



Photos by Sabrina Stairs | sabrinastairs@gmail.com

Kansas' most vulnerable now have even less health care, thanks to Gov. Brownback

By **STEVE VOCKRODT** | The Pitch | steve.vockrodt@pitch.com

Past the doorway to Finn Bullers' Prairie Village home are framed photos from his wedding day in 1994. There's Bullers, wearing his suit, standing upright and proud, smiling with a head full of strawberry-blond hair.

On this late-October day, Bullers is in his kitchen. The 49-year-old man's smile remains, but almost everything else has changed since he said, "I do." His body has been wracked by Charcot-Marie-Tooth, a form of muscular dystrophy. (He also suffers from type 1 diabetes.) His hair is gone, replaced by a flat cap. He's in a wheelchair, no longer able to stand. He can move his arms well enough to operate a phone and his iPad, but his hands have morphed through muscle loss to resemble claws, and he cannot make precise movements.

Bullers' voice, once clear, now sounds like gasps for air against the steady in-and-out of a ventilator helping him breathe.

Caregivers and a nurse provide Bullers with 24/7 support. They help him eat. They administer his insulin. They help him brush his teeth, bathe and use the toilet. They also operate a device that sucks phlegm from his lungs and they turn his body every few hours to prevent sores — like the one that nearly killed him a few years ago.

Since learning of his condition in college, Bullers has slowly lost control of his body. But his mind remains clear. These days, the former Kansas City Star reporter spends his days hounding a bureaucracy in Topeka in an attempt to keep in-home nurses all day, every day. This past January, the state transferred the care of 380,000 Medicaid recipients to three private companies as part of a program called KanCare.

Gov. Sam Brownback has said the wholesale privatization of Medicaid under KanCare was meant to save \$1 billion over five years. He also promised that the move wouldn't sacrifice Kansans' level of care, and the number of people on Medicaid's waiting list would be reduced.



But the only way for the three managed-care organizations to realize cost savings on clients with permanent physical disabilities, like Bullers, is by cutting Medicaid services. Bullers' 24/7 care was slated to be reduced by November 1 to 40 hours per week. Caregivers, who now work in three eight-hour shifts, could visit him only on weekdays for eight hours a day, or all seven days of the week for five hours each.

"To me, that's an Orwellian clusterfuck," Bullers tells *The Pitch*. "How can you take out that chunk of money on the backs of the most vulnerable and say with a straight face that you're going to improve services? It defies common sense."

State officials who look after KanCare say they're comfortable with the cuts. Privacy laws prevent officials from speaking specifically about Bullers' case.

However, on November 15, Bullers sent the state a signed form that allows officials to discuss his health information with the media. But Angela de Rocha, a spokeswoman for the Kansas Department for Aging and Disability Services, did not return a call seeking comment about Bullers' health.

In an earlier interview, de Rocha offered an analogy for Medicaid recipients upset by KanCare's reduction in services. She says it's as if she had been giving someone a new car every year and then suddenly stopped.

"Your natural response to that is going to be, 'Why is she being so mean to me?'" de Rocha tells *The Pitch*. "That's just human nature. It's very difficult to take away something once you get it. People get used to it. They think that's what you need."

To Bullers, access to caregivers isn't like getting a brand-new car, but rather is a life-and-death matter. If a tube feeding air from a respirator to a hole in his throat fell out while he was alone, he would have about three minutes to live. If that ever happened, there wouldn't be enough time for paramedics to reach him.

With caregivers nearby, Bullers would be able to throttle his throat to signal an emergency. Bullers' wife, Anne, can't care for her husband all day. She works full time in public relations for Johnson County Community College. (The couple also has two children, ages 13 and 9.)

Bullers is appealing the state's decision to reduce his care by more than 75 percent, and this preserves his benefits for now.

"I remain optimistic, but I've always been optimistic," Bullers says. "The realist in me knows that state bureaucracy is an unwieldy thing that operates slowly."

Medicaid is a health program for low-income Americans that's funded jointly by states and the federal government. Several states have transferred segments of their Medicaid programs to private insurers to curb rising costs.

While other states have dipped their toes into the privatization of Medicaid, Kansas has cannonballed into the deep end by shifting all of its Medicaid management to three private companies.

"It is the most extensive in the nation," says Gary Blumenthal, a former Kansas legislator who is now CEO of the Association of Developmental Disabilities Providers in suburban Boston and a member of the federal National

Council on Disability. "Other states have viewed managed care as an area to move slowly and cautiously in the use of managed care, to determine if the use of managed care can produce the savings that advocates claim can occur while preserving the quality and safety for people that it would be serving."

