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## **KanCare Extension Hearing Public Comments**

April 2017

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Report prepared by:

The Center for Organizational Development and Collaboration



WICHITA STATE  
UNIVERSITY

COMMUNITY ENGAGEMENT  
INSTITUTE

## Introduction

The state of Kansas is requesting a one-year extension of its existing 1115 demonstration Waiver, known as KanCare. The existing Waiver permission expires on December 31, 2017. Kansas is requesting an extension to allow time to fully evaluate changes that are being considered at the federal level and may offer new opportunities that may benefit Kansas' Medicaid recipients.

Kansas accepted public comment on the extension request from February 14<sup>th</sup> until March 27<sup>th</sup>, 2017. Comments could be provided via mail, email, or during one of five (5) public hearings that were held throughout the state. Kansas notified stakeholders of the public meeting locations and ways to provide input by mail, press release, website publication, listserv email, and provider bulletins. Public hearings facilitated by the WSU Community Engagement Institute Center for Organizational Development and Collaboration were held between March 20<sup>th</sup> and 24<sup>th</sup> in Wichita, Topeka, Hays, and Olathe. Participants had an additional opportunity to provide comments at the KanCare Advisory Council meeting, not facilitated by WSU on Monday March 27<sup>th</sup> in Topeka.

Date/Date	Time	Location
Mon., Mar. 20, 2017	3:00 – 5:00 pm	Wichita Marriott Kansas Grand Ballroom 9100 Corporate Hills Drive, Wichita, KS
Tue., Mar. 21, 2017	3:00 – 5:00 pm	Ramada Convention Center, Downtown Topeka Regency Ballroom 420 SE 6th St., Topeka, KS
Wed., Mar. 22, 2017	3:00 – 5:00 pm	Fort Hays State University Memorial Union Fort Hays Ballroom 228 700 College Drive, Hays, Kansas
Fri., Mar. 23, 2017	3:00 – 5:00 pm	Embassy Suites Olathe Salon D, E, F 10401 S. Ridgeview Road, Olathe, Kansas
Mon., Mar. 27, 2017	2:00 - 3:30 pm	KanCare Advisory Council meeting Curtis State Office Bldg., Room 530, 1000 SW Jackson, Topeka, KS

In total, 226 people attended these hearings and had the opportunity to share comments and questions live and/or by writing on comment cards. Comments from the KanCare Advisory Council are also included in this report. Total written comments included 25 written on comment cards during public hearings and 14 by mail or email.

## Technical Note

Comments during the public input sessions were recorded. Basic transcription rules were utilized to eliminate filler words and statements, false starts, and repetitions. Non-verbal nuances are noted where appropriate and names are eliminated or enhanced to provide appropriate reference. When the commenter provided comments on multiple topics in one statement, when possible based on clear language breaks, the statement is segmented and categorized into different thematic categories. When the statement is unable to be segmented, it is themed in the category that it overwhelmingly represents. Some comments overlap multiple thematic areas and are not repeated in both to keep the report concise. All verbal comments, comment cards, and written and e-mailed are included in the themed document and are included only once. Emailed letters are included in their entirety as an appendix at the end of the report.

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## KanCare Extension

*There were thirty-four (34) questions/comments regarding the KanCare Extension. Nine (9) general extension questions/comments, ten (10) about CMS' opinion of the extension, five (5) about the purpose of the extension, four (4) asking what happens if the extension is denied, and six (6) voicing opposition to an extension.*

### General Questions/Comments Summary

There were nine (9) general extension questions/comments. One (1) asking what the benefits are of extension, one (1) asking for assurance of better outcomes with extension, one (1) asking about the impact on MCO contracts, one (1) stating it makes sense to seek an extension, and five (5) indicating that the waiver gives the state time to address issues within the system.

### State Response

The State continues to work to improve KanCare, as evidenced by, most recently, the Lt. Governor's Process Improvement Work Group. Processes at the eligibility Clearinghouse are regularly examined for improvement. Recent changes include the addition of more staff and working with nursing facilities specifically to help improve the application process for their residents.

### Comments

1. We've heard from a lot of people and I think all of us are trying to express how concerned, frustrated, upset. We are families living this life. We know our children, our adults best. We feel like we've not been heard, and our worst fears have come to fruition. Could you recap for us what benefits are expected with the KanCare extension?
2. Basically, we're hearing the extension is going to go forward. We're here without any power over that. We'd like to have some reassurance from you, or advice from you, about how we go forward and get better outcomes?
3. Can you tell me how this affects physicians who are currently participating with the 3 MCOs? Does this contract have a termination date? Does this automatically get extended for a year? Can you speak to that please?
4. The basic premise of the one year extension of KanCare appears to be continuing for one more year to do the same as currently is the case. This seems to be a matter of practicality. It may not make sense to consider significant changes for just a short extension. Increased access to, and use of, primary health care while decreasing use of the emergency room has been reported as has overall improved coordination of health care services. Improved health outcomes at a lower cost is one of the benefits that can occur with a managed care service delivery model.
5. As an extension to KanCare is considered, we urge you to use this as an opportunity to address critical issues facing the program. There has been an eligibility backlog for nearly a year and a half, concerns about the adequacy of provider networks as a result of burdensome administrative processes and denial rates, and the lack of appeal processes for both providers and consumers. In addition, outside factors -- including record numbers of children in foster care and cuts to community-based services -- are providing unsustainable pressure on the KanCare program. Changes such as uniform paperwork and procedures for each of the MCOs could significantly improve the program.  
While we are hopeful the Kansas Legislature will restore the four percent Medicaid reimbursement rate reduction this session, currently it is impacting access to care for our state's most vulnerable youth and has placed additional burdens on the already stressed child welfare system. The result has been agencies scaling back operations and questioning whether they can afford to continue participating in a program that pays less than the cost of providing care.  
  
Child welfare agencies are important health care providers who respectfully ask that if KanCare is extended, it is also improved. The health care needs of children in child welfare are vast and often compounded by their circumstances. Ensuring access to stable health care services is good policy that is in the best interest of all Kansans.
6. The KanCare demonstration waiver has not effectively or efficiently served Kansans who are Medicaid eligible,

nor has it served as a model worthy of replication by other states considering similar undertakings. If CMS deems it appropriate to continue the KanCare demonstration waiver, Kansas Advocates for Better Care would support a one year extension for the demonstration project and respectfully request that: 1) CMS maintain active oversight of the areas defined for correction in its letters to Kansas of December 2016 and January 2017; 2) CMS maintain active oversight of the state’s implementation of an approved correction plan; 3) CMS require an aggressive correction in the state’s grossly delayed Medicaid eligibility determination process; 4) CMS include special terms and conditions for the extension which require a fully independent and functional, legally based ombuds program for Medicaid beneficiaries, preferably housed outside of state agencies.

7. The HCBS network has never stabilized after the move to managed care. In response to the compliance issues noted by CMS, the State has slowly begun addressing problems within KanCare, but there is not currently a stable, adequate network. Older adults need a stable, reliable provider network, as do others who use long-term care waiver services. Such a network would be confirmed through data that demonstrates that the health care and HCBS provider networks are strong and that KanCare is meeting its original goals.

The waiver extension gives the State time to address KanCare’s compliance issues. If CMS approves the extension, we are asking CMS to provide for consistent oversight of the State’s efforts to reduce the risk of harm to frail elders and all Medicaid recipients. Further we ask that CMS to direct the state to work more closely with all stakeholders (not only providers and state agency staff) to assess the program and identify gaps in services to improve the health and well-being and outcomes for frail elders and of all KanCare recipients.

8. The KanCare Advocates Network (KAN) supports an extension of the existing KanCare program for a year, or until the current problems are resolved and the CMS compliance issues have been satisfactorily addressed.
9. I appreciate that no adverse changes are being proposed, however, there are problems with the program as it currently stands, and I implore you to consider making changes to the program, in order to make it truly and fully meet the needs of Kansans like my son. His life and independence depends on it.

<i>Status of Extension with CMS Summary</i>	<b>State Response</b>
<p>There were ten (10) comments/questions about CMS opinion of the extension, all were related to whether CMS is ‘on board’ with extension and KDHE thinks it will be approved and whether ‘fixes’ are happening now, rather than waiting on extension approval.</p>	<p>CMS indicates they will work with the State on the extension request. The State is committed to continually improving KanCare, as demonstrated by the Lt. Governor’s Process Improvement Work Group and an additional 20 staff positions now being recruited to improve monitoring, contract compliance, data analysis and eligibility determinations. The State is working to meet all the requirements for submitting an application that can be approved. The State has submitted two Corrective Action Plans to CMS – one on 1.31.17, related to HCBS 372 reporting, and one on 2.17.17, related to the CMS on-site review in the fall 2016</p>

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. So your timeline that you showed for everything is okay with CMS as far as you know?</li> <li>2. So, none of decisions were based on accessibility to people, they don’t do that? Because when they did the state hospital it was how patients were treated so it’s not based on how patients or treated. Just administrative is the only thing?</li> <li>3. Do we have a high confidence level that the extension will be granted, as we move forward?</li> <li>4. It is the extension that was denied earlier this year and can you tell us why that was denied and if those issues have been addressed/changed?</li> </ol>

5. I read in the paper some of the criticisms the federal government had of KanCare and I wonder if you're not doing anything yet to fix those problems, why do you think they will give us an extension?
6. Maybe I missed this, does the state anticipate knowing we're going to have approval from CMS on the extension prior to doing the summer meetings on the renewal? Or is this going to be drug out? Is this going to keep going on? Is there a deadline?
7. The federal government was not happy with KanCare. Why wouldn't you try to rectify some things now? Some of those problems are pretty bad situations.
8. I thought that there was an application to the Centers for Medicare and Medicaid Services (CMS) that was rejected and they have some very serious concerns about it earlier this year. Is that playing into the fact that we need an extension?
9. DATA: In its Jan. 27 letter to Secretary Mosier, CMS pointed to limited evidence of data, reports and performance information that contribute to program evaluation and continuous improvement of the program's operation. Additionally, CMS cites whole sections of the KanCare 372 report that are absent data, including sections measuring the health and welfare of recipients and qualified providers.

Incomplete and unavailable data has plagued our ability to evaluate the effectiveness of KanCare programs and the strength of the long term supports and services provider network under the seven HCBS waivers. As we move toward renewal of KanCare, it is imperative to look at meaningful measures to identify gaps in the system, develop solutions, and provide better care for older adults and persons with disabilities being served by the waivers.

10. KAN is a coalition of advocates whose collective interests include issues impacting children and adults who are served by KanCare under the Kansas Medicaid program. KAN has tracked the obstacles encountered by beneficiaries and the financial strain KanCare has placed on providers of services of both long term supports and services and medical care. To further document those issues, we hosted 3 public forums across the state in May, July and October and heard from at least 500 individuals, families and providers.

Since KanCare began, we have consistently heard from consumers and families across all waivers who struggle with finding and coordinating services to help them with their activities of daily living. This anecdotal evidence has been confirmed by the CMS audits which found serious compliance issues around plans of care, documentation, care coordination and eligibility determinations.

The State is in the very early stages of addressing the problems identified in the CMS compliance audits. Many of the problems are technical in nature and will require the State to commit significant staff and resources to fix them. Few of these fixes can be accomplished quickly and without the input of stakeholders and advocates.

KAN has been consistent in our message that the following problems must be resolved before subjecting KanCare members to more change. We have repeatedly opposed all actions to eliminate the current HCBS Kansas waivers until KanCare problems have been resolved and details of the any major program changes are made public.

<i>Purpose of 1-year Extension Summary</i>	<b>State Response</b>
There were five (5) questions about the purpose of the extension, all related to why it is needed and the timelines for extension and renewal.	The original 1115 demonstration is approved to run from 1.1.13 through 12.31.17. In order to prepare for a renewal request and to determine how changes in the federal administration may affect Medicaid, the State is requesting a one-year renewal of our current demonstration – <i>with no changes</i> . This extra year will provide time to develop our five-year renewal request in a



	way that can reflect new flexibility that the new federal administration may offer states.
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**Comments**

1. If this goes through, then you say that we'll have flexibility. Does that mean that we're not going to lose any services? If it doesn't go through and government steps in, are we going to start losing services?
2. After you get this to January of 2018, what happens then? Do you have to go through this process all over? It's over, it's done? It's set in gold, or what?
3. I'm a little confused, we heard at the last oversight committee hearing that the extension request is for one year. I'm hearing you're planning to submit a renewal request later this year to launch in 2018. Am I missing something?
4. I am just a little bit confused. The first agreement started in Jan 2013 and it goes for 5 years. Well my math goes to 2018. So are we talking about what we have right now goes until 2018. And then you're going to be putting in a request from there for a year extension?
5. I'm just wondering, why are you just asking for a 1-year extension. Why not more than 1 because I don't understand. Everybody will just get familiar with the new assessment or and then we'll have to do it all over again next year.

