

INDEPENDENCE
INCLUSION
INNOVATION

February 20th, 2013

TO: Brian Weber, Chair, and
Members of the House Social Service Budget Committee

FR: Matt Fletcher, Associate Director, InterHab

RE: HB 2029 – Excluding I/DD Long-Term Care from KanCare

Chairman Weber and members of the Committee, thank you for the opportunity to speak in support of House Bill 2029, which proposes to permanently exclude long-term care services for Kansans with intellectual and developmental disabilities from the State's Medicaid managed care program known as KanCare. I urge the Committee to listen very carefully to the words today of parents, guardians, professionals and concerned community leaders who will share their numerous concerns with the planned inclusion of I/DD long-term care within KanCare. Thomas Jefferson once said that "the will of the people is the only legitimate foundation of any government" and I believe that you will hear clearly today that the 'will of the people' is that Kansans with intellectual and developmental disabilities not be subjected to the massive policy experiment that is KanCare.

A phenomenally small number of states that have actually placed their I/DD population's long-term care services within Medicaid managed care models. **None of them have done so in a manner similar to KanCare.** Only four states have already placed their entire I/DD long-term care system within their Medicaid managed care structure. In each of those four examples, a vastly different approach was employed from what the State of Kansas has pursued. There is no example anywhere in which one can see that the KanCare model will not negatively impact the supports that Kansans with intellectual and developmental disabilities rely upon every day.

Some have pointed to the overly-optimistic self-reporting by KanCare on its early stage of implementation and proclaimed that there is nothing to fear. That type of analysis is premature. The fact that, 50 days post-implementation, MCO's continue to field around a thousand calls **each day** from Medicaid recipients and service providers is an acknowledgment that the system was broken at implementation.

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Canaries in Coal Mines

Medical services for Kansans with intellectual and developmental disabilities were included in the January implementation of KanCare. Medical services are supposed to be the strong suit for the three MCOs managing KanCare. It's their bread and butter. They have widespread experience with it nationally. However, Kansans with I/DD who are accessing their medical care through MCOs have a different story to tell. Here are just some of the issues that have been shared with us:

"19 year old young woman with Cerebral Palsy. Shunt stopped working and is complicated with low weight. MCO agreed to pay for 2 of the days she was admitted and is denying the rest of her hospitalization at this point (2/5/13 - still in the hospital). DD Case Manager called, is told that they are still waiting on the nurse to complete the clinical and return it to their prior auth. dept. Once this is received she may qualify for everything to be paid but they won't know until they get the clinical back. This is a family that lives in poverty as the father is a single father and is on disability himself. This has significantly caused a great deal of unnecessary stress on this family."

"I am a case manager and an individual I serve threatened suicide and was having hallucinations. His doctor placed him in protective custody and was court ordered to receive treatment at Osawatomie State Hospital the first week of January. A short time later, he received a letter indicating that the service billing was denied by Amerigroup as a "non-covered service". Several calls to Amerigroup left me with a fax to complete in order to file an appeal. The fax was intended for the PROVIDER, not the PATIENT. I then contacted the Ombudsman."

"I am a case manager for an 18 year old young man who has worn incontinence briefs his entire life. When he was switched to his KanCare provider, he was denied these briefs. The pharmacy had to intervene and get it approved so he could continue purchasing them."

"As a case manager, I attempted to change the PCP on one of my individuals with Amerigroup. I was told that I was not listed as the medical rep. I explained that I have fulfilled this roll for over four years but they said they would have to talk to the individual. I explained that she is severely disabled and cannot speak so they said that they would try to send out a "form" to get this changed. They also would not contact the guardian. I have waited two weeks and still have not received the form."

"All individuals signed up with Sunflower have been assigned to either an unknown doctor from the Kansas City area or a doctor who left this area approximately 10 years ago. No calls returned although promised within 24 hours. "

"When guardian received medical card, saw that the doctor was no longer in area but was curious about the phone number listed. Called it and got the local Chinese restaurant."