Florida, for example, started privatizing Medicaid by moving 9,000 seniors in nursing-home care to managed-care organizations. In the system, the state passes its Medicaid money to insurance companies, which then pay for providers. For states, the move is purported to cut the costs associated with running a bureaucracy by reducing hospitalizations and other medical costs. For the insurance companies, it's a new revenue stream.

For clients, it can be a mixed bag.



In 2012, Connecticut dumped the insurance companies that were managing its Medicaid program to the tune of more than \$800 million a year. A USA Today report said those insurance companies were "erecting barriers to care" while plowing the state's Medicaid money into administrative salaries and profits.

States have moved areas like behavioral-health and acute-care Medicaid programs to managed-care organizations, which some experts believe can increase efficiency and cut costs. But many are leery of moving Medicaid recipients with long-term physical or developmental disabilities to private insurers, especially those receiving home- and community-based services as Bullers is; the only real way to cut costs on their care is to reduce the amount of care they receive.

"I think in some areas, managed care can be effective with respect to health-care services of a general population," Blumenthal says. "With respect to people with significant disabilities, it's very questionable how much can be achieved in savings without sacrificing the quality of services."

Bullers says his caregivers make \$10.30 an hour from Medicaid reimbursements. That suggests a lean-running program.

In late 2011, Brownback approved KanCare through an administrative order, meaning that the Kansas Legislature didn't vote on the matter. KanCare went into effect in January 2013, so it's not yet known what kinds of savings the state may realize.

Earlier this year, Brownback announced that he would plow \$9.2 million in savings from KanCare back into the Medicaid program to whittle 250 people (including 110 Johnson County residents) off the developmental-disabilities waiting list. The list totals 5,000 people, 900 of whom live in Johnson County.

Some lawmakers have expressed skepticism about Brownback's predictions of how much KanCare will save.

"I have concerns that the amount of money that is going to be saved, that it won't become a reality," says Barbara Bollier, a Republican House member from Mission Hills whose district includes Bullers' home. "That remains to be seen, and it may. I'm a physician, and I married a physician, and I'm well aware of how hard it is to control costs in the medical realm."

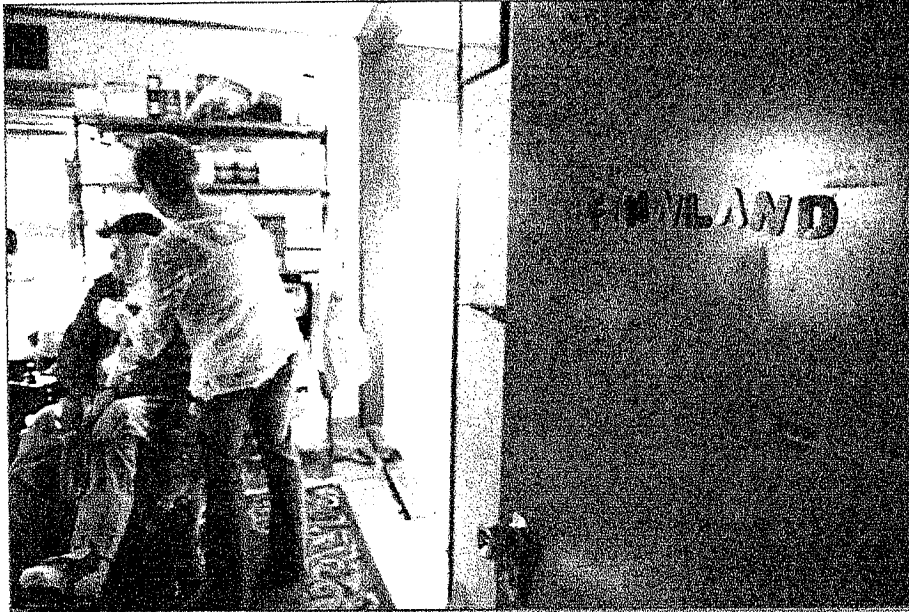
KanCare contracted the state's Medicaid to three private managed-care organizations: UnitedHealthcare Community Plan, Sunflower State Health Plan and Amerigroup. Those three have contributed directly and indirectly to Brownback's coffers, according to records with the Kansas Ethics Commission.

