

December 6, 2013
Via Electronic Mail

Shawn Sullivan
Secretary, Kansas Department for Aging and Disability Services

Senator Mary Pilcher-Cook
Chair, Joint Committee on Home and Community Based Service and KanCare Oversight

Dear Secretary Sullivan and Senator Pilcher-Cook,

United Spinal Association is writing to express our concern regarding severe cuts in personal care attendant hours and services to KanCare recipient Mr. Finn Bullers. Mr. Bullers is a husband, father of two, journalist, dedicated advocate for people with disabilities, and policy adviser for the Greater Kansas City Spinal Cord Injury Association, a chapter of United Spinal. Mr. Bullers and his family have relied on 24/7 in-home care -- directed as a medical necessity by his team of doctors -- to manage his muscular dystrophy, insulin-dependent diabetes and ventilator breathing machine. Mr. Bullers relies on a specialized wheelchair for mobility.

We are also concerned: that there are other KanCare recipients with significant disabilities facing cuts to vital services, with high rates of complaints related to transportation services; that the ombudsman's office lacks the resources to provide sufficient services or keep detailed records; and that continued denials and delays in claims could be affecting people with disabilities. We believe these policies, performance and service hurdles are inconsistent with KanCare's stated goal of "Establish(ing) long-lasting reforms that sustain the improvements in quality of health and wellness for Kansas Medicaid beneficiaries and provid(ing) a model for other states for Medicaid payment and delivery system reforms as well."ⁱ

Founded in 1946 by paralyzed veterans, United Spinal Association is the largest disability-led nonprofit organization serving and representing the interests of more than a million Americans living with spinal cord injuries and disorders (SCI/D). It has approximately 40,000 members in all 50 states and reaches out to these individuals through its approximately 42 chapters and 200 support groups, including the Greater Kansas City Spinal Cord Injury Association. Throughout its history, United Spinal Association has dedicated its energy, and programs, to improving the quality of life for these Americans of all ages and advancing their independence.

As you know, KanCare provides Medicaid managed care to more than 355,000 individuals, nearly 4,500 of those individuals rely on waiver home and community based services (HCBS)ⁱⁱ such as home delivered meals, transportation, physical therapy, personal care attendants and sleep-cycle support, and respite care.ⁱⁱⁱ HCBS allow consumers to remain integrated members of their communities, following the Supreme Court's *Olmstead v. L.C.*^{iv} decision which requires that individuals be provided the supports they need to remain in the most integrated setting possible.

Our understanding is that Mr. Bullers' managed care organization (MCO) is recommending reducing his personal care attendant hours from 168 hours a week to 40 hours a week. These changes are based on a new Plan of Care and a state policy, suddenly being instituted, which requires family members to provide support when at home. Mr. Bullers' spouse works full time and, along with Mr. Bullers, cares for their two children. It would seem unreasonable and impossible for her to wake several times during the evening to provide needed services to her husband, while maintaining her employment, especially when sleep cycle support and respite care are amongst the waiver benefits the MCO provides. Should Mr. Bullers' wife need to excuse herself from employment, the Bullers' family would surely need to apply for government assistance.

Reviewing the most recent KanCare Quarterly Report to CMS, it cites more than 200 transportation-related complaints, including no-shows and late pick-ups.^v According to a 2003 Department of Transportation report, more than 520,000 people with disabilities are homebound due to lack of access to transportation.^{vi} People with disabilities, and other disadvantaged communities, must be able to access transportation to attend medical care appointments, commute to work, school and places of worship, and participate in the community as they choose. We note that, according to testimony from the November 25th oversight committee hearing, the Ombudsman's office lacks the resources to provide adequate services and detailed reports regarding the issues consumers are facing.^{vii} Finally, we are concerned with reports that healthcare and support services providers continue to struggle with denials for authorization of service and delays in reimbursements.^{viii}

United Spinal Association asks you to consider recently released Centers for Medicare and Medicaid Services (CMS) Guidance to States on Managed Long Term Services and Supports (MLTSS) programs.^{ix} CMS states that "MLTSS programs should allow for ongoing innovation in the delivery of services ... that might better integrate care management, promote independence, employment, wellness and recovery; or detect and delay the progress of chronic disease."^x

CMS suggests several key elements for effective MLTSS programs. Key Elements include:

3. Enhanced Provision of Home and Community Based Services

"All MLTSS programs must be implemented consistent with the Americans with Disabilities Act (ADA)^{xi} and the Supreme Court's Olmstead v. L.C. decision. Under the law, MLTSS must be delivered in the most integrated fashion, in the most integrated setting, and in a way that offers the greatest opportunities for active community and workforce participation."^{xii}

7. Comprehensive, Integrated Service Package

"MCOs ... must ensure that participants receive those services and supports in the amount, duration, scope, and manner as identified through the person-centered assessment and service planning process." CMS lays out the complete array of services and states, "Service packages should be

broad enough to support participants and their family or caregivers in receipt of all services based on the goals articulated in the person-centered plan. ^{xiii}

The drastic cuts to Mr. Bullers' personal attendant service hours are inconsistent with key elements #3 and #7 listed above. Decreasing home and community based supports would: make it more difficult for Mr. Bullers' to leave home during the day; to participate in community or workforce activities; and, most importantly, endanger Mr. Bullers' health. Needed assistance would not be available should he be home alone and suffer a medical emergency. Personal care attendants have reattached Mr. Bullers' ventilator when it has loosened in the past. Should this happen without an aid present, he might be able to dial 911, but would not be able to speak to an operator. Shifting the responsibility to provide service in the evenings and weekends to Mr. Bullers' wife decreases support to the family and is inconsistent with key element #7.