<i>Denial of an Extension Summary</i>	<b>State Response</b>
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There were four (4) questions asking what happens if the extension is denied.	The State does not anticipate the extension will be denied. Conversations are occurring with CMS to ensure our extension request meets their requirements and can be approved.
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**Comments**

1. I'm here as an individual very interested in this program, KanCare. Since I retired, kind of retired, and then I've become aware of some problems with KanCare and I thought this can't go on. Something has to be done in order to alleviate the deficiencies in the system, by the federal government which requires this program and its delivery. That's why I'm here today, to learn what you're doing to meet those deficiencies. Now question 1, if the proposal for the extension is denied what then?
2. Worst case scenario – CMS has already denied the extension once. What if they deny it again? What is the timeline? What is the process?
3. If you're not looking at the renewal process right now, you're just doing the extension. What happens if you don't get the extension? Are you going to be way behind on the renewal and is there a good chance you won't get that renewal and we can go back to the way it was before?
4. What happens if Feds refuse your request for extension? Collection of public input about KanCare- 3-24- Olathe location?  
They are going to screw it up no matter how much public input they get. How many trips up here did we make last year; for nothing? All the money the state spent on committees and meeting was a waste of time. Nothing came of it. All talk no action. 2016 meetings galore about what can and should be done. Now March 2017 and is KS going to take another year to clean up their act? You can bet the consumer is going to get screwed!  
  
It was much better before it was privatized.

<i>Opposition to an Extension Summary</i>	<b>State Response</b>
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There were six (6) comments opposing extension. Two (2) directly opposing, two (2) expressing concern about potential block grant funding, one (1) concern about the delay in MCO RFP, and one (1) about MCO profits.	The State believes the extension will provide time to develop a high-quality renewal application and MCO RFP. It is not known yet what, if anything, will happen to Medicaid at the federal level.
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**Comments**

1. You mentioned that one of the benefits of KanCare was that it provided more efficiencies in KanCare and I think all of the providers, all the individuals would agree that there is, there is no efficiencies that have been gained by this. In fact, there is just more redundant things that have to be done. The MCO care coordinators are just doing what TCMs were doing. There's just more billing and more chasing claims, and correcting claims, and refiling, and rechecking because nothing's right. We can't even get answers if we can get one, there's no efficiency that has been gained by in all of this process. Really that's all I have to say. I don't see any reason to renew or extend.
2. I heard you say that one reason KanCare needs to be extended is to take advantage of flexible programs that may be handed down from the new administration I have no confidence that our state will utilize a Medicaid block grant without cutting services. It will gut the 1115 protections.
3. I'd like to suggest to you, and I'd like to go on record that that savings has been on the back of Kansans that can't afford that. I'm in a current situation with my daughter right now where they've cut her services 50%. 50%! The people that I know, the families that I serve, the families that I see every day, their services are being cut. We're talking about people that can't do one thing for themselves. Not one thing. I also want to go on record, because every time I attend a KanCare oversight committee meeting or a hearing at the legislature, Dr. Mosier and Mr. Randol I believe it is, they always talk about the wonderful statistics about KanCare. They talk about the statistics on the medical side of it. You never hear them address what's going on, on the HCBS side. The fact we can't get new providers. People won't get a license. They haven't done a new license in Johnson County in 2 years as one example. The fact that CMS came back to Kansas and said, "No, not only are you not going to get this extension, but you've got some big problems there". I also find it interesting in reading the state's response to CMS' letter that they're taking until October or December of 2017 to fix all the items that CMS wrote them up for. So basically you're asking for a 1-year extension so you can get your ducks in a row. This whole process was rushed into being in order to make it in time for the last election and now you've got a year basically to fix the mess that has been created. But again, that \$1.45 billion is on the backs of needy Kansans. It's just, it's ridiculous. And the fact that MCOs just all posted there was a \$25 million profit that they made off of those same people, that is a travesty. Thank you.
4. I am Walt Hill, I'm executive director of High Plains Mental Health Center. We cover over 20 counties in northwest Kansas. I want to really focus on the issue of the extension of the current Waiver request. I won't talk a lot about the 4% rate cut. Only in the terms of a concern I have is in the extension is we may lose some opportunities to make changes in the KanCare system that are being talked about a great deal. Some legislative committees are talking, there's quite a bit of chatter about opportunities for refinements. As a provider you wonder if there are more opportunities for that if it wasn't an extension but actually updated bidding of things like spenddown and other opportunities. I fully understand the ambiguity of the situation and the position of the federal government about what changes with the Affordable Care Act changes the changes with Medicaid and understand your rationale of not wanting to forge ahead, release your bids, and then the federal government changes everything out from under you. At a logical level very understandable. Amidst my concerns is waiting longer for some of the opportunities for streamlining processes, consistency of processes between the three MCOs, like he was talking about, differing timely filing requirements between the three MCOs. It's all of those differences that really add to our cost structure with doing things three different ways, sometimes three different sets of definitions. So with respect to the 4% rate cut we'd love to see new bids so there's more opportunity for value-based purchasing by the MCOs so that we can get in a whole different kind of model, more out of the fee for service potentially. I'll stop there. Anyway, I understand the dilemma that we have of this feels like seeing an opportunity go another couple miles down towards the west and we have to wait even longer for something it seems.
5. Is it permissible to criticize KanCare? I'm not sure it's going to get better whether or not you're getting an additional year. As far as I'm concerned, KanCare has been broken for the case I've had since June. I can't get them to cooperate or to respond. I've been promised a call from supervisors; I'll ask for their supervisors. I've

called the managed care organizations (MCOs), the clearinghouse, and the state. It's like they're completely snowed under.

6. Lois Ferguson and I've been in this service field for almost 30 years now and I'm a case manager. I heard you say earlier that one reason that you want to extend KanCare, that the state wants to extend KanCare, is to take advantage of maybe some flexibility that the new administration might pass down to the states. Are you referring to the Medicaid block grants that they are talking about doing in place of waivers? The comment I want to make about that is that the we actually, in the DD field, see the federal government, CMS, as somebody that is helping to oversee this program, and we look at them in a friendly manner, not in a too much oversight manner. The block grants, the Medicaid block grants, sound like a way to cut our funds and I have absolutely no faith in the state of Kansas to implement those without not only cutting services but also without stripping all of the regulations and all of the protections that we have from the 1115 waiver. So just as a human being I would be totally against renewing KanCare for that reason.

## Public Notification & Input

*There were twenty-seven (27) comments regarding public notification and input. Two (2) general questions/comments, three (3) inquiries about the process of giving input on the request for proposals (RFPs) and the timetable for input, five (5) asking about prior public meetings or prior/standing workgroups, four (4) questions/comments about notification of programmatic changes, eleven (11) questions/comments about the current public engagement tour, and two (2) requests for the state to continue working on communication and engagement.*

### General Questions/Comments Summary

### State Response

One (1) question asked if KDHE has the ability to carve IDD out of KanCare and one (1) inquired about the meetings and commented that they have not been passionate enough before to appear at meetings.

HCBS for persons with IDD was carved out for the first year of the demonstration. The State does not intend to carve those services out in the future.

### Comments

1. As I understand, you're here to talk about the extension and we probably don't have any input in that. So what you've basically heard was all the frustrations that we've had with the current system. My understanding of politics is that you go to the people who have the power to make the changes. Are you saying that KDHE does not have the power, currently, to carve out IDD from KanCare?
2. As the owner of a practice that takes KanCare, and as a former Medicaid provider since 1992, I would like to appear at the public hearing, preferably on March 21, but I would travel to Wichita to take part if I can only appear on the 20th.  
Please advise how this is arranged, or if it is arranged in advance. I have not been passionate enough about anything before to appear, and it is clear that this was unfortunate now that Kansas is in such a situation with KanCare.  
I can provide a unique prospective on how things have been for providers recently, how they were under KHS and how they were under the original system in the 1990s. Moreover, we have hand-to-hand and face-to-face experience with all aspects of KanCare and have since it's inception under the three MCOs. And I would gladly face off against any of their staff in a discussion of our experiences, particularly over the last 9 months.

### Request for Proposals Summary

### State Response

Three (3) commenters inquired about the process of giving input on the request for proposals (RFPs) and the timetable for input.

Public input meetings on the new RFP will occur in the summer of 2017 and, again, in fall 2017. The FRP has been, and is being, worked on. We have already incorporated input from the May 2016 public input meetings and will incorporate input from the future meetings.

### Comments

1. I don't think most of us understand why you're extending this, but in any case you may be running out of time to do these new RFP's for what you might call KanCare 2.0. I would like to know how we can have input in revising the RFPs? As you have heard from many of us, we don't think the KanCare waiver is working to our advantage. It's actually squeezing the providers to the point that they are not able to survive. You can't hire. Would you like to come and work at \$10/hour in one of these providers' homes? What is the process for having input?
2. There were meetings similar to this in May of last year where everyone was hard at work on the request for proposals (RFP) knowing the KanCare contract was set to expire at the end of 2017. What happened to the effort? Now we're asking for an extension. What is going on?
3. So you'll give us a timetable for having input on the new RFPs?

*Prior Public Meetings and Workgroups Summary*

**State Response**

Five (5) questions/comments asked about prior public meetings or prior/standing workgroups. One (1) asked how many prior meetings Kansas has held regarding KanCare, one (1) asked if any were in Johnson County in 2013, two (2) inquired about the Lt. Governor's workgroup, and one (1) commented that decision makers don't listen to IDD stakeholders.

Before and after implementation of KanCare, the State held 136 separate meetings in 25 different cities to inform and educate people about KanCare, as well as to hear comments, concerns and questions. The greatest number – 18 – of these meetings were held in Johnson County. These meetings do not include the many meetings held about HCBS settings rule or waiver integration. The Lt. Governor's Process Improvement Work Group consists of 40-50 stakeholder representatives. Members were not invited based on geographic regions, but to represent major groups of stakeholders.

**Comments**

1. Another question. You mentioned a hundred and thirty-some times that you met with that as KanCare came into play? Since then, in the Last 5 Years, how many meetings have you had?
2. Did you have any public meetings in Johnson County in the last round in 2013?
3. I'm having trouble understanding is why over the past 4-5 years of KanCare we've had the exact same concerns. The advocates and providers have been bringing, there's been multiple workers, there's been all sorts of meetings like this. It's the same concerns over and over and over again, and now there's a little bit of an impetus on getting quick wins. The Lt. Governor put together the newest workgroup that's focused on, again getting quick wins on, the same issues that we've been discussing for 4-5 years and there's been no progress up until this point. I guess, why?

Maybe I'm not being very clear in my point. I think that advocates understand that there are positives to KanCare. Most folks that are involved, I know myself personally, I've seen some positives from the program. I've also seen the exact same concerns coming for 4 or 5 years and some of these have been pretty easy wins that could have been achieved long ago. There's been no attempt to do so by the state. That is very concerning. I think advocates and providers and all the stakeholders are pretty much ready and we all want the same thing, we want a program that works, although I think sometimes we're treated by the state as some sort of instigators that isn't after that exact thing. We all want a program that works and we want to be brought to the table in a legitimate way and actually see some progress. This impetus right here in the end, it just shows sort of a disingenuous angle.

4. Secondly, you may have come to Johnson County before when you were working on the original KanCare back in 2012, and we provided tons of comments. The IDD community was at Topeka, around the Capitol. We were there for carve out IDD. Our problem is, people in Topeka in charge apparently don't listen to us or don't give a crap what we say. You went ahead, you kept us out of KanCare for 1 year. At the next year you put us in it, and

yet you're out here asking us why we should think this is such a good deal. It's not a good deal for the IDD community, for the long-term services. Your medical side, I don't have a problem with that. I wish that you would distinguish between the medical side and the long-term care side whenever you do your statistics and those kinds of things, because we are not being heard is the bottom line.

5. I keep hearing quality of care and you had it up on your screen that one of the purposes was quality of care, and we talked about Managed Care case managers, care coordinators, MCOs. In all of that there should be some consistency for care. I mean, if you have that many people and that many different type of people dealing with the individual care of individuals, we should have some consistency of care and that's what's got me worried really about that situation. I question the Lt. Governor's committee. I'm just curious how many on that committee out of that number how many are from Western Kansas? I mean when the group meets tomorrow how many do you anticipate being there?

<i>Notification of Program Changes Summary</i>	<b>State Response</b>
Three (3) questions and one (1) comment were about notification of programmatic changes. The questions ask to be notified, to notify providers, for notifications to be timely and if they'll come through the website, and the comment was about seeking stakeholder feedback in the thoughtful planning for KanCare 2.0.	KanCare members will be notified directly about public meetings. Providers will receive bulletins through e-mail and notices will be placed in the <i>Kansas Register</i> , on the KanCare website and sent to tribal organizations. No changes to coverage will occur in the extension year.