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These accounts are at odds with the rosy picture of KanCare that has been painted thus far. Each of the above examples, as well as countless other incidents that have occurred, has come with a cost. Consider the costs extracted in the examples above. The anxiety, the frustration, the countless lost hours navigating a seemingly endless bureaucratic maze... This is just a glimpse at what is in store when long-term care services for the I/DD population is included in KanCare on January 1, 2014. These are the examples from how medical services for Kansans with I/DD have been managed thus far by MCOs. Medical services are The MCOs' strong suit, their bread and butter.

Imagine what will happen when they are charged with managing the Kansas I/DD long-term care system, something they know very little about.

DD Pilot Projects

You may also hear from those who will say that the planned DD pilot projects will alleviate any systemic issues associated with inclusion of long-term care services within KanCare. **They will not.** After struggling for the better part of a year, the planning group that worked on pilot designs came up with a pilot process intended only to familiarize the I/DD long-term care system with managed care in a basic manner. The pilots will not test the legitimacy of the KanCare model in its applicability to the Kansas I/DD long-term care system, nor will it test the vital payment mechanisms to providers that are at the heart of so many issues with managed care systems in other states. The fact that State contractors involved in the pilot planning process expressed confusion as to what the pilots would even be able to measure in the short timeframe that has been allotted for them indicates that the pilot projects are not to be trusted as any legitimate measure of the appropriateness of KanCare for the I/DD long-term care system.

Fishy Fiscal Findings

We ask that this Committee request an independent fiscal note be generated by Legislative Research for HB 2029. Our members have reviewed the fiscal note generated by the Administration and have a great number of questions as to the validity of the numbers included, as well as the process utilized to arrive at those numbers.

Further, we ask that the Committee consider the divergence between assertions made by the Administration that KanCare will not equal funding cuts to the I/DD service system, and the assertions contained within the Administration's fiscal note that 'carving out' I/DD services from KanCare will result in more than \$20 million per year in increased costs to the State. If I/DD services are to be included in KanCare, does the Administration somehow intend to realize more than \$20 million a year in 'savings' from this system? The fiscal note seems to suggest that the Administration plans to cut funding for I/DD services by about 7% per year.

Listen to the People

We understand that you will receive tremendous pressure to do nothing in regard to HB 2029. We know that you'll hear that leaving the long-term care services of this population out of KanCare will result in headaches-a-plenty for those who administer the Medicaid managed care system. We expect you'll hear from others that it doesn't work from a money standpoint. We

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ask you to ignore those voices and listen to the voices of the people here today as well as the written comments from several others, all representative of the sentiments of tens of thousands of Kansans who do not want I/DD long-term care included in KanCare. Ever.

Last legislative session, more than 20,000 Kansans sent messages to legislators urging a 'carve out' of I/DD long-term care services. Take a second to soak that in. 57 counties in Kansas passed resolutions directly urging the exclusion of I/DD long-term care services from KanCare. Clearly the will of the people is that I/DD long-term care services not be included in KanCare. The result of that advocacy was that a one-year delay was enacted for the inclusion of I/DD long-term care services. The sentiments of those Kansans who reached out last session have not changed since that time. They still want I/DD long-term care out of KanCare. Permanently.

