

Monday, Oct. 7, 2013

TESTIMONY FROM KANCARE RECIPIENT

TO: Rep. Robert G. "Bob" Bethell Joint Committee on Home and Community Based Service and KanCare Oversight

Sen. Mary Pilcher-Cook (R-Shawnee), chairwoman
Rep. Dave Crum (R-Augusta), vice chairman
Sen. Laura Kelly (D-Topeka), ranking minority member

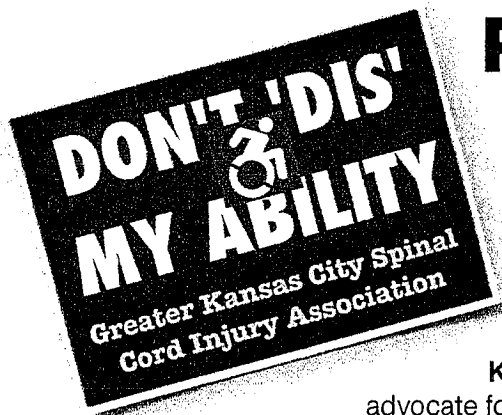


Sen. Jim Denning (R-Overland Park)
Sen. Marci Francisco (D-Lawrence)
Sen. Michael O'Donnell (R-Wichita)
Rep. Barbara Ballard (D-Lawrence)
Rep. Willie Dove (R-Bonner Springs)
Rep. John Edmonds (R-Great Bend)
Rep. Jim Ward (D-Wichita)
Rep. Ron Ryckman Jr. (R-Olathe)

FROM: Finn M. Bullers, 3515 W. 78th. St. | Prairie Village, Kan. 66208 | Cell: 913-706-2894
Home: 913-649-6693 | finn.bullers@aol.com

RE: First meeting of KanCare Oversight committee

Dear oversight committee member:



Prairie Village man and his KanCare experience

'Government just wants to kill us off'

By **FINN M. BULLERS** | *Freelance writer/editor*

KANSAS CITY -- As a KanCare state Medicaid recipient, advocate for people with disabilities and policy adviser for the Greater Kansas City Spinal Cord Injury Association, I would like to thank the oversight committee for the hard work facing its 11 members in helping to shape a managed-care system that is fair, balanced and fiscally responsible.

Under new managed-care rules in Kansas, I face a 76 percent drop in care, a move doctors say is wildly unrealistic and a move my wife says will force her to file for divorce -- and as a result, tear our family apart.

Said SRS Secretary Rob Siedlecki when the state's revamped Medicaid program was launched in November 2011: "This is a great opportunity to put our principles into practice and ... help children and the most vulnerable, strengthen families and encourage economic self-sufficiency,"

Robert G. (Bob) Bethell Joint
Committee on Home and Community
Based Services and KanCare Oversight
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"Through this plan," said Dr. Robert Moser, Secretary for Health and Environment. we will continue to identify very specific outcomes to improve the health of Kansans,"

For me, that "very specific outcome" to "improve" my care means that KanCare will reduce my level of care from 168 hours a week to 40 hours a week.

How is that even conscionable?

My current 24/7 in-home care -- directed as a medical necessity by my team of doctors -- is designed to manage my tissue wasting muscular dystrophy, my insulin-dependent diabetes and my ventilator breathing machine.

In turn, the state expects my wife -- who works full-time to pay the bills and earn the family health insurance -- to provide care 16-hours a day and on weekends, a level that is unworkable -- and, as she says, "impossible."

My wife is the family bread winner who bears the heaviest load for keeping the family together. No simple task, even with full-time nursing support to care for me. And there is no extended family living within a five-hour drive upon which we can rely for respite care.

My doctors say it is imperative to receive 24/7 care or the quality of my health -- and life -- will be severely compromised. Is this what the state defines as "improved outcomes?"

The cuts are imminent, health officials say off the record, but refuse to acknowledge to me and those like me. The drastic cut in care hours are expected to be in place by Nov. 1, although no one will say for sure.