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. When you find out something, will you send us a letter or something to let us know what's going on? I'm really nervous about this. My medications along come to about \$2,500 every month and I only make \$733. Let's figure that out, you know?</li> <li>2. Will our providers find out what's going on? In talking to the providers right now. They're saying we don't know yet.</li> <li>3. Are those updates going to come through your website? You're going to tell us what these new program are going to entail? That's all going to be put out there very quickly for us to have that information?</li> <li>4. Streamline processes is needed, with that said, seek stakeholder feedback &amp; plan accordingly. Would suggest thoughtful planning for KanCare 2.0. be done, to hopefully not repeat a disastrous implementation. Such as experienced w/ current system.</li> </ol>

<i>KanCare Extension Public Engagement Summary</i>	<b>State Response</b>
Eleven (11) questions/comments were about the current public engagement tour. One (1) comment was thankful for having the meetings, nine (9) were clarifying comments and questions largely around notification processes and information for other sessions.	All KanCare beneficiary case heads were sent invitations to these public meetings. In addition to the notice published in the <i>Kansas Register</i> and on the KanCare website, the notice was sent out through various list serves at KDADS and through the KanCare Ombudsman's office. A press release was sent to selected newspapers. This process will be repeated for future public input meetings.

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. I have been on KanCare since the start. I enjoy this meeting and thank you for having it. And now we know what ol' Spicer has to put up every day dodging questions for Trump. Thank you very much for doing this. We need to do more of these meetings.</li> <li>2. The advisory council meets next Monday you said and they'll take public comment for that. What's the process to sign up to testify for that?</li> <li>3. That room that's generally that the advisory council meets in, is not really accessible to wheelchairs and people with mobility issues. Is there some thought about moving that to a room that would be more accessible?</li> </ol>

4. I guess I'm showing my ignorance, that's, that's in the papers that's out in publications? And that was in Western Kansas too?
5. You said there's going to be a collection of information and one of those places was Olathe, do you have a location yet?
6. If I hadn't accidentally read it in the paper, I had no idea about this meeting whatsoever. Are we not making people aware of these meetings at all?
7. How did I get off of the notification list? I was invited to the last round of meetings several years ago. I have also been notified of my renewal requirements. This year, all of a sudden I'm not notified of anything. It is my understanding there's a number of people who are having the same problem.
8. So where do we need to go? I didn't get anything. I got an email Monday that we were having this meeting today that was it, "Oh, hey, by the way we just got this." So I, as a provider of 21 years, I'm not on your list to send things out to.
9. I am the addressee/rep for my daughter, but I did not receive any notice of this meeting. Saw one very small newspaper article.
10. I'm just curious, what kind of feedback did you expect to get from your audience regarding the renewal. Because I know how I feel about KanCare overall and if I had my way it would not be not renewed but it would also not be extended past its drop dead date. I mean are you expecting people to say, "Hey, I really love it and it's the best thing since sliced bread.", or what?
11. First of all, when those notices went out, there was not a meeting in Johnson County at all. It was not until we raised the issue with the legislators that I believed this meeting was scheduled. Therefore, everybody in Johnson County thought, "Oh, well we've missed our opportunity unless we drive to Topeka or Wichita."

*Public Engagement Strategy Summary*

There were two (2) comments encouraging the state to continue working on communication and engagement.

**State Response**

The State is committed to a process that will allow us to engage stakeholders representing over 400,000 beneficiaries, over 20,000 providers and numerous advocacy organizations.

**Comments**

1. Please continue to work on flow of information
2. We appreciate the continued communication and working together on the renewal & current system improvements. Please continue to get stakeholder involvement & feedback on solutions.

## Utilization and Cost Savings

**There were ten (10) comments/questions about service utilization and costs relating to KanCare, summarized below.**

Summary	State Response
<p>There were ten (10) comments/questions about service utilization and costs relating to KanCare. Five (5) asking for additional utilization information, three (3) asking for utilization and outcomes information specific to HCBS participants, two (2) commenting on costs data relating to HCBS and KanCare, and one (1) expressing skepticism about the data.</p>	<p>The State posts quarterly and annual 1115 demonstration reports on the KanCare website: <a href="http://www.kancare.ks.gov/policies-and-reports">http://www.kancare.ks.gov/policies-and-reports</a> . These are the same reports submitted to CMS. These reports include utilization data, grievance and appeals data, quality measures and many other measures. In addition, these reports contain the budget neutrality calculations that are required. Much of this data is reviewed and /or calculated by Kansas Foundation for Medical Care, the State’s External Quality Review Organization (EQRO). Individuals and agencies can request data from KDHE regarding KanCare through a data request process that is also posted on the KanCare website: <a href="http://www.kancare.ks.gov/policies-and-reports/request-for-records-data">http://www.kancare.ks.gov/policies-and-reports/request-for-records-data</a> .</p>

### Comments

1. Explaining the increase in inpatient and outpatient percentages in the chart?
2. Decreased inpatient because it’s NOT ALLOWED as much. Data are skewed & don’t tell the REAL story
3. I’m a mother and also a provider in Johnson County and I drove here today because I wanted to hear what people thought about this. Did I understand you to say we’ve saved \$1.45 billion with KanCare?
4. I’m going to turn some of these comments into questions because comments don’t get any feedback from you. You say you’ve saved \$1.4 billion. I’m a tax accountant. I’d like to see those projections and how you did that. If you’re doing that for the entire KanCare, for all waivers, that may be the case, but I don’t think that’s the case for DD. DO you have a breakout for what you saved on the IDD waiver? We want to know what it is for the DD. These are, that’s the most important thing for us because we know that has a very lean program up until 2013 when you turned this into some sort of KanCare demonstration. So if you would be kind enough, I would love to see that portion. You had to have done some cost accounting per waiver.
5. I wanted to take the opportunity to make a 2nd comment because we had time. A couple of times, one again more of a macro umbrella concern I have. When we embrace these free market economic motivation approaches as being superior to prior historical, maybe more government centralized and monitored approaches... I think we take a look at that graph and some people would say, “Wow, that’s great. You know, we avoided spending \$1.4B dollars that that old antiquated government approach would have spent because we embraced this new economic motivated free market approach.” I think that’s where we have the flaw because when we moved from the old to the new approach that saved \$1.4B, we didn’t just try and change a model from being in a bureaucracy to in theory being in a free-market, highly skilled place. We decided as we were doing that, we were going to gut the benefits by gutting the amount that’s spent. So I think we really make a mistake when we think we are doing something to improve the process. We simultaneously cut all the costs we were investing into it by 25%. I think it’s flawed to say we’re getting the same outcome from the free market economic approach that we would have we would have expected from higher cost approach.
6. The second item is the numbers you put up there, all very positive, showed statistically 60%, whatever the percentage was, I don’t have the slides up in front to read. Do you have other data that shows other statistics in other areas besides the ones you mentioned where there’s some that were not positive, some indifferent. Where is your complete statistics package that shows all the parameters that you measure each and every year?
7. Questions remain, however, about the efficacy of the managed care model vis-à-vis home and community based services and supports. Available research seems to indicate that some advances in measures of quality may



obtain with managed home and community based services and supports (HCBS), but cost savings concomitant with advances in quality are uncertain according to the limited evidence that exists. Topeka Independent Living Resource Center continues to have concerns with KanCare as it pertains to home and community services and supports.

Reports from KDADS/KDH&E on increases in quality and on cost savings metrics have been about provision of managed acute and chronic health services of KanCare. However, managed HCBS remains a cipher. KanCare needs to develop and adopt and benchmark clear quality performance measures for HCBS and begin reporting on them To the general public. Over this next year a workgroup made up of people with disabilities of all ages, including consumers of services, providers, advocates and academics needs to be appointed to develop standards and measures of quality of HCBS for KanCare. Such measures need to include, for example, community integration and inclusion, independence, self-care, improved health and well-being, employment, and overall satisfaction. Clear information and reporting about quality measures and metrics would go a long way toward fostering better understanding about how KanCare is working for those served through HCBS.

In late 2016, the National Quality Forum published a report on quality measures for HCBS. This report represents the product of two years of work that included top researchers and thinkers representing universities, state government, the aging community, the disability community, and the HCBS workforce in the area of home and community-based long term services and supports. This document should form the basis for KanCare HCBS quality measures and related metrics and would provide a great starting place from which a workgroup on managed HCBS quality could begin. The link to the NQF document is below:

[http://www.qualityforum.org/Publications/2016/09/Quality\\_in\\_Home\\_and\\_Community-Based\\_Services\\_to\\_Support\\_Community\\_Living\\_Addressing\\_Gaps\\_in\\_Performance\\_Measurement.aspx](http://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living_Addressing_Gaps_in_Performance_Measurement.aspx)

8. As there was no true pilot or test period for LTSS for I/DD in KanCare, we have treated KanCare 1.0 as such. What we have learned is this, managed care for LTSS has been an exercise in managing costs. This is one of the most significant flaws in this program. It is impossible to keep the same rates that have been in place for nearly a decade and assume they can be squeezed to get more out of them. It simply doesn't work. An environment where three managed care organizations show a \$40 million profit while Medicaid providers experience a four percent cut and HCBS providers are cut through policy changes is not only not conducive for quality services but is in fact placing the system in crisis.
9. Publicly stated concern at the start of KanCare related to Medicaid spending and how it had grown to unsustainable levels. I believe it is vital to understand and differentiate between all Medicaid dollars spent, and those specifically spent on community services for persons with IDD and LTSS for people with IDD. A couple of observations are noteworthy regarding spending on LTSS for persons with IDD. In the years leading up to KanCare, IDD LTSS funding had been held flat (since July 2008). Flat funding cannot cause a 'growth in spending'. From 2013 to present, those same rates paid for IDD LTSS have remained flat. As a side note, overall funding for these community services has actually gone the other direction since KanCare began.
10. HEALTH: While the State recently pointed to an increased number of well-child visits, improved treatment of alcohol/drug addiction and better diabetes care as measures of KanCare's effectiveness, the State provided no improvements on the health outcome measure related to the reduction in the misuse of anti-psychotic drugs on older adults with dementia. KanCare was to reduce use by 10% annually beginning in 2014 and going forward. The improvements referenced by the State represent very limited measures of medical/healthcare metrics, and cannot be used to evaluate the effectiveness of and access to long term supports and services which serve frail elders and beneficiaries under the other six Home and Community Based Services- waivers.

## Applications, Renewals, & Clearinghouse

*There were thirty-seven (37) questions or comments regarding KanCare applications and the Clearinghouse. Five (5) general comments/questions, eight (8) relating to applications and renewals, five (5) relating a preference to return to local processing and personal contact for assistance, six (6) questions or comments relating to the backlog or delays in application processing, eleven (11) relating to clearinghouse relations, and two (2) specific comments relating to nursing home resident applications.*

<i>General Questions/Comments Summary</i>	<b>State Response</b>
<p>There were five (5) general comments/questions about KanCare applications and the Clearinghouse. These comments and questions focused on when KDHE took over responsibility for application processing, systemic issues that subsequently arose, and attempts to fix those issues.</p>	<p>An Executive Reorganization Order (ERO) moved all responsibility for making Medicaid eligibility determinations to KDHE, effective 1.1.16. Previously applications for the elderly and persons with disabilities (E&amp;D) were completed by staff in the Department for Children and Families (DCF). Once this change occurred, the KanCare Clearinghouse was expanded to begin taking E&amp;D applications. Since that time, both contractor and state staff have been added to the Clearinghouse and improvements to the application process have been made, including dedicating some staff to work applications for persons living in nursing facilities. The number of applications which have not been worked has decreased significantly.</p>

### Comments

1. I have a couple of questions after hearing some of the information shared here. Mike [Randol, Kansas Medicaid Director] are you the one in charge of oversight for KanCare? Okay so you're in charge of making sure everything's running kosher. So it sounds like there's a major glitch in 2015. I don't know how things were running prior to that, but what I'm hearing from people here anyway, is that things kind of went to pot a little bit after 2015, to some degree anyway and it's taking us two years to become proactive or at least acting towards moving in the right direction. I guess I'm having a little bit of difficulty understanding why it's taking that length of time. So if I'm understanding, then 2015 is when KDHE took over?
2. My comment is this. When you call KanCare, you ask them a question, they don't know. So then they switch you to somebody else and it's like the right hand doesn't know what the left hand is doing. They tell you, yeah, you have a spenddown. Then the next time around they told us to call Amerigroup. They said we know nothing about no spenddown, you are fully covered. Talked to the doctors, you're fully covered. But then we get a letter from KanCare saying you've got a spenddown. Then we call them and they know nothing about it. Does anybody know what they're doing there?
3. I do understand your efforts to try to put in place some fixes and some streamlined processes and just compliment you specifically, Mike [Randol, Kansas Medicaid Director] for the record, that you know, I've been in touch with you about some clearinghouse issues and your staff have been excellent in helping our staff advocate for our consumers to get their issues clarified for eligibility, particularly for the HCBS waivers. So, I would say on the positive side, I really appreciate the responsiveness of your office, KDHE, and all the staff that when we call, and I do occasionally call...Not all the time, but you're very responsive. We appreciate that. Thanks.
4. I just want to put your mind at ease. I worked through this situation in my home. I worked 3 months with KanCare. My daughter's KanCare all of a sudden just cancelled for no reason at all and I worked with them and I called KanCare I think every day or every week for sure. They know my number over there at KanCare already. All of a sudden she was approved and her spenddown is \$0. So just hang in there.
5. My only concern is with the inefficient delivery of services by the KanCare Clearinghouse. Long wait times on the phone and timely response to beneficiary inquiries. It also takes an unreasonable amount of time to see updates in coding changes in KMAP for HCBS and Nursing Facility beneficiaries. This can delay delivery of services due to ineligibility as well as delay payment room providers. Thank you for considering my comments.