Centene Corporation, which owns Sunflower State Health Plan, donated \$2,000 to Brownback's election campaign in 2012. Kansas Association of Health Plans, a nonprofit whose board of directors in 2010 included employees of both UnitedHealthcare and Amerigroup owner WellPoint Inc., also contributed to Brownback's war chest, in 2010.

All three companies are publicly traded, so their obligation is first to their shareholders, which they do by maximizing profits.

It's widely speculated that Brownback wants to run for president in 2016. (His 2008 effort fizzled early; the career politician's Senate record wasn't strong enough to mount a serious campaign.)

Many of Brownback's directives since becoming Kansas governor — eliminating income taxes on several types of businesses and privatizing Medicaid — have been viewed by opponents as steps to bolster his conservative credentials for a more fruitful 2016 White House bid.



Brownback has also been a critic of the Affordable Care Act, the national health policy passed by President Barack Obama that has gotten off to a miserable start. KanCare also hasn't fared well. The handoff to the private companies was sloppy. Hospitals and other providers have complained that they haven't been reimbursed by insurers quickly or accurately, especially for patients with long-term needs.

"The process has not gone as smoothly as the people at the Statehouse would have you believe, as far as the implementation is concerned," said Allen Van Driel, CEO of Smith County Memorial Hospital in north-central Kansas, according to a September 23 Kansas Health Institute News Service report. "The party line is that the managed-care plans are working and that KanCare is a huge success, that it's processing claims and all that. But that's simply not factual."

Other hospital executives say they are seeing increases in the number of contested claims.

Brownback officials have passed off such criticisms as "bumps in the road," according to various news reports. De Rocha says managed-care organizations are penalized if they don't make reimbursements within 30 days, and delays are often the result of clerical errors.

"In order to get paid, they have to enter the correct code in the billing mechanism," de Rocha says. "If they don't do that, oops, it gets shot back to them."

When KanCare went into effect, Bullers temporarily lost his in-home care.

"It was a very rocky start, to be honest with you," Bullers says. "They have yet to recover from that."

And not all Medicaid recipients have yet become part of the program. Kansans with developmental disabilities, such as Down syndrome and cerebral palsy, don't become part of KanCare until January 1, 2014.

Johnson County Developmental Supports, a county agency that assists residents with developmental disabilities, predicts some difficulty with signing on to KanCare at the end of the year.

"We're anticipating, once we get involved, that there's going to be a few challenges through billings and a lot of our small providers who need reimbursement immediately, that they may go out of business," says Lurena Mead, JCDS's community-relations manager.

For the pro-business Brownback, shuttered providers is just one contradictory aspect of KanCare.

Bullers was a sophomore at Iowa State University when he learned that he had Charcot-Marie-Tooth. The diagnosis wasn't entirely unexpected; his mother had the same condition, which affected the way she walked. But the disorder tends to take a heavier toll on men.

Bullers studied journalism, serving as editor of the student newspaper his junior year, even though his disorder started making it harder for him to make his way across campus. He did an internship at the Miami Herald, then bounced around various newspapers in middle America before ending up at The Kansas City Star in April 1997.

Bullers covered Johnson County for more than a decade for the Star. One of his more memorable dispatches detailed how former Kansas state Sen. Kay O'Connor disliked the 19th Amendment, which affords women the right to vote. O'Connor argued that if men took better care of women, then women wouldn't need to cast ballots. The news made its way to Jay Leno's monologue, embarrassing the Olathe Republican and rankling conservatives.

Meanwhile, Bullers' fine-motor skills and his voice began to deteriorate, although he could still function as a journalist by using a tape recorder and manipulating his computer enough to fire off stories. During that time, the Star underwent several rounds of layoffs that gutted its editorial staff.

The paper's Johnson County bureau, where Bullers worked, moved from its tony offices along College Boulevard, in Overland Park, to a dark industrial building within spitting distance of a railroad track, in Olathe. The new office space was the type of disability-unfriendly environment that the Star would blast within its pages. Bullers couldn't use the bathroom there. Instead, he would go to the Johnson County Courthouse, about a mile north, for his restroom breaks.

"That was a big hit on my dignity," Bullers says.

At one point, Star executives tried to devise some Rube Goldberg-style mechanism to make the newsroom's restroom functional for Bullers, but the reporter was already getting ready to check out.

"It got to a point at the end of 2009 that the daily grind of doing the job was so taxing," Bullers says. "It was in the middle of winter. Everyone was so busy doing their work that they didn't answer the door. I sat there for five to 10 minutes trying to get in."