The matrix used under new managed-care rules to determine the hours of care needed does not consider unexpected medical emergencies, frequent doctor visits, pharmacy runs, medical equipment fittings and civic involvement.

These are all part of daily living and activities envisioned under the self-determination and independent-living movements that have been under way since I was born in 1963.

The disability community believes strongly in these hard-fought rights that advocates before us fought to earn for our generation. It is now our obligation to see those strides do not erode while disability advocates of today work to meet the challenges of our time.

For disability advocates in Kansas, cuts under Gov. Sam Brownback's new managed-care plan are the challenge of today.

Gov. Sam Brownback has said KanCare, will save the state \$853 million over five years and improve services for consumers, reports the Kansas Health Institute.

Says Brownback with a straight face: "These savings occur without cutting provider rates, throwing people off the system, or reducing essential benefits."

So dramatic cuts in medical expenditures equals better quality care?

Short anecdote: In my case, doctors on Team Bullers are essentially telling me that it takes four apples to keep me alive. And the governor is telling me the state will provide only one apple. Best of luck, love, Sam.

This message from Topeka leaves disability advocates dazed and confused.

"It has been my notion ... the intent of the governor is to keep those of us in the advocacy arena constantly off balance -- that any time we start to get a handle on what's happening, he'll introduce some change up, throwing us off balance and causing us to have to reconfigure our efforts," said one state disability advocate. "The goal of (Gov. Brownback's) scheme is to wear us out and force us to just give up."

In a state public hearing in June 2012, Celia Chase, who receives care through Medicaid home- and community-based services, had this to say to KanCare officials:

"You've already cut most of our benefits -- what are we supposed to do? ... Some of the people where I live think the government just wants to kill us off. Get rid of us. They literally think that."

KanCare puts insurance companies -- not doctors -- in charge of medical decisions affecting the lives of Kansans with disabilities.

Critics see self-aggrandizing politics at play.

In his bid for the White House in 2016, Gov. Brownback is setting the foundation for a presidential run by focusing his slash-and-burn tactics on cutting \$1 billion in healthcare benefits in five years on the backs of the disabled, critics contend.

Everyone involved with the bureaucratic end of keeping me alive say quality care is the goal we all seek. Yet the rules made by politicians only end up destroying the quality of my life and the lives of the people who love me.

My wife is seeking a divorce. Disability is the motivator. And Kansas Gov. Sam Brownback is the cause.

Managed-care cuts will only put additional stress on my family.

Already, my children -- strong, loving, independent and caring -- have been forced to grow up way too fast. My 13-year-old son often teaches certified caregivers how to run my breathing machine, perform breathing treatments, inject insulin and do blood-sugar readings. And under direct supervision, my 9-year-old daughter has helped to inject insulin since she was four.

At the same time, my care agency, a nationwide firm with 500,000 clients in 43 states -- "the nation's largest private provider of services to people with disabilities; the largest one-stop workforce contractor and the largest privately-owned home care company," the agency's website says -- has let me go as a client, effective Oct. 13. They say they don't have the resources to adequately care for me.

Medicaid reimbursement rates, the say, allows them to only pay caregivers \$9 an hour, a rate that ensures revolving-door care for clients, no continuum of care and increased expensive hospitalizations.

My first agency, another nationwide firm with franchises across the country, let me go because the profit margin to provide care was too small to make it worth their time, former employees confirm.

Without reasonable in-home healthcare support costing a small fraction of institutionalization, my life could easily be turned upside down by rule makers who know nothing about the people whose lives they are destroying.

For me, that means I will lose a 19-year marriage. I can't be the involved father I am to my two children. And I can't be the good advocate for people with disabilities that, along with my family, has given my life value.

It means my life.

You can reach Finn Bullers of Prairie Village, policy adviser for the Greater Kansas City Spinal Cord Injury Association, at: finn.bullers@aol.com or 913-706-2894.

stuff media

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The business card features a wavy, striped background. On the right side, there is a black and white portrait of Finn Michel Bullers, a man with glasses and a slight smile. The text is arranged in a clean, sans-serif font, with the company name 'stuff media' in a larger, stylized font at the top.