*Applications & Renewals Summary*

**State Response**

There were eight (8) comments related to applications and renewals, four (4) related to delays in processing applications or renewals, three (3) questions/comments related to KanCare renewal, and one (1) related to assistance with applications/renewals.

The movement of all Medicaid applications to the Clearinghouse did have problems, but, with additional staff (and more being recruited), as well as focused process improvement, applications are being worked timely. Applications for the elderly or people with disabilities can be complex and require several additional documents, so if all documents are not submitted with the application, it will take longer to completely work the application. Many, but not all, Medicaid beneficiaries must renew their application annually. Notice of renewal is sent to the case head or the person listed as the representative. If either address is not current, the notice will not be delivered accurately. The State is committed to meeting the obligation to process all complete applications within 45 days.

**Comments**

1. Can a person who is going through the application process, can they go to Kansas legal services and get a lawyer to help them? How many people on Medicaid are college educated or wealthy or know what they're doing? My brother in law has been trying since October of 2015 and hasn't been able to do that.
2. Addressing the Medicaid eligibility processing. It used to be 45 days, we could get in and help someone. My father-in-law died the day after we got denied his Medicaid application 4 months later, then they denied him because they didn't have a current bank statement. It is a frustrating process.
3. The process that was handled by the state was much better before it was KanCare. It would only take about 2 hours to have an answer before now it takes months.
4. It would be extremely helpful to limit the step of renewal process with aged out of foster care medical insurance due to placement instability.
5. The re-sign-up. So you have to sign-up for this yearly if you've been getting it. Is it from the date that you first receive it, when do you find out when your expiration?
6. I am a little concerned about communication. I was never notified of my renewal requirements for my brother to continue on Medicaid and from talking to people at KanCare it sounds like there were a whole lot of people who were never notified that renewal applications needed to be submitted.
7. If KanCare is renewed, applications and renewals need to be handled in a timely manner for all populations. My experience right now is with my mother who is in a nursing facility. My understanding is that the wait time for new applications is much too long.

My mother started in KanCare, I believe about 2012. It was very easy to apply, renew, and get information through the local DCF office.

When my mother moved from assisted living last August to a nursing facility, both the nursing facility and I notified the clearinghouse. Neither one of us received information but the nursing facility took the amount of my mother's obligation from the KanCare website.

To make a long story short, my mother underpaid at the nursing facility and now owes money for her obligation. When the nursing facility bookkeeper finally was able to get through to the clearinghouse, we both received two envelopes with three letters stating three different obligations that had been determined. We think we are working on the correct one now. There is no excuse for this.

If KanCare is renewed, the Clearinghouse needs new administration. Someone should be responsible for situations like the above.

Other problems are – my mother received a letter November (her regular time for renewal) which started out "Your request for medical assistance in INCOMPLETE. You will be DENIED if the following information is not received by 11/21/2016."

I called immediately and asked if I had received a previous letter. The person that I talked with was apologetic and said everything was fine just send in the information. She even gave me a short extension because my mother's bank statement for December was needed.

The next week I received another letter stating that her obligation would be starting January 2017. I called and asked if I still needed to send in all of the information, which I was waiting for. They said go ahead and that her caseworker would be contacting me. That never happened. According to them, the information on the letter was probably not correct because it had no basis for its determination and to just wait to talk with a caseworker.

So I sent in the information, and even added to it weekly with faxes of changes that would occur to her insurance, etc. in January. Still no one contacted me.

Finally on Feb. 1, the nursing facility and I received all of the letters mentioned above.

The last time I talked with someone there, they said they were filing a complaint/appeal (?) for me since my mother had not been notified of the amount of her obligation. I have never heard anything about it.

This is not good management. My mother now owes about \$1,300 in back payments because the information on the website was not correct.

8. Assure funding and procedures are in place to accomplish processing of Medicaid applications in required 45 days.

*Local Offices Summary*

**State Response**

There were five (5) comments about local offices, all relaying a preference to return to local processing of applications and personal contact for assistance.

Maintenance of local offices for Medicaid applications would add significant costs to the KanCare program.

**Comments**

1. It would be better, in my opinion, if it would go back to local offices. When my mother went on Medicaid in 2012 or so, every year we would just renew. This past year has really been a mess. So I really don't know why you did that. Like I said, maybe it is because maybe we can just ignore these people if they don't keep calling back.
2. Thank you for coming here. Why did you leave Wichita, the biggest city in the State? The elderly and disabled department? I find it easier to talk to someone across the table. I think we get more done that way than make phone calls, I get transferred 3-4 times, and have to go through the same process with each call.
3. I don't know if this is a question you can answer or even the appropriate place to ask it. When you separated your medical programs from DCF, those contacts all came by phone or email through the computer system. For the majority of consumers that I deal with, that is a confusing system because there's not place locally they can ask a real person a question. They have to get somebody on the phone, sometimes that's a very extended thing. If they don't have phone carry service that has unlimited minutes on it, they're on the hold for a very long time; it uses up all their free minutes. Is there any hope that some place in future, that you will become aware that's really caused difficulties in accessing services, even being determined eligible for services; even when the person clearly is receiving public benefits through social security and could access those services? Is there any hope that you'll find a real person in some communities or some local place where they can ask a knowledgeable person who has the ability to process those applications and get services going sooner than later?
4. Next question I have is regarding personal contact. I think it's become evident how the individuals have already responded and I would be surprised if someone else in various other areas where you are meeting have not also identified the need for personal contact. We have people within the community who have some knowledge of Medicaid. We're underutilizing those individuals; they may or may not be hired by KanCare. Whatever the situation is, people that come out and study for a month and they try to figure out what's going on about how to help people when they're hired. I'm not going to try and tell you how to do that, but we do have individuals. We are cutting our own throats when we don't see that the needs of the individual, especially those that are in dire need the help that they need in order to have their needs met before they die. I guess that's the only comment I'd like to strongly suggest is that more personal contact be there if needed and impersonal contact doesn't work in the texting and the faxing isn't working where's the communication? How are we getting that individual into the system in an appropriate manner as the government requires within 45 days? It's not happening. I've seen the statistics, how many of those applications are processed within those 45 days in the state of Kansas that would tell you if you move from 20% to 40%, okay we're moving but if nothing is changed and we still have all of these months, then what's happening? I also note that your extension was based on some of those deficiencies and right now you're saying that your main purpose is to see what the federal government's going to do. We can't wait for what the federal government's going to do. The Lt. Governor got together people to work to meet some of those deficiencies, am I wrong? Is it that why he's meeting with the groups of people?
5. I will start with the obvious conclusion. Whatever you do do not renew this contract. This process is the biggest

joke. It must be brought back in to the regional DFS offices like before. I can speak from experience.

I started the process for my elderly, disabled father right before the move to KanCare happened. I spoke to a very capable knowledgeable person in a local office. Then before the original application was completed KanCare took over.

My only choice was to then deal with an office in Topeka. Many complicated documents were necessary with proof of various items necessary. Not trusting that a mailed application would work, I drove to Topeka and went through the application carefully with a staff person. It seemed to go well. Then I waited. And waited. After several months something came back that completely misstated my father's income. I had to make several calls to straighten it out.

Again something came back that was still wrong. He had been accepted but the income amounts were still wrong. I faxed back additional proof. And never heard back despite repeated calls. Then this November we received a renewal request and were told we had two weeks to apply or be denied. Again I drove all the paperwork to Topeka and was told everything was in order (although the ongoing mistake in income was still not rectified.) Then I waited and waited. We called every week and were told things were in process. Over three months later we received a letter saying the application was incomplete and would be denied if we didn't respond in a week. The missing item was a February bank statement. For an application that was due in November and which, when made in November, we included a November bank statement. Just let that sink in.

I could go on and on but the bottom line is that it is clear the sole purpose of the KanCare process is to keep putting up barriers until someone gives up or they can otherwise be denied. And my story is just one in thousands.

Stop this charade. End KanCare. Bring the process back to local offices. Expand Medicaid. Do what is right for the thousands of hard working Kansans who now need help at the end of a long tax paying life.

***KanCare Clearinghouse Backlog Summary***

**State Response**

There were six (6) comments related to pending applications and renewals, all were comments or questions about backlogged applications and delays in application processing.

The State will continue to work on improving processes at the Clearinghouse to ensure such situations do not happen.

**Comments**

1. I actually have a question for you. You were very quick on that statistic the 600 number from processed claims. How many do you have that are over 45 days? That are in process that are waiting to be approved?

Ok, how many are over 6 months? The reason I ask is because, my mother was on Medicaid. She, when you guys switched over the computer system over to KEES system. Some glitch in that system got her kicked off of Medicaid. I think it was in November of 2015. They could not get her back on. She called, she contacted people, she spent hours on the phone trying to get her coverage put back on and she was basically told to reapply and she got stuck in that huge backlog. Now, she had, she's disabled. She had several medical problems that required medication, doctor visits, labs, and she was living on \$800/month from... of... of support income. She couldn't afford to go to the doctor. She couldn't afford to go get her labs. She couldn't afford medication. She kept getting these, she kept getting these requests for information. It was all the same information that she had already provided. It was banks statements, it was, they wanted her to a re-apply for social security. She was denied for Social Security and disability due to, basically because she raised kids. She didn't work enough so she was not eligible for Social Security and that was told to them the first time. Then it was, she had to reapply and get redened from Social Security before they would move forward. Then they sent another packet of basically, again, more paperwork that was the same stuff that she had already submitted multiple times. This went on, all



through 2016. I think the last thing that we got from them was something, it was another request for information they sent it out. I had learned my lesson that we're going to, we sent them return receipt, got the return receipt back, then we got a thing from them saying that they were going to close the case because we never sent the information. January 2 of this year [2017], my mom died. She was 58 years old. I nearly had a heart attack when I got on [KanCare], February 23, the day after my mom's, what would have been my mom's 59<sup>th</sup> birthday. I got an envelope from KanCare with two letters in it. One said "We're approving your claim retroactive back to May of 2016." The second is that, "We've been informed of the death of [commenters mother] and we're closing the case". You have no idea what we went through. That I had to watch my mom go downhill, and then I had to come home from work and find her dead of a heart attack. So, what are you doing to fix this problem? There's no way to get ahold of anybody who knows what they're doing, or who knows anything, who can tell you anything, except for sending out another request, another copy of it.

2. The numbers requested earlier for the backlog. Is there a location that we can go to find the backlog numbers, current?
3. Could you give us the status in numbers in terms of the backlog for both new enrollments and redeterminations? One of the reason for the question is to follow-up on the gentlemen who was asking about the AHCA, which granted is just a proposal right now, but one of the things it would do is make redeterminations on a 6-month basis not a 12-month basis. So I was wondering how many we are waiting for on the 12-month reviews and how many on new enrollments.
4. Are these meetings a part of the corrective action that you're required to have by CMS? Well, I know that KanCare got a letter from CMS and that part of this is probably due to that corrective action because you guys are required to do. Actually that's what this is, probably what this is all about, you haven't been renewed technically because you kinda have to have all these corrective action plans in place. So what have they actually addressed, so far, besides these public meetings? Because from what I understand Kansas failed to establish clear rules and responsibilities, which that's what I'm dreading. I'm here not for myself, but for my dad, because my dad was in long-term care. He's since died. We've been, since April 2016, nearly a year, spent trying to get dad on KanCare. I actually have been visiting with the KanCare people, which have been really nice, but I told them also, I said to them, the process of getting this done in the timely filing period... Besides that, besides Dad, I'm also a billing manager and nurse, and I deal with insurance billing and coding on a daily basis so I realize there's a timely filing period, of 6 months. My dad has been out of that hospital in April, he went in September, and then went into the nursing home. The April bills haven't been paid for by the hospital because, although I sent in the process and the application several times, I got letters saying they haven't got the information. When I call the information is there, however it's out batched in different faxes and they have to physically go out and match those faxes up. If I wouldn't have called this last time, I would have never known that's what the problem was, which was probably what the problem was before, I just didn't take the time to call. I told them, I said, "you guys are making a ton of money" the clearinghouse is making a ton of money for the three KanCare HMOs or payers. I think United made \$30.1 Million last year, Sunflower made \$5.1 million, & Americorps made \$3.1 million. They all had a profit in 2016. The clearinghouse plays a part in this because they are not getting these processed in a timely manner, for whatever reason that is, who knows. I physically kept the guy on the phone last week when I faxed it because the last fax I faxed from the nursing home, just so they would know that we had it there. All of the information was there. I physically gave it to an employee at the office to fax again, kept the guy on the phone until I knew it was there. That's been 2 weeks ago. I still haven't heard anything. Dozens have died in the process. What is going on with getting this corrective action and getting this stuff taken care of? Why am I having to come here and do this? I mean why can I not make a phone call? Dad's not unique, this is all over the place all of the time... From what one of the guys told me just to put in like dad's birth date or the number I faxed from, he would have to put in like [phone number redacted] and you have to track it with the dashes and then you have to try to get with the spaces. What kind of work around crazy system is this where you can't just do it? And he said that that's part of the problem. I can't fix you guys' side and like I said Dad's one of... there are maybe 600 now, but there was 10,000 when you guys were put on notice, so I don't know what you've done more power to you. And 10,000 doesn't mean, those 600



may still be part of when I went out on the website from you guys, the website itself. Most of those cases were denied, so you may be down to 600 cases but over 50% of those were denied for whatever reason.

