your time.