Bullers resigned in 2009, precluding the possibility of a layoff and allowing him to secure longer-term benefits. Not long after, he suffered a bout of double pneumonia, nearly suffocating on the phlegm building up in his lungs. He was placed on a ventilator, and his doctors began discussing end-of-life options with him.

"It was pretty dark moments where the demons started taking over," Bullers says. "I told my wife that I have two kids to take care of and a life to live. I'm not done yet."

Bullers was granted Social Security Disability Insurance and Medicaid. The payments allowed him to stay at home to care for his children and occasionally make it out of the house to volunteer. He helped start a student newspaper at Corinth Elementary School.

Going to a nursing home wasn't an option in Bullers' mind. Medicaid waivers allow people with long-term disabilities to opt out of institutionalized care in favor of home-based community services. Medicaid pays caregivers to come to a patient's home and provide services such as meal preparation and laundry. In Bullers' case, they also keep him from getting pressure sores, make sure his breathing tube is secure and help administer medications.

Home care is often less expensive for the state than nursing-home care.

When KanCare went into effect, Bullers was assigned to UnitedHealthcare. A case manager paid him a visit to see how he lived, to determine what kind of care he needed. The manager noted how long it took for him to brush his teeth, to use the restroom and so on. Those observations later formed the basis for UnitedHealthcare's decision to reduce his caregiver hours from 168 a week to 40.

Bullers says the assessment ignores the incongruities of life that can disrupt the assembly-line style of care that UnitedHealthcare plans to ration to him.

"What if I'm constipated? What if I have a loose stool and it takes longer?" Bullers says. "I don't know what my body is going to do."

Bullers has turned to activism to protest the state's reduction. He has testified before the state's KanCare oversight committee. There, he ran into James Bart, the KanCare ombudsman. It wasn't the first time the two had spoken.

Bart also paid an assessment visit to Bullers' home. Bart says he can't comment on the specifics of Bullers' case.

"It would be presumptive to do that because I'm not an expert on the physical disabilities waiver. I'm not an expert on his needs. I was not there during the assessment process," Bart says. "It concerns me that the collaboration or the exploration for an effective solution has not advanced further. I'm not pointing fingers about why it was not advanced."

Bart, a lawyer from Lawrence, is the only ombudsman for all of the state's Medicaid set. Bart says he's not supposed to be an advocate for consumers, but rather to function as a mediator, helping them get answers to questions or the assistance they need from the state bureaucracy or managed-care organizations.

But his office has been criticized for its lack of independence. (Bart's boss, Shawn Sullivan, is the secretary for the Kansas Department for Aging and Disability.) The title of ombudsman is also misleading to consumers, who mistake Bart as an advocate and a partner to investigate KanCare's problems while his main function is a point of contact in the state's bureaucracy.

"The current KanCare ombudsman program is neither independent nor external from existing programs serving the Medicaid population in Kansas," said Rocky Nichols, executive director of the Disability Rights Center of Kansas, in written testimony to the KanCare oversight committee on October 7. "Moreover, the ombudsman's office clearly tells consumers that they cannot directly advocate for them. Consumers want and need in an ombudsman an independent advocate who is going to be on their side, free from conflicts of interest."

Nichols adds that Wisconsin's Medicaid program has one ombudsman for every 3,500 consumers; Kansas has one for 380,000.

Bart, whose son is autistic and receives Medicaid benefits, had reservations about KanCare before he was hired.

"It wasn't a political belief that made me skeptical," Bart says. "I'm from a business background. I look at organizational charts and try to understand budgets. ... And seeing how money came from the federal government to state government and made its way to my son was very frustrating."

Bart has been contacted by about 1,600 people who have questions about KanCare — they're figuring out if they're eligible, or they have problems with billing or with getting prior authorizations, or they're getting their plans reduced. Bart says he hasn't been besieged by consumers complaining about cuts in their care plans.

"It's way too early to tell if KanCare will be effective in addressing those consumer needs," Bart says. "But I'm encouraged."

Bullers is less so. He's appealing the reduction in his hours of care to the Kansas Office of Administrative Hearings. If Bullers loses, his marriage could end, too.

"My wife will divorce me," Bullers says. "It's not out of a lack of love. It's a financial deal. They would have to re-evaluate my needs, and I would be eligible for more benefits."