5. Backlog: Increasingly frail older adults are waiting 6 months and longer for eligibility determinations and entry to the KanCare program placing them at risk of serious injury and illness. Hospitals report difficulties in identifying nursing facilities which will accept Medicaid pending older adults ready for discharge from the hospital setting. Nursing homes report the inability to “float” the cost of care for older adults with pending Medicaid applications. Older adults and family members are increasingly reporting an inability to locate nursing facilities which will accept Medicaid pending individuals unless that individual can show up to six months of financial resources to pay privately. Older adults are going without HCBS services, as there is no retro-activity of reimbursement for waiver services.

Impact: Increased risk of harm to older adults unable to access services at home or in a facility. Force older adults to consider geographic displacement in order to access care, separating them from their families and support networks. Increased cost for hospital stays which are longer than is needed for care required. Increased unwillingness for nursing facilities to accept older adults who have pending Medicaid. Before moving forward, advocates and policy-makers must have a thorough review and analysis is critical to improving KanCare’s HCBS waiver services as well as the medical care provided.

6. The backlog issues, including problems within the KEES program, have impacted the health and well-being of thousands of Kansans waiting for home and community based services or nursing home care. Not only does the backlog need to be eliminated, we must be sure that it doesn’t reoccur.

**Clearinghouse Summary**

**State Response**

There were eleven (11) clearing house comments related to difficulty reaching clearinghouse staff, long wait times, and the hardship this can cause for participants.

The State has added both State and contractor staff to the Clearinghouse and worked to improve processes there.

**Comments**

1. Other things, access to the system, I’ve asked this to every person that I’ve called there. When you call you get something that says press 1, 2, 3, you know, that’s fine, I can hear that. The second that you go though, you cannot hear and I tell them that. I’m not hard of hearing. If I were an elderly person I would just give up because you cannot hear the second set of options so I usually just press a number and say I don’t know if I’ve hit the right one or not, but you know. So, how they access the system when elderly I have no idea. I figure they just give up and that is what the state of Kansas wants and they just give up.
2. I can only imagine for these caretakers and that how difficult it is to get information. As an individual myself I call clearinghouse, I sit on the phone 12 hours and did not get an answer. Three times that phone was cut off at the clearinghouse, and then when you do? You get told to go, “get an email to us” or get a website. What about people that do not, for religious reasons or financial, have computers? How are they to get information other than phone or snail mail? I have sent certified letters. They still have my information from 5 years ago with my private pay insurance listed up there as \$502. My insurance is \$1299/mo. That’s private pay. No, it’s not affordable care act. I was not qualified for that because of a job that I had beforehand. So, I have private pay through Blue Cross and Blue Shield. They can’t even get it on their website. My social security this year, on their website, was 3 years ago. They didn’t even put in cost of living on that. I can get through to social security. I can get through to Medicare in nothing but 10 minutes. They will tell you, you’ve got a 5, 15-minute wait. 3 minutes. What is wrong with this system? It was supposed to get better when they went to the clearinghouse. Put it back into the offices like over there at the Lenexa office. You had a case manager. Sure that case manager may not get back to you for maybe 24-48 hours. But when they did, you had left a message and they had an answer for you then. If they did get to you that day and said they couldn’t, they had an answer within 24 hours, one way, either negative or positive, whether you wanted to take it that way. I don’t understand how this was supposed to be better. And then my doctors, they are actually going, “Wait a minute here.” They already know what I’m going to have to pay them, because they know that they’re not going to get their money yet. It’s taking them anywhere from 6-8 months to get payments back and that is not from private pay. They have billed private pay;

they have billed Medicare. They were still waiting on Medicaid to pick up a whole \$5, \$6, \$8. What about these others that don't have the privilege of having in between like Blue Cross and Blue Shield or an Affordable Care Act? What are they doing? How much are they getting stuck with while they're waiting? This is wrong. Is there any answer how they're going to fix this? Why is there such a wait on either getting an answer or why is it, "go to the website", "go to an email"?

3. The clearinghouse still is not working. We have people that are becoming ineligible for no reason at all or they call the clearinghouse and they just, they are their own guardian. They actually just can't sit on the phone for an hour to 2 hours waiting for an answer about why Medicaid has stopped or why they can't go to the doctor because their Medicaid has stopped. It's still not, it's not working. That place in Topeka is not working. I still need to go visit that place.
4. It is absolutely impossible to get anybody at the KanCare office to return your calls. I had to go through the Ombudsman 3 separate times to figure out what it was they needed. And then I ended up in a hearing where they said they didn't get the information and I had proof that I mailed the information. Well then the information showed up. It was in my file the whole time. [Participant indicated they had an outstanding issue and Director Randol offered to take their contact information and investigate after the meeting.]
5. My problem is with your clearinghouse. I can't ever get a response from them. I sent a fax last June that's about social security taking \$250 out because they over paid me 20 years ago and I never got a response back from them. I called, can't get no response. Can't get nothing from your clearinghouse. They said they never got my fax. I've refaxed it 4 times since June and I still haven't heard any response from them. So, the clearinghouse needs to be something drastically done with it.
6. I've got an idea. There's a lot of people unhappy here. What if you did a survey yourself or someone in your office or whatever to call your different KanCare offices to see if they're put on hold? There's a lot of people here that have a lot of trouble with communication. Maybe the orange team needs some help with people skills?
7. As much as you'd like to believe & report- the issues with the clearinghouse have not been resolved. 1. Phone calls are not returned; and if you happen to reach someone, staff are rude or don't know answers to questions. 2. Forms are often "lost" by staff @ clearinghouse. We have mailed, faxed, & completed forms on-line; seems to have made no difference; forms are "lost" or "never received." 3. At risk consumers wait considerable lengths of time to have their applications approved or not.
8. I'd like to say this whole clearinghouse issue harkens back to when the state of Kansas redid the motor vehicle software. Kind of a big screw-up and they just kept digging in and digging in and that's exactly what the clearinghouse is. They keep digging in and digging in and it's not getting any better. You mentioned earlier about some changes that the state's going to propose for the waiver renewal. I'd be curious about what that's going to look like.
9. We work primarily with folks on the PD and FE waiver. They need to use their phones to clock in/out when their attendants come and go to work and get done every day and to expect them to use that phone that they rely on to do that, to be on hold for extended period of time, just isn't workable. Now what happens is those people end up having to come in to our office and meet with an advocate and call from there, we're happy to do, but that's just a system that doesn't work for that population.
10. One more thing, the Clearinghouse phone system is very difficult to maneuver. The first options that are given are very easy to maneuver but the next options are very, very, hard to hear. I have complained about this every time I called. People with hearing difficulties as most elderly have might very likely give up. Good for Kansas, huh?

Then after you finally push a number, a recording comes on that says you must make a choice but then it says continue to hold. What sense does this make?

11. Once again, if KanCare is renewed and Kansas really wants to take care of its elderly and disabled, new management is needed at the Clearinghouse. Someone needs to be accountable. These problems are unacceptable. I do want to say that every person that I talked to there was very nice and often apologetic.

<i>Nursing Home Applications Summary</i>	<b>State Response</b>
<p>There were two (2) comments related to nursing home resident spend downs, both expressed that delays in processing new spend downs prevented residents from having their allowed resources and the impact on residents and providers.</p>	<p>Nursing facilities use a provider spreadsheet process to report inquiries to the Clearinghouse to review. An automated email is sent to the facility contact confirming receipt. A follow up email is sent if the inquiry is still pending if it has not been resolved. Please contact the KanCare Clearinghouse at 1-800-792-4884 to report an expense that has been submitted and if you have not received notification stating the expense has been applied to the resident’s patient liability. Medical expenses like insurance premiums reduce an individual’s patient liability to allow the resident funds to pay this expense. If delays occur in applying an insurance premium, staff are allowed to process a retroactive patient liability. This will reduce the liability back to the date the insurance premium was reported.</p>

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. What we have done in my nursing home is that we have taken the brunt of not getting all of the private their portion because since Jan of 2016, not everyone has gotten their new private pay source (what the private pay is supposed to be) because their insurance will go up, their secondary, whatever they pay out before we get ours. We felt that the \$62 was mandated, that every person had to have, so we’ve taken a hit on the nursing home side and taken less money from the resident and so yes it is a bigger than just 1 person. I have 4 people in my facility that are in the same boat as a previous commenter, 2 people who have died. We’ve done the spreadsheets like we were told to. We’ve explained the problem and every 2 weeks we get a reply that they’re going to reply in 2 weeks.</li> <li>2. Why is it taking so long to get a redetermination for someone that when you resubmit a medical, like their insurance went up? Why is it taking so long, because that’s eating in to their \$60 they’re supposed to get? So if your insurance goes up \$40 for the beginning of the year, and you’re still waiting to find out what that amount that you’re going to be paying the nursing home, she’s now receiving \$13. What can you get for \$13? You tell me. And that’s been since January 1st. We submitted another claim back in September and we still have not heard from that. I would think that’s a little long to be finding out what you’re amount you’re supposed to pay then nursing home is.</li> </ol>

## Spenddown & Division of Assets

**There were eight (8) comments regarding spenddowns and division of assets. Three (3) general questions/comments, two (2) about errors or delays in processing changes to the amount of a member's spenddown, two (2) regarding changes to spenddown, and one (1) relating to division of assets.**

<i>General Questions/Comments Summary</i>	<b>State Response</b>
There were three (3) general questions/comments about spenddown and division of assets. Two (2) were technical questions and one (1) was a comment about the amount of the commenter's spenddown.	Spenddown and client obligation are similar. Spenddown is a requirement for a person to spend some income on medical expenses before Medicaid will pay. Client obligation is similar, but is related to people in nursing facilities or on HCBS programs to pay their provider some amount, while Medicaid pays the rest. For more information about Medicaid eligibility and these terms, please go to: <a href="http://www.kancare.ks.gov/consumers/apply-for-kancare">http://www.kancare.ks.gov/consumers/apply-for-kancare</a> .

### Comments

1. I have a question on the spenddown and qualification for Medicaid about reaching a number for a Medicaid application to move forward. There's exempt asset involved I guess?
2. Is the spenddown now referred to as the client liability? Or are they interchangeable terms? Client obligation? Is there any particular word that is the lab?
3. My spenddown is more than I make a month, that I get in my disability a month, and that is per month. There's no way that it's doing me any good. Between that and people aren't getting their announcements and renewal notices, plus you have a waiting list. Are these your ways of increasing your numbers for good show?

<i>Tracking Spenddowns Summary</i>	<b>State Response</b>
There were two (2) comments/questions about errors or delays in processing changes to the amount of member's spenddown.	Medical expenses such as insurance premiums are allowed to reduce an individual's patient liability to allow the resident the funds to pay this expense. If delays occur in applying an insurance premium, Clearinghouse staff are allowed to process a retro patient liability. This will reduce the liability back to the date the insurance premium was reported.