It is our understanding that Mr. Bullers has not been provided his Plan of Care. Consistent with person-centered planning, we ask you to ensure that Mr. Bullers' receive a copy of his previous and new plan of care. Please also provide, in writing, the state policy that leads to these cuts in services and hours and how these cuts are consistent with CMS Guidance and KanCare's stated goal to improve the quality of care provided.

According to Kansas' CMS application, in a response to consumer questions of whether services or hours would be cut under KanCare, "the same amount of services will remain available to participants, based on individual need and existing service limitations."^{xiv} Please consider making public how necessary levels of care are being determined by each MCO. According to a Kansas Health Institute article, 8% of recipients receiving HCBS are facing cuts.^{xv} If these cuts apply to the Waiver population, that is approximately 350 Kansas residents with disabilities losing access to services they have relied on to remain in their homes and community.^{xvi}

We urge you to make addressing transportation complaints and grievances a priority. Consider contracting with alternative transportation options such as taxi (and accessible taxi) services, or other creative measures, that may save the state money in the long run. We urge you, also, to ensure the KanCare Ombudsman is able to provide conflict-free service, adequate support to consumers and detailed reporting to state level officials and CMS. Finally, we urge you to address the denials and delays in claims processing that are harming local providers, and will ultimately harm consumers who rely on these services.

United Spinal Association understands that states need to address budget shortfalls and are searching for ways to run more efficient Medicaid programs, while continuing to provide quality service to their residents. In addition to the CMS guidance on providing effective MLTSS, we offer, for your review the attached Consortium for Citizens with Disabilities and the National Disability Leadership Network principles for provision of Medicaid Managed Care to people with disabilities. Both sets of principles highlight the need for continuity and quality of care, and person-centered planning that allows the individual to live independently in the setting of their choice.

United Spinal Association will continue to work to advocate on behalf of our members and for quality Medicaid Managed Care services. We hope to hear from you. Should you have any questions, please contact United Spinal Association's Senior Policy Associate, Carol Tyson at (202) 556-2076 ext 7104 or at ctyson@unitedspinal.org.

Sincerely,

Alexandra Bennewith



Vice President, Government Relations
United Spinal Association

Enclosures

cc: Dr. Susan Mosier, Medicaid Director
Rep. Robert G. "Bob" Bethell Joint Committee on Home and Community Based Service and KanCare Oversight Members
Sen. Laura Kelly
Rep. Dave Crum
Sen. Jim Denning
Sen. Marci Francisco
Sen. Michael O'Donnell
Rep. Barbara Ballard
Rep. Willie Dove
Rep. John Edmonds
Rep. Jim Ward
Rep. Ron Ryckman Jr.

ⁱ Kansas Department of Health and Environment Division of Health Care Finance (September 2013), *KanCare Quarterly Report to CMS – QE 9.30.13*, p.3, Retrieved from http://www.kancare.ks.gov/reports/KanCare_Quarterly_Report_to_CMS_QE_93013.pdf.

ⁱⁱ Kansas Department of Health and Environment, Op. cit.

ⁱⁱⁱ UnitedHealthcare (2013), *UnitedHealthcare Community Plan: Long Term Care Benefits*, p. 8-14, Retrieved from http://www.uhccommunityplan.com/content/dam/communityplan/plandocuments/alternateplandocuments/KS_LTC_Supplement_v12_12.6.12.pdf

^{iv} *Olmstead v. L.C.*, 527 U.S. 581 (1999).

^v Kansas Department of Health and Environment, Op. cit., p.15.

^{vi} U.S. Department of Transportation, Bureau of Transportation Statistics. (2003). *Freedom to Travel*, BTS03-08 (Washington, DC), Retrieved from http://www.rita.dot.gov/bts/sites/rita.dot.gov.bts/files/publications/freedom_to_travel/index.html

^{vii} Shields, M.(7 October 2013) "Kansas Medicaid Providers complain to oversight committee," Kansas Health Institute, Retrieved from <http://www.khi.org/news/2013/oct/07/kansas-medicaid-providers-complain-oversight-commi/>.

^{viii} Cauthon, P. (25 November 2013). "KanCare reimbursement problems continue for providers," Kansas Health Institute, Retrieved from <http://www.khi.org/news/2013/nov/25/kancare-oversight-committee/?print>.

^{ix} Centers for Medicare & Medicaid Services (CMS). (20 May 2013). *Guidance to States using 1115 Demonstrations or 1915(c) Waivers for Managed Long Term Services and Supports Programs*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf>.

^x CMS, Op. cit. p.2.

^{xi} The Americans with Disabilities Act (ADA), 42 USC 126.12101.

^{xii} CMS, Op. Cit. p3.

^{xiii} CMS, Op. Cit. p11.

^{xiv} State of Kansas. (6 August 2012). "KanCare Section 1115 Demonstration Application," p. 9. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/downloads/ks/ks-kancare-ar.pdf>.

^{xv} McLean, J. (7 October 2013). "Prairie Village man Fighting KanCare service reduction," Kansas Health Institute, Retrieved from <http://www.khi.org/news/2013/oct/07/prairie-village-man-fighting-kancare-service-reduc/>.

^{xvi} According to the most recent KanCare Quarterly Report (p.3) there were 4,365 enrollees from the Waiver population.