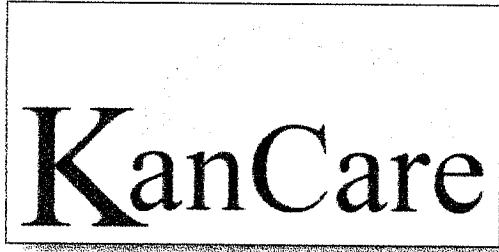
Bullers acknowledges that it's a calculated move to end a 19-year marriage, but he and his wife couldn't live together after the divorce.

"The hypocrisies are rife," Bullers says. "This is an administration that came in on family values. ... The hypocrisies are mind-blowing."

Monday, Nov. 25, 2013

TESTIMONY OF:

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



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

Sen. Mary Pilcher-Cook (R-Shawnee), chairwoman,
mary@pilchercook.com

Rep. Dave Crum, (R-Augusta) vice chairman,
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Sen. Laura Kelly (D-Topeka), ranking minority member,
Laura.Kelly@senate.ks.gov

Sen. Jim Denning, (R-Overland Park), *jim.denning@house.ks.gov*

Sen. Marci Francisco, (D-Lawrence), *Marci.Francisco@senate.ks.gov*

Sen. Michael O'Donnell, (R-Wichita) *Michael.ODonnell@senate.ks.gov*

Rep. Barbara Ballard, (D-Lawrence), *barbara.ballard@house.ks.gov*

Rep. Willie Dove, (R-Bonner Springs), *willie.dove@house.ks.gov*

Rep. John Edmonds, (R-Great Bend), *john.edmonds@house.ks.gov*

Rep. Jim Ward (D-Wichita), *Jim.ward@house.ks.gov*

Rep. Ron Ryckman Jr., (R-Olathe), *ron.ryckman@house.ks.gov*

Dear Gov. Brownback, KanCare officials:

My wife and I cordially invite you to pull an eight-hour care shift in our home

PRAIRIE VILLAGE -- Madame chairwoman, KanCare oversight committee members and distinguished guests, I come before you as a KanCare 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 the 11 members in helping to shape a managed-care system that is fair, balanced and fiscally responsible for thousands of Kansans like me.

As I have stated in my Oct. 7 testimony before this committee, under new managed-care rules in Kansas, I face a 76 percent drop in care, a move three of my doctors -- primary care physician, MDA doctor and respiratory doctor -- say is wildly unrealistic and a move my wife says will force her to file for divorce. Reductions in hours would also cause me to be forced to seek care in an institution.

I'm here today to cordially invite Gov. Sam Brownback, Sec. Shawn Sullivan of the Department of Aging and Disability Services -- and any other KanCare officials eager to walk in my moccasins -- to pick up an eight-hour shift caring for me at the rate of \$9.30 an hour.

We are looking for bright, energetic and problem-solving caregivers who are willing to take on the task of care for a 49-year-old father of two with muscular dystrophy, type-1 diabetes and a ventilator to breathe. Don't let that intimidate you. My 13-year-old son Christian is a whiz at Dad's gear and my nine-year-old daughter Alora does blood-sugar readings and administers insulin.

We would expect the same skills that a home health-care agency expects from its employees: transfers to bed and toilet, dressing, bathing, oral hygiene, light housekeeping, meal preparation, laundry, errands/shopping

110-7

Be prompt to your scheduled shifts and treat us the way you would like to be treated and we'll hit it off. Non-smokers with a high-school diploma or G.E.D. and a driver's license are the folks we are looking to hire and train.

What you can expect from us is a friendly and engaging home environment where the children are busy with their activities, my wife is working full-time and I am engaged in writing projects and national advocacy efforts for people with disabilities.

Personal care attendants are really the unsung heroes of the healthcare field. Without you, I am not able to live a quality life in my own home -- and away from an institution. That means a lot to me and my family.

I am unflappably serious about this invitation and would welcome the opportunity to invite state officials into my world for an eight-hour shift.

In others news, the incongruities and contradictions inherent in my case has drawn increased state and national media attention. The links are listed in my written testimony.

A petition I have started on www.change.org asking Gov. Brownback to restore my full-time care to stay alive and care for my two children has attracted nearly 1,000 signatures -- a majority of them from Kansas, but hundreds from across the country as well. In the search field type in "Brownback" and "Bullers" and the petition will pop up.

In the last week I have been compared by the state to a welfare mooch demanding a brand new car (health care) every year and then getting angry when the state decides to refuse to provide me the new car each year, Angela de Rocha, the KDADS director of communications told reporter Steve Vockrodt in The Pitch, an alternative Kansas City newspaper.