### Comments

1. My name's Marie and I'm a case manager. An additional problem that I've encountered with people on my caseload is with the KanCare clearinghouse. Several of my folks have obligations. It seems like I assist them and we're sending receipts. If it's a medical expense, their obligation should be lessened by that amount, and it seems like we're just faxing them kind of into a black hole. I don't think my ever since the KanCare clearinghouse happened I've... How do you track it? How do you track what the obligation is? What was used? What was subtracted? What's the balance? I think they're having a hard enough time getting through the applications that this maybe is not high on their priority list. I'm telling you some of my folks, I mean, it's down to the penny for them to get by every month and to have a cut on your obligation is really going to be helpful. They've got a big problem there.
2. First off, I want to tag along with this gentleman right here [gestures] about access to the phone system. My mother received a letter, I'm going on to frail and elderly for a minute here, she received a letter saying... My mother received a letter saying that she was going to be cancelled because she had not turned in her information. This was the end of November; about the time she usually renews. I called and I said, "Have I missed something?" They said, "No, you haven't missed anything. I'm sorry we sent out that letter." In fact, everybody I've ever talked to at the office, everybody I've ever talked to at the office has been very nice. So, I talked to the person and she says, "No she's not going to be cancelled. Go ahead and send in the information." 3

days later, before I could have ever gotten the information, they sent out an award letter saying how much her spenddown was. 3 days later. So I call back and I say, "Do I still need to send this in?" and they say, "Oh yeah, go ahead and send it in." Well anyhow, to make a long story short, since last August she's has had 3 different amounts. I was never notified until November of any of those amounts. The nursing home went on your site and they decided to charge her \$1,300. The amounts have ranged from \$1,300 to \$2,000/month. For a while we were paying \$1,300, now we owe back pay because it's really \$2,000/month now. So we owe back pay because they were going by your site that said how much she was supposed to pay.

<i>Changes to Spenddowns Summary</i>	<b>State Response</b>
There were two (2) comments/questions about spenddown, one about accessing services with a spenddown and the other about eliminating spenddowns in Kansas.	Spenddowns are similar to deductibles in the private health insurance world. One must spend some amount of income on medical expenses before Medicaid will start paying. Spenddown amounts are related to the income limits for various populations in Medicaid. States that do not have spenddowns may have expanded Medicaid or may cover people at higher income limits than Kansas does.

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. I'm a parent. Talking about spenddown, if you had a spenddown, you would no longer get the services. Is that what you're saying?</li> <li>2. I have a question about spenddowns. Many states no longer have spenddowns. We have clients at our mental health center that have extremely large spenddowns. Has there been any discussions about reducing them or eliminating them?</li> </ol>

<i>Division of Assets Summary</i>	<b>State Response</b>
There was one (1) question related to division of assets.	Staff at the KanCare Clearinghouse calculate the division of assets. If the applicant has not heard from the KanCare Clearinghouse, please have them call 1-800-792-4884 to request the status of their application.

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. I helped a family last fall [September 2016] fill out an application for a division of assets. I received an email 2 weeks ago that they had not heard back in regards to the division of assets. The father was in a nursing home; the mother was going to be in the home. My understanding was they were to fill out the KanCare application and they were to send it in and the division of assets would be done. Is that really the process, what do I tell them, is that really the process, and what needs to be done?</li> </ol>

## Managed Care Organizations (MCOs), Service Delivery, & Network Capacity/Adequacy

*There were twenty-nine (29) comments regarding Managed Care Organizations (MCOs), service delivery, and network capacity/adequacy. Seven (7) general MCO comments/questions, two (2) about service delivery, three (3) expressing concern about a potential duplication of services between some work performed by MCO care coordinators and targeted case managers (TCMs), two (2) expressing concerns about a potential conflict of interest when MCOs determining service allocations and pay for services, one (1) related to the cost of value added benefits, two (2) related to MCO oversight, six (6) commenting on care coordination, and six (6) relating to network capacity.*

<i>General Questions/Comments Summary</i>	<b>State Response</b>
<p>There were seven (7) MCO comments/questions. One (1) question related to what the difference is between the MCOs, two (2) were a question and clarification between audience members, one (1) question of whether KDHE would contract with the same MCOs, one (1) question about plans to streamline processes, and two (2) specific questions about the contracts with the MCOs.</p>	<p>KDHE contracts with three MCOs for KanCare services. They all must cover all services we specify in our Medicaid State Plan as well as the services we specify in our 7 HCBS waivers. The two methods which MCOs use to differentiate themselves is through their customer service and in what value-added services they offer. These are services for extra things which KanCare does not cover and for which the State does not pay the MCOs. These services include adult dental cleanings, extra vision services, extra respite services and other things. Each MCO's website details their specific value-added services. The State continues to work with the three MCOs to standardize and streamline processes that they can. The three MCOs currently contracted will continue for the extension year, but a new RFP will be posted for MCOs to bid on in fall 2017. New MCOs may be available after that depending on the proposal evaluation. There will still be just three MCOs.</p>

### Comments

1. I would like to find out what is the difference between the three KanCare managed care organizations (MCOs) – Amerigroup, Sunflower, and United Healthcare. What's the difference between the three?
2. I selected Amerigroup for my KanCare. And then this January, a United Healthcare representative came informed me that I can join United. So now I'm on 2 of them.
3. I don't have a question, just an explanation, about United. The way it works, if your Medicare is with United and your KanCare is with United, then you can join into the new program, it's called United Dual Complete. And that's a totally different program. They give you \$180 every quarter for extra spending for your healthcare. You need to be careful that your primary care provider is in the loop. Your hospital is in the loop. If they are not in the loop, then you are in trouble. It's a good program, but you need to check out a lot of things.
4. Are you considering using the same MCOs? I have a child who's on Medicaid and I work for a physician's office. I understand the frustration here, but people here don't understand the frustration on the physician side. Are you going to use the same MCOs, all 3 of them?
5. Along the lines of communication. The 3 MCOs often have often different requirements, different processes, different procedures and for providers it becomes extremely confusing. What work is being done to improve that?
6. I haven't read in depth the MCO state contract, but I'm curious, is there a cap on the profit they can make?
7. If MCO provides service in a certain month why are they paid? This should be monitored

<i>Service Delivery Summary</i>	<b>State Response</b>
<p>There were two (2) service delivery comments, one (1)</p>	<p>Service complaints should be shared with the respective</p>



<p>related to transportation difficulty and one (1) comment with an opinion about a specific MCO.</p>	<p>MCO through their grievance process, something the State monitors. You need to simply call the MCO and tell them you want to file a grievance about the service issue.</p>
<p><b>Comments</b></p>	
<ol style="list-style-type: none"> <li>1. The problem is transportation. I've had to cancel three of my last 3 appointments, for the last three weeks with my primary care doctor because I can't get a ride to my doctor's appointment. I'm sitting there waiting for a ride, nobody calls me. Access to care is who they use, United Healthcare, and I don't get a call telling me "We don't have a ride for you today". I called in said where's my ride, and they said, "Well we don't have a ride for you". Well what about my doctor's appointment? I've had to cancel the last three Fridays of my doctor's appointments.</li> <li>2. Don't include Sunflower in KanCare 2.0. They are a provider nightmare &amp; do not show willingness to work with the provider.</li> </ol>	
<p><i>Duplication of Service Summary</i></p>	<p><b>State Response</b></p>
<p>There were three (3) comments expressing concern that the overlap of work between some MCO programs and medical services or the work of TCMs and Care Coordinators is a duplication of services.</p>	<p>The State expects the MCOs to provide care coordination to ensure the right service is received at the right time and to avoid care gaps. Care coordinators with the MCOs have specific tasks that are sometimes similar, but not identical to those of targeted case managers. Both the State and the MCO will continue to work to ensure services are not duplicated. The MCOs also offer disease management programs for specific chronic conditions, like COPD, that may be helpful to beneficiaries in managing their chronic conditions. These programs are not the same as a provider working directly with you, but do include education and resources to help beneficiaries understand and participate in the management of their own chronic conditions.</p>
<p><b>Comments</b></p>	
<ol style="list-style-type: none"> <li>1. I'm just wondering if there's anyone here who can answer how the duplicated and triplicate of the paperwork and meetings is not a duplication of services and double dipping. The ISP, it's a person centered plan. We've gone from having 1 or 2 meetings to 4, 6 more meetings a year covering the same things over, and over, and over again. Quite frankly, that has cost providers thousands, upon thousands in administrative costs that could be going to staffing. I'll tell you a lot of reasons that a lot providers aren't here is because they are physically working because we cannot find staff. So how, somebody tell me how is that not a duplication of services and not double dipping into Medicaid?</li> <li>2. I have a question, I'm with Sunflower and I got a letter I think it was for something-something health. It was for respiratory, I can't think of what it was called. Anyway they wanted to set me up on this program. I have COPD, so they wanted to set me up on this program to see if there's anything they can help me with. I already have a respiratory therapist and his nurse. I'm thinking, can't she do the same darn thing that they want me to do through sunflower? Anyway she called me twice now and gives me tips and that and I thought, "Well heck, if KanCare is going to pay for it sure. You can call me up." Then I'm thinking, isn't that kind of double-dipping sort of? Or dual services I guess you could call it?</li> <li>3. Why do MCO provide services that provider can?</li> </ol>	
<p><i>Conflict of Interest Summary</i></p>	<p><b>State Response</b></p>
<p>Two (2) people commented that they see a conflict of interest in MCOs determining service allocations and paying for the services.</p>	<p>In all Medicaid managed care programs that are capitated, at risk, the MCOs manage service authorizations. The MCOs are at financial risk for all health care costs of their members, including physical, behavioral and long-term</p>



	<p>supports and services. They have an incentive to work to keep members as healthy as possible in order not to incur higher costs. This incentive includes providing community-based services that will ensure the member remains as healthy as possible and avoids inpatient admissions and other higher levels of care. In addition to the right to appeal a decision, there is also the right to proceed to a State Fair Hearing, following the MCO appeal.</p>
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<b>Comments</b>	
<p>1. One of my concerns is extraordinary funding. If I’m correct, as of last year, the MCO determines extraordinary funding. Is that still correct? That is a concern of, is there a way have KDADS or KDHE, because they are the holder of the purse, and then they are deciding who divvies up funds? It just seems like a conflict of interest.</p> <p>2. I had a quick question and this is for Mr. Randol [State Medicaid Director]. I guess I’m very concerned about the conflict of interest that I see with the MCOs because they hold the purse strings and they come into our homes to evaluate our individuals and to the home of the parents. They determine the hours. Can you explain to me how that is okay?</p> <p>I believe it is true because they [the MCOs] have the money. We don’t, we cannot determine the hours for people. So they’ve been given all these millions of dollars to decide how they’re going to spend this money and we are sitting there and they’re saying, we’re saying they need so many hours, they need at least, well let’s just say 5, and they’ll say no I think they can get by with 3 and they the ISP for 3. That’s not right. They have the money and they are determining the hours. That is a direct conflict of interest.</p> <p>[In response to Director Randol’s question if the speaker has appealed any reductions in hours on the ISP]. Appeal? Have heard anything? I’m sorry, but if you appeal. I have appealed many things and have gotten denied every time so it’s not worth it to hardly appeal.</p>	

<i>Value Added Benefits Summary</i>	<b>State Response</b>
<p>There was one (1) comment related to the cost of value added benefits.</p>	<p>The State pays nothing in the capitated payments to the MCOs for any of the value-added services. We do require them in the contract to provide value-added services, but the costs of those services are not included in the calculation of the per member per month capitated payments made to the MCOs.</p>

<b>Comments</b>	
<p>1. I’ve got two items I have a question on. On the supplemental things that are added on to KanCare by MCOs. You stated was \$12M a year that Kansas is saving that was free items. Did you state that’s free to the state of Kansas? I’m questioning that. Part of the original contracts, they were requested to provide free services, benefit added services. So they’re being paid indirectly through their contract, because they were issued contracts to provide those services. I don’t see how you can say those are free. If the MCO didn’t have the contract they wouldn’t be providing them at all. I don’t see why you say they’re free when they’re value added with the state contract. It’s an indirect service they’re providing and not charging for.</p>	

<b>MCO Oversight Summary</b>	<b>State Response</b>
<p>There were three (3) comments about MCO oversight, both requesting more oversight of MCOs.</p>	<p>State staff review over 100 monthly reports from the MCOs, performs yearly on-site audits of each MCO, withholds certain amounts of money in the monthly payments to the MCOs which must be earned back through meeting certain outcomes (both quality and operational) – called pay for performance measures – and</p>

meets monthly with each MCO at the leadership level and at the operational level to ensure the MCOs are performing as specified in their contracts. In addition, they are subject to an audit from CMS or the U.S. Department of Health and Human Services Office of the Inspector General at any time. All beneficiaries receiving in home supports should have an emergency back-up plan as part of their plan of care.