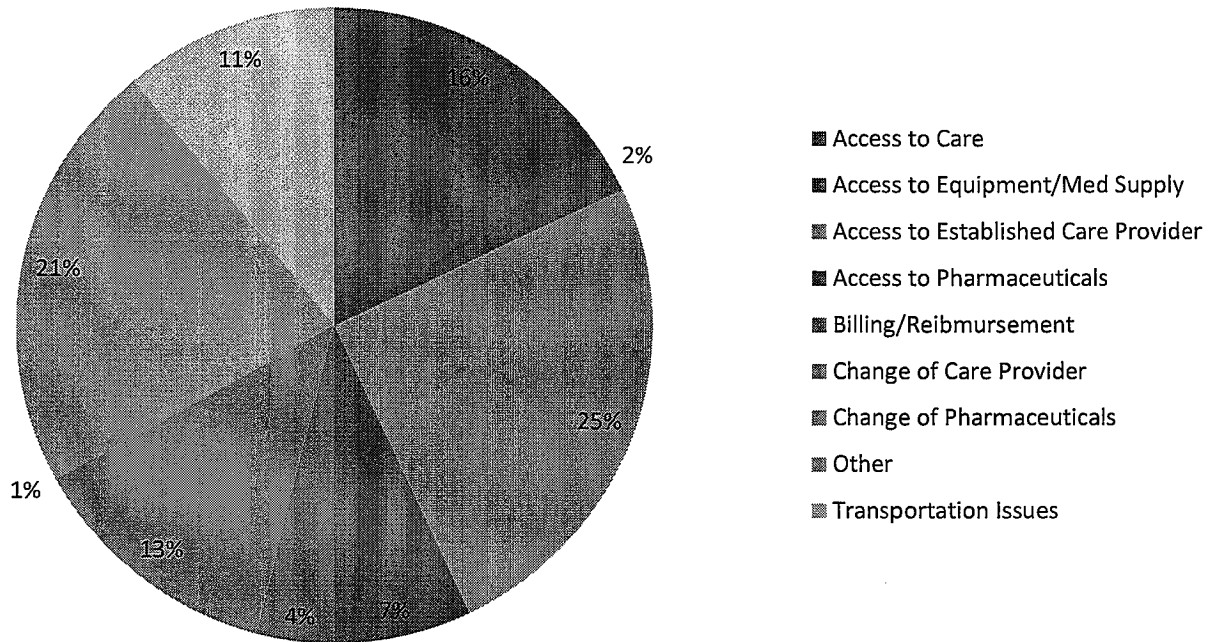
I want to leave you with the concerns of one parent who cannot be here today. He shared with me that:

"The issues faced by the DD community are not medical. They're developmental. My son does not have a disease. He is Autistic. He has a set of developmental challenges that are not curable. These disabilities must be managed in a planned, controlled environment by well educated, well trained professionals who understand his complex set of needs. For-profit insurance companies do not have the experience nor the expertise to address his unique set of concerns... His challenges are life-long. Like most autistic individuals, any change is a major life issue for my son. Changes brought about by the implementation of KanCare can pose a significant threat to the level of development and stability we have achieved with Steve to this point. I am dramatically opposed to anything that jeopardizes the progress we've made to date, and that certainly includes KanCare."

The Kansas I/DD long-term care system is a highly-efficient, advanced and progressive network in its support of the independence of Kansans with intellectual and developmental disabilities. This system is the result of decades of direct partnership between your predecessors and communities in every county of Kansas. It is the envy of many other states. It is not broken. It does not need fixing. It should not be subjected to a system that is untried and new masters who are unequipped and ill-prepared.

The membership of InterHab strongly urges your support of HB 2029. Thank you.