I also have been told by the state that there is a finite amount of money and a finite number of hours "for people like me," said de Rocha. So if I receive my medically necessary 24/7 care, she said, then some of the 2,800 people on the state waiver waiting list won't receive care.

But spending is a political priority -- not a Darwinian struggle where only the fit survive and receive state funding. Where is our shared humanity and where are our shared family values, I ask Gov. Brownback. How can a Kansas Governor play God and divine who lives. And who dies?

Other problems remain:

- KanCare allows for-profit managed-care firms to trump doctor-ordered medically necessary care.
- Drastic reductions in hours leaves the medically fragile unattended and in life-threatening situations.
- Reductions in hours forces my wife, the family breadwinner and 10-hour-a-day employee, to be my caregiver from the time she gets home until the time she leaves the next day.
- Strict adherence to one-shoe-fits-all care allows no room for daily living functions like grocery shopping, doctor's appointments, civic involvement, PTA meetings, Boy and Girl Scouts ...
- It defeats the foundational underpinning of the disability civil rights movement now more that 40 years old that deinstitutionalized the disabled to live independently with necessary supports -- a far less-expensive option.
- Home- and community-based services are significantly less expensive for taxpayers than warehousing people.

We have been sold an Orwellian dream that KanCare is a "great opportunity to put our principles into practice and ... help children and the most vulnerable, strengthen families and encourage economic self-sufficiency."

It's time to wake up from that dream.

Since I first appeared before the KanCare committee, my case has received additional media attention :

-- On Nov. 20, Pitch Magazine, a Kansas City alternative newspaper, released an analysis (enclosed) of Kansas "KanCare." Read it here:<http://www.pitch.com/kansascity/kancare-sam-brownback-finn-bullers/Content?oid=4031015>

-- On the same day, the national Daily Kos: "Brownback (Kansas) Turns Medicaid Over to Private Companies.. and these are the results" :

<http://www.dailykos.com/story/2013/11/20/1257166/-Brownback-Kansas-Turns-Medicaid-Over-to-Private-Companies-and-these-are-the-results#>

Other statewide news reports:

-- <http://kcur.org/post/kancare-means-big-medicaid-cuts-prairie-village-man>

-- <http://www.kshb.com/dpp/news/health/prairie-village-man-upset-after-kancare-cuts-back-his-personal-coverage#ixzz2hxKpDOcf>

-- <http://www.kansascity.com/2013/11/02/4592113/kancare-savings-result-in-hardship.html>

-- <http://www.kctv5.com/story/23950898/prairie-village-man-with-muscular-dystrophy-fights-to-keep-247-care>

-- <http://fox4kc.com/2013/10/08/planned-kancare-cuts-have-some-with-disabilities-scrambling-for-contingencies/>

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Aimee B



Kansas Insurance Department

Sandy Praeger, Commissioner of Insurance

HEALTH INSURANCE MARKETPLACE UPDATE November 25, 2013

ROBERT G. (BOB) BETHELL JOINT COMMITTEE ON HOME AND COMMUNITY BASED SERVICES AND KANCARE OVERSIGHT

Madam Chair and Members of the Committee:

In response to the request for an update on the Health Insurance Marketplace received by the Department on November 18, 2013, we are providing the following information:

We understand that Blue Cross Blue Shield of Kansas issued approximately 10,000 cancellation notices to Kansas insureds advising them that their non-grandfathered health insurance policies would be cancelled on December 31, 2013. As a result of the announcement made by President Obama on November 14, 2013, Blue Cross announced on Tuesday, November 19th that it will rescind those cancellations and allow those policies to be renewed into 2014. We expect that Blue Cross will be sending letters to these insureds in the very near future explaining the various options that are available to them with regard to continuing that non-grandfathered coverage or purchasing other coverage available either inside or outside of the federal Marketplace, which would become effective on January 1, 2014.

At this time no "mandate lite" policy forms have been submitted to the Department for review and approval under the law passed during the 2013 Legislative Session. Therefore, these products are not available for sale in Kansas at this time.

I am happy to stand for any questions.

Linda Sheppard
Special Counsel & Director of Health Care Policy and Analysis
Kansas Insurance Department

Robert G. (Bob) Bethell Joint Committee on
HCBS & KanCare Oversight
Date November 25, 2013
Attachment 9