**Comments**

1. This is kind of a selfish question, because this came up last year with my brother because he is medically fragile and we basically run an ICU through our home but at a much more affordable rate. So for him and his instance he was approved for extraordinary funding. We got a letter saying he was approved, and the MCO, nothing in writing, but called and came by the house several times and asked for a lot more information. Told us that we had to do a huge amount of hurdles and even came to our house more than once wanting more papers and more forms and more things for him to be approved even though he already was approved; and until I involved the state, and then they radio silence, they gave up they quit. That’s where I feel like the MCOs need a little bit more oversight, because as long as it’s not in writing and you don’t have a voicemail proving that they said something they’re coming to members’ homes and they’re saying things that are not exactly truthful. I think that oversight... they just happened to pick on the wrong person, and now we record everything and we won’t answer the phone unless we have it recorded, because we’ve learned from the care coordinator that her intent was never for the member, it’s for the MCO. A lot of the people that have high cost, they’re looking for ways to cut them. I know that there were some simple things. It’s been an issue of trust for the MCOs, when they have said that they oversee and they’re the ones that... and looking at the verbiage, you’re still having a role and you can still oversee. The state is not just giving them free reign.
2. There is no oversight over the MCOs which I have a problem with that. They actually write the ISPs, and they come into the homes, and they say you need this amount of hours, they are cutting people’s hours, but think if every care coordinator across the whole state of Kansas cuts a few hours from one family and every care coordinator, say they have 100 people, say they have 100 families. Say they cut, you know that is a lot of hours being cut, but to a family, they’re like, “It’s just a few, it’s okay.” No. It’s not okay because they actually need those hours. We’re not asking for hours for families where they don’t need it. We don’t do that.
3. 5. Lack of Emergency or Extraordinary Help/Procedures  
 Currently, there are no procedures in place when there is an emergency.  
 What does a consumer do when they can’t find anyone to work, or agency hire workers fail to show up to work?  
 The consumer is alone and unsafe.  
 What is the process when the consumer does not want to go to the nursing home and has a right not to be, but there are no services available to fill in the gap of services?  
 What happens when a consumer contacts Nursing homes and they say the case is not within their scope of work (or case is too difficult or costly)?  
 What does a consumer do when they know the Nursing homes won’t be able to keep them safe?  
 We have experienced these situations and asked these questions of the MCO and State officials, but no one has provided an answer.

**Solution**

Qualified case managers with access to resources need to be available. It is critical to share of information between agencies, and have access to emergency funds during critical situations.

Paying a going rate, would be the solution because the consumer could retain workers and reduce turnover.

<i>Network Capacity/Adequacy Summary</i>	<b>State Response</b>
There were six (6) network capacity comments. Four (4)	The State must follow federal requirements related to the

<p>stating there is a lack of capacity, one (1) related to retention of staff, and one (1) that MCO provider lists are inaccurate.</p>	<p>managed care network adequacy. The MCOs constantly work to recruit providers, but in some areas of the state – especially frontier areas – this is difficult. The State monitors MCOs’ network adequacy monthly. Certain providers are in low supply for any system, not just KanCare. Kansas does have issues with sufficient dentists and psychiatrists; efforts continue on many fronts to recruit more of both. MCOs are required to keep their network information updated.</p>
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**Comments**

1. In Newton, we don’t get a lot of opportunities. My friend called one of the clinics and they said if you only have KanCare they won’t accept you as a new patient. We get that a lot. We only have 2 places, Axtell clinic and Via Christi and we get that a lot. No we won’t accept KanCare. No we won’t accept Medicaid. I don’t understand why. Or, they’ll say okay if you have Sunflower we’ll accept you but if you have United Healthcare we won’t. Or vice versa among the three and it’s always the one you don’t have is the one they’ll accept.
2. I just find it very interesting that you talked about, the statistics say inpatient has gone down by 23%. Well that’s because they won’t take anybody. The utilization of services. Dental services, KanCare services, good luck finding a dentist or psychiatrist.
3. KanCare doesn’t have updated/correct list of providers (ex: dentist)
4. Provider network improvement
5. VERY difficult to find dentists/psychiatrist
6. Many provider’s have no representation today because admin staff have to cover shifts- CAN’T FIND + RETAIN STAFF

<i>Care Coordination Summary</i>	<b>State Response</b>
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<p>There were six (6) care coordination comments. Four (4) related to lack of coordinated care, one (1) expressed concerns about lack of communication and one (1) related to inconsistencies among MCOs.</p>	<p>To clarify, care coordinators do not work at the eligibility Clearinghouse. Care coordinators work at MCOs and may not get involved in any Medicaid eligibility issue. The primary purpose of care coordination is to ensure the right services are provided at the right time and to help address or prevent gaps in care. The State expects the MCO care coordinators to perform the duties outlined in contract, to avoid duplication of effort, to communicate timely and effectively with providers, and to help the beneficiary access needed care and services. Beneficiaries who experience problems with their care coordinator should access their right to file a grievance with their MCO.</p>
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**Comments**

1. Again we’re going to go back to the care coordinator with the MCOs, which you supervise the MCOs, right? Kind of? You know, they say they don’t know who the care coordinator is. I do know who the care coordinator is on the clients that I serve as provider, in-home provider. But, I get a 47-page fax that tomorrow, this client chose another agency because they can self-direct with a granddaughter. Absolutely no phone calls. They do an annual assessment; I get a 47-page fax. They don’t ask us how are things going. We’re in there 7-days a week for some people, they don’t call. They being the care coordinator, that should be working with the provider to make sure that the services are appropriate in that home. We just get a fax, they change providers and you don’t get a phone call. It’s very frustrating as the provider who sees what’s going on every day and then somebody else making the decision and you have no idea and you think “what’s coming?” and it’s just frustrating. Out of the 3 MCOs, United is the best. They at least talk to us. The others don’t.
2. Okay, it sounds like you’re trying to address that situation to make it a better situation where the care coordinators work together with the individuals. Okay, that’s all I have.

3. The evaluation of care, again this goes with consistency of care and I guess again, if you've got, someone was speaking earlier about care coordinators or somebody out sending out someone a letter for respiratory care and two services being provided by the same organization... Okay my question is why did that even come up, because if that individual case worker or whatever you call that individual is there to re-look at that case and see if what they can do to help that sort of thing, why wasn't she able to say? I'm just saying it should always be, anytime there's a discussion about the individual in the system that person should have a representative, that person be in the room.
4. I'm Kristin Fairbank. A little overwhelmed. I'm trying to figure out where to prioritize, I'll try not to ramble. I want to piggyback on case managers versus care coordinators. I have some pretty big horror stories of the care coordinators failing. One of an individual recently and the battle back and forth. If we didn't have a case manager right now we would not be making any progress. We do have the Ombudsman involved, but the bottom line is that care coordinators work for an MCO and they're very good at shuffling papers, but they're not very good actually helping an individual. I see absolutely no benefit. I see an extraordinary amount of cost with no real benefit. Just going back with the MCO and having high levels of the MCO in this particular case, they did quote the capable person. So, if that is no longer in play the MCO may need reminded of that, because in one of the letters back and forth capable person did come up which wasn't even a part of the topic. So, just so you are aware that is one facet. We also need to be aware of, with the rapid changes in the system over the past few years not everybody gets every memo. Not everybody is aware of every change. Whatever they read last or they heard last, whether it's still in play or not, that's what their base knowledge is and that's how they're going forward. So, sometimes the changes don't reach the individual. So something may have been put out and then changed, but they don't know, so they're operating however they know. I don't know if there is a better way or how that would work. We've always relied on our case managers in the past to be the wealth of knowledge to help the individual understand what is or isn't going on above them and surrounding them. I always kind of view the individual I serve as the ground and all of the stuff above him is all the strings attached and every string has a purpose, some don't, some I think are salaries that don't need to be collected. But sometimes different levels know things that never reach the member until maybe a year later. He had an MCO care coordinator that he hadn't even met for an entire year. We didn't even know they had changed for an entire year, so I think that level needs to be reevaluated. We need to help the case managers be able to do what they do best and then to be able to bill for some of the things they cannot bill for currently right now. I know there's a difference between a targeted case manager or a case manager. Come up with a creative new word, do whatever you need to do to get the do in order to get the funding to follow what the job is because there's a lot of case managers out there especially in the IDD world that are doing things to keep the individual in their home, out of hospitals, simple things that no one else is providing, and they do it because it has to be done. If they don't do it the person's going to fall through the cracks and there's no simpler way to do it. Every case manager is different, there are bad out there too but for the majority they are really good.
5. The other thing I just wanted to point out, another reason I would not be in favor of extending KanCare is because we have seen consistent problems with the MCOs not reaching the same conclusions on very similar if not almost identical scenarios. One quick example that I can give you is I have a person that is with Amerigroup who has a minimum wage job in with, in a school system and works days that the students are in session. I have another person similar situation; they happen to have Sunflower. Amerigroup was willing to give us day supports for compelling and legitimate reasons for the summer, Christmas break, and spring break. Sunflower would only give it to us for the summer, and only if we promised to get that person trained so they could have a second job. It just makes no sense. When we have a process where I'm getting two different answers from two different people who are supposed to be representing the state of Kansas. I'm not for a system that works that way. The other thing is just that, somebody mentioned that we should appeal. I could tell you if you start talking, if you start using the word appeal with one of the MCOs, suddenly the person who is the care coordinator and their boss disappear. They won't negotiate, talk, or interact with you anymore. Suddenly everything has to be on paper and it becomes a negotiation with someone behind the scenes and it's simply just an exchange of paper where you're being asked to re-justify or come up with even better reasons. Then they just simply slide the

piece of paper back that just says no. So the appeal process is not working in KanCare. That is another reason I would not be in favor of continuing it.

6. Coordination, that was a big issue and what you guys got dinged about from CMS and I'm still seeing lots of problems with it. People that have no idea who their care coordinator is, problems of coordination between the different entities involved in providing KanCare services. I'll give you a great example of something that just happened to a consumer of mine. That we had a tough time straightening out. She's on the on QMB program. She got billed for some part B services, when contacting the clearinghouse, they said, "Oh, QMB doesn't cover the part B coinsurance, we only cover copayments". I said, "No, that's wrong. I'm looking here at looking at Medicare.gov that clearly says it does, it always has". They referred me to KMAP, which they tried to tell me the same ridiculous stuff. They told me I had to tell them exactly what the bill was for. So we called back to the hospital to find out what the exact Part B service was. In the meantime, they rebilled it and they said we sent it back and they covered it. That's something that really concerns me because that consumer, I was able to help them because we pursued it and wouldn't take no for an answer. We got it straightened up so she didn't have to pay that bill, but how many other people get that bill and just think, "Oh, I guess I owe it and I pay it." Or they call the clearinghouse and they give them the same "bs" and they're like, "Well hey these guys are the experts I guess they ought to know". That's just one example of where I'm seeing lots of problems with coordination in various areas of the system in which have got to get fixed.

## Home and Community Based Services (HCBS)

*There were ninety-three (93) comments regarding Home and Community Based Services (HCBS) in KanCare. Twenty (20) general comments and questions relating to HCBS services in KanCare, one (1) about delays in accessing Waiver services under KanCare, seven (7) relating to self-directed service, nine (9) relating network capacity comments/questions, seven (7) regarding managed care organizations (MCOs), five (5) regarding reimbursement rates, four (4) reflecting concerns about targeted case management and care coordination being a duplication of service, eleven (11) relating to HCBS policy, five (5) regarding HCBS care coordination, nine (9) concerning waiting lists, five (5) related to service allocation, six (6) relaying a preference to carve the IDD population out of KanCare, and four (4) sharing experiences as HCBS recipients in KanCare.*

<i>General Questions/Comments Summary</i>	<b>State Response</b>
<p>There were twenty (20) general comments and questions related to HCBS services in KanCare, these related to topics such as: Money Follows the Person (2), delays being experienced in accessing Waivers (2), KanCare not helping or creating additional challenges for Waiver recipients (10), making contact with appropriate people when experiencing challenges (1), outcomes for Waivers in KanCare (1), adequately funding/filling surveying positions (2), chemical restraint of elders (1), and one (1) comment “HCBS-Waiver”</p>	<p>The State maintains that care is best coordinated when all services – physical and behavioral health care and long-term services and supports – are managed together so that care is provided holistically. It is committed to continually improving KanCare so that the program works well for all members. Since HCBS waivers are not entitlements, as the services in the Medicaid State Plan are, costs of HCBS can limit how many people will be served on some HCBS waivers. This results in waiting lists. Savings from the KanCare program have been used to significantly reduce waiting lists. The State’s Quality Improvement Strategy, part of the KanCare program, includes numerous outcome measures specifically for people served on HCBS waivers. The State expects that these beneficiaries to receive the same high quality of care as any other KanCare members.</p>

### Comments

1. If I understood you correctly, earlier, I thought I heard you say that KDHE was looking at adding resources that would help individuals access nursing care more expeditiously. I was wondering is KDHE also looking at adding resources to help people avoid nursing home care and use HCBS instead?
2. My question has to do with MFP program which is going to end at the federal level at the end of June. One of our core services that we provide at our center is doing deinstitutionalization and community reintegration. We help a lot of people that are in institutions move back out into the community and we rely on that MFP money to help facilitate that, to get people set up with deposits and all kinds of things that need to set up a new household after they’ve been in an institution for an extended period of time. We need to come up with some way that there’s going to be a guarantee, not just a request or encourage the MCOs, but a guarantee that there’s going to be some kind of money available to help pay for those transitional services in the future when that federal program goes away. How are you going to address that in the extension or renewal?
3. The loss of Money Follows the Person (MFP) may very well be a catastrophic loss of basic liberties and civil rights for institutionalized individuals and those at immanent risk of being institutionalized. The number of individuals transitioning from nursing facilities appears to be less than half of the number from the prior year. Care Coordinators and state program partners often impose special terms and conditions on people seeking to leave institutions, treating community integration as a privilege, not a right. Very few agencies take referrals and provide the hands-on, direct assistance and support to individuals that is necessary to effectuate successful transitions. A significant issue is that an agency must expend its own resources and then pursue reimbursement from the MCOs; a process that is time-consuming and never results in being reimbursed for all of the expenses. These costs must be covered if the twin goals of cost-savings from use of HCBS instead of institutions and increased independence and life-satisfaction for people with disabilities are to be realized.