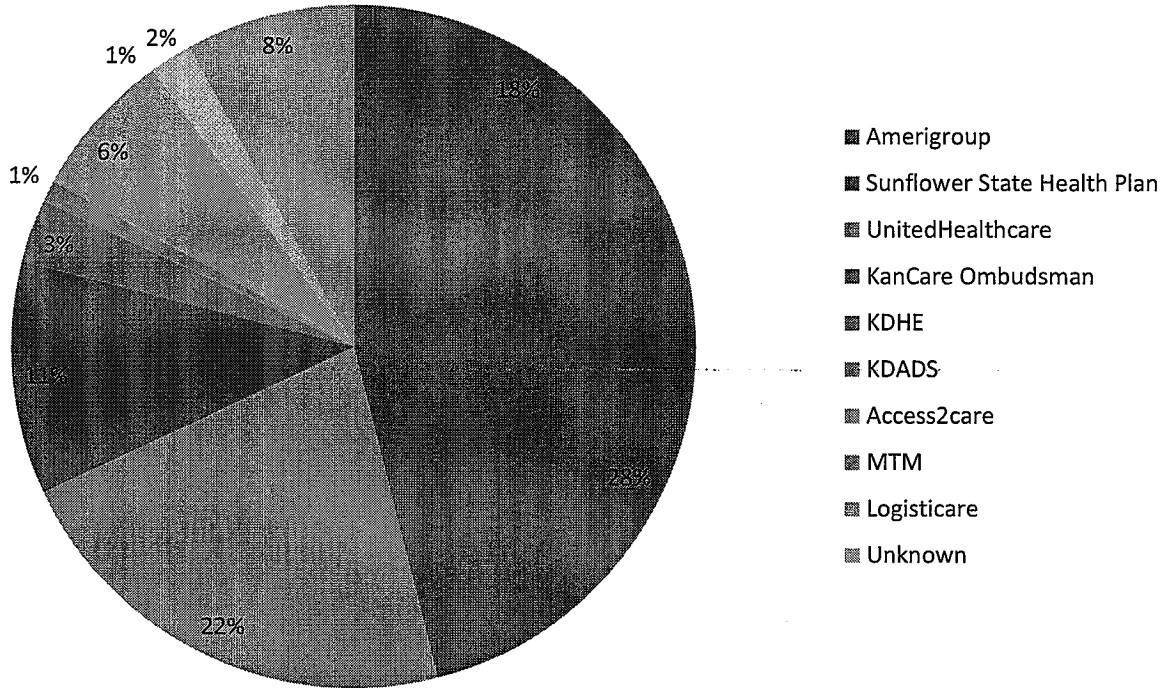
Types of Issues Experienced with KanCare Implementation



Sample of written responses for "Other" KanCare Implementation Issues

- Unable to communicate with MCO
- Difficulty getting established primary care physician listed with MCO.
- Primary Care Physician update not processed by MCO.
- Confusion with MCO regarding whether person served receives Medicare.
- ILC Assessments
- Differing MCO's for a surgery on a client
- PCP not correct on medical card
- KanCare/MCO Info.
- Access to Amerigroup value-added overnight respite care
- Rush of implementation
- Complaints by providers
- Guardian unable to access specific information from MCOs

Parties Contacted to Resolve Issues



SAMPLING OF REPORTED ISSUES:

ACCESS TO CARE ISSUES

FEB. 18TH – FAMILY IN POVERTY

A shunt stopped working for a 19-year-old young woman with Cerebral Palsy whose health is complicated by low weight. A shunt allows fluid to move from one part of the body to another. The MCO agreed to pay for 2 days. She was admitted and the MCO is denying the rest of her hospitalization at this point. The I/DD Case Manager called, and was told that they are still waiting on the nurse at Wesley to complete the clinical and return it to their 'prior authorization' department. Until this is received, the young woman and her family won't know if any of the stay (exceeding 2 days) will be fully covered. This is a family that lives in poverty as the father is a single father and is on disability himself. This has significantly caused a great deal of unnecessary stress on this family.

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FEB. 18TH – PERSON IN CRISIS

I am a case manager and an individual I serve threatened suicide and was having hallucinations. His doctor placed him in protective custody and was court-ordered to receive treatment at Osawatomie State Hospital the first week of January. A short time later, he received a letter indicating that the service billing was denied by Amerigroup as a "non-covered service". Several calls to Amerigroup left me with a fax to complete in order to file an appeal. However, the fax was intended for the provider, not the patient. I then contacted the Ombudsman.

Jan. 23rd – PREVENTIVE SERVICES DELAYED

An individual's dental appointment is being delayed by the dentist until the dentist's contracts with the MCO's are completed.

Jan. 28TH – DENIED AUDIOLOGY CARE

A Medicaid beneficiary with I/DD received a letter from current audiologist indicating that as of 01/01/13 they will not be in network with any KanCare plans and they do not accept out-of-network insurance payments for hearing aids.

Jan. 17TH – LOSS OF ESTABLISHED CARE PROVIDERS

A woman with I/DD that our organization serves sees a family care physician, psychiatrist and audiologist. None of these Doctors have signed up with KanCare.

FEB. 18TH – LOSING ACCESS TO DAILY NECESSITIES

I am a case manager for an 18-year-old young man who has worn incontinence briefs his entire life. When he was switched to his KanCare provider, he was denied these briefs. The pharmacy had to intervene and get it approved so he could continue purchasing them.

JAN. 18TH – MEDICALLY FRAGILE LOSES SPECIALISTS

Client is medically fragile and has 20 doctors who are specialists. Only two are on plan.

AUTHORIZATION TO ACT ON BEHALF OF BENEFICIARY WITH I/DD

FEB. 18TH – SPEAKING FOR SOMEONE WHO CANNOT SPEAK

As a case manager, I attempted to change the Primary Care Physician on one of the individuals I support. They are assigned to Amerigroup. I was told that I, the case manager was not listed as the medical representative. I have fulfilled this roll for over four years. However, Amerigroup indicated they would have to talk to the individual. The person I support cannot speak and is severely disabled. The managed care organization said they would send a "form" to get the PCP changed. They also would not contact the individual's guardian. It has been two weeks since my original attempt to work with Amerigroup. I still have not received the form.

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JAN. 23RD – GUARDIAN NOT AUTHORIZED

I am a guardian. I finally got my individual's doctor changed today. Yesterday, I tried to do the change and they refused because they didn't have a certain authorization form. I wonder who they do authorize to make changes, if not the guardian! Anyway, I called back today and was rather persistent. They made the change effective today, but STRONGLY recommended I get this form into them.

FEB. 4TH – CASE MANAGER/CDDO NOT AUTHORIZED

A person with I/DD and Medicaid recipient received notices from managed care organization with wrong Primary Care Physician and Hospital listed. The consumer's address also had the wrong zip code listed. The individual's Case Manager phoned the MCO and was told they couldn't discuss the matter because they did not have any information from the State indicating that the Case Manager was authorized to exchange information. The Case Manager explained that the MCO's own Outreach Specialist had previously informed Case Managers that any Community Developmental Disability Organization staff could communicate on behalf of clients associated with that CDDO. MCO customer services still refused to proceed.

INCORRECT PRIMARY CARE PROVIDERS

JAN. 17TH – PCP = HOSPICE NURSE

A woman with I/DD served by our organization was assigned to hospice nurse as Primary Care Provider.

JAN. 28TH – PCP NOT PRACTICING IN AREA FOR 10 YEARS

All individuals signed up with Sunflower State Health Plan have been assigned Primary Care Physicians that are either: unknown doctors from the Kansas City area (the beneficiaries live in Southeast Kansas); or doctors who left the Southeast Kansas area approximately 10 years ago. Phone calls made to rectify this situation have not yet been returned, despite assurances by managed care organization that phone calls would be returned within a 24hr period. No calls returned although promised within 24 hours. Our organization's staff are filling out paper "change" forms.

JAN. 23RD – PRIMARY CARE PROVIDER WILL NOT ACCEPT BENEFICIARY

A woman with intellectual/developmental disabilities was assigned to a Primary Care Physician, but the Doctor will not accept her as a new patient (despite the assignment) because she does not also have Medicare. Now this individual cannot access the doctor to whom she has been assigned. She had previously been accessing a free clinic.

JAN. 28 – PCP = CHINESE RESTAURANT?

When a guardian of a person with I/DD received their individual's medical card, they found the assigned Primary Care Physician was no longer in area. Out of curiosity, the guardian called the phone number listed on the medical card. The guardian got the local Chinese restaurant. The guardian requested the individual's Case Manager to complete a "change" form and submit to the managed care organization.

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MULTIPLE DATES, MULTIPLE ENTRIES

Jan. 25th – Incorrect primary care physician listed on medical card.

Jan. 28th – Individual assigned wrong primary care physician.

Jan. 22nd – Random Primary Care Physicians were issued to many individuals.

Jan. 17th – None of the Primary Care Physicians listed on the cards are the correct PCP.

Feb. 4th – The managed care organization, Sunflower State Health Plan mailed several individuals medical ID cards with the wrong primary care physician listed. A Case Manager of our organization phoned Sunflower customer services and made arrangements for the cards to be corrected. Another batch of cards was subsequently mailed and they still listed the wrong physicians.

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