TILRC is appreciative of the earnest offer of KDADS staff to work on structuring a state MFP program to continue transition efforts post-federal MFP. The plummeting numbers served while there are substantial federal resources is cause for grave concern, however, and indicate there are current problems that must be addressed. In a similar vein, the apparent significant reduction in total financial resources available per capita in the PD Waiver is also of concern and raises a question of correlation between reduced MFP numbers and reduced per capita expenditures.

4. HCBS- Waiver
5. I have a friend who has a son who has a traumatic brain injury (TBI), he's on the KanCare program and he does have home care so he does have someone come into the house in terms of helping. Her concern is these are not trained people and when she has concerns and wants to address what's going on, she feels like there's no one that she can really talk to. So do you have a map of some sort that's available that sort of indicates that this is a person you can talk to and if that doesn't work then go to the next person, and so on?
6. We were promised better outcomes with moving the IDD population into KanCare. Two of those outcomes were more employment for IDD and also address better outcomes for those with dual diagnosis.
7. My name is Ron Fugate. My son 42 years old. He's intellectually, developmentally disabled. For the past 15 months he has resided at Lakemary Center and I'm here today really concerned about a number of things. I think my first concern has to do with KanCare in general. I come from a managed care background. I work for a managed care company. I understand managed care and how it works. I don't dispute any of the numbers that you've presented, because that's typically what happens when managed care comes into operation. Here's what my issue is. My issue is, is that this is a medical model. It does not have a fit with HCBS services. I don't know how a medical model can understand how much support my son needs to get support for his job at Taco Bell. I don't understand how a managed care model would understand the assistance he needs to buy groceries and to prepare meals and to do those other kinds of things that he relies upon to remain active and a participant in his community. So I've got a basic issue with the overall concept.
8. Todd Brennan, I'm a targeted case manager (TCM) and an independent living counselor. I wanted to bring up a few points in my comments to you guys. I think first of all, independent of KanCare, I think we have a real problem with Kansas having an attitude about disabled people and properly serving disabled people. I think KanCare was a mechanism for people who wanted to get out of the business of helping people that needed help. It was a tool to pursue that plan and that approach. So I think first of all, we're constrained by an overall attitude by the state of Kansas and the people that are running the state of Kansas at the moment. That they don't feel that the people that need help should get that help from the state. I think KanCare, whatever you replace it with, is still going to be constrained by that attitude and that approach. I simply say that because actions speak louder than words, both written legislation... The other thing I want to bring up is that what we're really seeing with KanCare, in my opinion, is a failed outsourcing approach. It was chasing dreams and fairytales. We saw a lot of corporations do the same type of thing back in the late 90's and early 00's where they were presented with this fantasy world where I can go to this 3<sup>rd</sup> party who knows more than me, they specialize in this, they're better at that than me, and guess what, they're going to do it at half the price than I am currently incurring. Corporations figured out they were sold a bill of goods and figured out they were getting that savings by making their customers pay for it through a very bad experience. Currently, Kansas is making disabled people pay for these savings through a very bad experience.
9. First of all, thank you for coming here we appreciate that. My name is Randy Clinkscales I'm an elder care attorney here in Hays. I'm past president of the Kansas chapter of National Academy of Elder Law Attorneys, and also a member of the Kansas Elder Law Bar Association. My comments are really about the delays that we're experiencing since the change to KanCare and the centralization of the Medicaid system. Our most vulnerable people are having a much more difficult time getting into the Medicaid system. It used to be when someone came to my office, if we were able to determine if they were Medicaid eligible, we could send them down to DCF or what used to be called Social and Rehabilitation Services and they would meet with a real person who would grab their case and carry them through the system. Now we don't have that, as you know, and so now

with the KanCare system, everything is centralized, as this woman just spoke of. Communication has to be by email, by fax, mail doesn't work, telephone, we're experiencing long delays. We actually in our office, are calling after hours to connect with to actually get ahold of somebody 5 to 7 in the evening. We sent them a list of our pending cases, they usually can return that list to us with a status report, now in the last two to three weeks, we're not even getting that. If there are six hundred cases, a hundred of them must be mine. As an elder care attorney this is what we're experiencing. We're supposed to be getting, under federal law, an answer within 45 days on our Medicaid applications. They're taking months at a time and it's only through our prompting that we're getting answers. Sometimes the delays are so long that in rendering decisions that by the time KanCare gets to it, the information we submitted is now out of date so then, they want updated information before they'll consider an application that was timely filed. Many times, as she has spoken, and this is not just me, this is other elder law attorneys, they can't find information that we submitted, though we have the proof of the fax or the email where it was submitted. Attorneys across the state are running into the same problem. Rarely do you get to talk to the same person, although we have a couple people with KanCare that are trying to be very helpful, I thought that some of them are really trying very hard to be helpful. Contrary to maybe what you said on your slide, we're having more trouble of getting people HCBS. It seems like the program is shutting down. We can no longer tell somebody that they're going to be able to get into HCBS, the dollars may not be there, the personnel may not be there. It used to be, about the same caseload two years ago, we had a person that works three fourths of the day on Medicaid work. Now we're about the same case load, we have two people working full-time on the same number of cases, whether it's new applications or renewals we're running into that problem. The system has become much less user-friendly. The other problem that we're running into is, while a Medicaid application is pending, of course, the nursing home cannot discharge the patient, but that does not mean that other providers have to continue services. So as an example, pharmacists are now turning off providing medications, so we have clients that are not getting medications because Medicaid has not approved the application. So we have families going out and borrowing money to pay for medications because Medicaid is not going back and paying all the way back for medications, even though they were Medicaid eligible, 3-months, 6-months earlier. Many times we have to file an appeal, one week we filed 12 appeals only because Medicaid had not ruled on our Medicaid applications and please understand we're not filing after 45 days, we're filing after they've been on record for months. Then to add insult to injury, we have an appeal pending and then our client dies. Medicaid moved to dismiss the appeal because we have no standing because our client is dead. The appeal has been dismissed. So as a result, then the person left holding the bag is going to be the nursing home. We have fewer nursing home beds in Western Kansas than we did two years ago, and I'm concerned that we're going to have a lot fewer when we have one client waiting on Medicaid application that now owes the nursing home \$40-50,000. A small nursing home, a small privately owned nursing home, a small community nursing home, cannot survive that kind of challenge. I don't represent nursing homes but please understand they can't survive that. It's 70- 80% of their clients are Medicaid people and they are getting that kind of interruption of cash flow. They still have to pay their staff. They still have to pay their nurses, they still have to buy food, and they can't survive in that kind of system. I'm concerned about the clients, I'm concerned about the impact on nursing homes, I'm concerned that if we continue the superization of Medicaid without having local offices that we can deal with directly. So my resolution would be to put the offices back into the public [?]. My concern is we're going to lose nursing homes. We're going to have clients deprived nursing home care. We're going to find more nursing homes that will not willing to take Medicaid clients. If we can't get a client in on private pay, we have nursing homes that are going to say no if the person's not already Medicaid eligible. And I understand, once they're in there and they run out of money, then they can't discharge them if they're a Medicaid facility, but I would think you're going to see more and more nursing homes that are going to refuse to become Medicaid facilities. Finally, I'm concerned that we're going to have clients that aren't going to be provided healthcare just from the cessation of pharmaceutical health or again, not having a place to go.

10. I know this is about me but what about others like me I'm sure there are hadie capes that can or cannot help them selfs that's why they have parents but what about others

**11.** What do you consider the state responsibility to serve special needs individuals in the state of Kansas? It's kind of a broad based question, but what is the state responsibility to a special needs individual? Secondly, for 6 years people have been saying we need to this, we need to do that, and everybody has different opinions depending on where you're coming from. We've discussed a lot of things that people do not care for here. Does the state, or KDADS , or KanCare, have an action plan where they actually reported, or showed how they studied it and said this is the decision and will go with this and populate that out to the people so we know what's going on? A lot of times people feel that they're saying things and not heard and nothings done after the fact. So what is the action plan for KanCare going forward? But first of all, what is the state's responsibility for servicing special needs individuals.

I was actually asking, for the last 6 years there's been meetings after meetings and people have expressed concerns on one topic or another. Sometimes there's results published on the website, sometimes not. How do people know you've actually listened, seriously considered what is being said by people statewide, and then a decision is made yes or no to go with or not go with and why?

**12.** I don't know where all the HCBS clients are going and maybe they're going to the other agencies and that's fine. There's a lot out here that do self-direct, but then you run into problems. Also, they have, who do you hire? When you live in a small town there's a lot of people out there that want a job that they should not be hiring, but they need somebody tomorrow so they do. It's a lot of staff turnover because it just doesn't work out. The reimbursement for the HCBS isn't there. If my client goes into the hospital, that worker doesn't get paid and there's absolutely no benefits. I can't guarantee hours. I'm not a huge home health agency that has another avenue of income coming in, so it's hard to keep good workers. Area Agency had to cut their budget a couple of times in November, before that. I had one worker, they cut her 10 hours a week. Well now when I call her to see if she can pick up a new client, nope, she found a job somewhere else. It makes it very hard to keep people, especially the small towns that are dependable people and that we went to have hired. So, as you roll forward some of the issues that we need addressed out here is: consistency with staffing, being able to pay them a wage that they'll hang on with us; and, care coordinators versus case management.

**13.** The Physical Disability (PD) Waiver continues to serve many individuals in a satisfactory manner. TILRC has received reports of unnecessarily deep cuts to service plans, however. It also appears that based on the current census and the current budget figures for this program, the PD Waiver has had its average per capita costs significantly reduced. For years prior to KanCare's commencing, the average per capita expenditure was about \$22,000 for the PD Waiver. It appears that the average per capita expenditure is now about \$17,000. It is true that averages do not tell the tale of what individual expenditures may be. However, this much of a reduction in overall per capita spending for PD Waiver services causes concern about support for those with the most significant needs. A question must be raised as to whether individuals with high service needs that are over the cost cap are unnecessarily ending up in nursing facilities. This question is of particular concern because national research indicates that working age individuals with physical disabilities are one of the fastest growing cohorts of nursing facility admissions. A related concern is that numbers of individuals transitioning from nursing facilities to their own homes have plummeted. Is the civil right to community integration and independence being compromised by KanCare's cost containment motives?

**14.** During KanCare 1.0, we have learned that managed care simply does not work well with long-term supports and services.

**15.** As a statewide system we have seen increased bureaucracy without the additional benefits promised prior to KanCare 1.0. Two key elements stressed prior to KanCare 1.0 were the assumption that those with I/DD would see increased employment opportunities in the community and have increased access to behavioral health services. Managed care has not brought additional expertise in either of these of areas or even a basic understanding of LTSS.

**16.** Prior to KanCare beginning in Kansas, we expressed our concern and belief that the LTSS for people were not a good fit within the KanCare model. Since then, we have worked to make the best of a difficult situation. I cannot speak to the savings that may have occurred outside the LTSS community services we provide. I can say the IDD – LTSS system today has not been strengthened by KanCare. In fact, it has been made more difficult and the

negative implications are real for both providers and for the individual with IDD. A vital link to these individuals and their ultimate success in the community, is through the supports they are provided by community service providers. The promise that we would have better outcomes and savings under KanCare, 'without any cuts in services or rates paid to Medicaid providers' simply is not accurate. I can appreciate the desire to have every element of Medicaid included in KanCare, however, the LTSS for people with IDD remains the round peg that continues to be forced into a square opening.

17. Adequately fund and fill survey/inspection positions to assure KDADS can achieve its oversight and protection functions for frail elders in nursing facilities within state required timeframes. Provide oversight for KDADS inspection timeliness.
18. Survey/Inspection Deficit – KDADS is lagging 3+ months behind in meeting its statutory requirement to inspect all Kansas nursing homes every 12 months (average). There are 350 nursing facilities and a similar number of assisted type residential care facilities. KDADS is responsible for conducting survey/inspection and for assuring the protection of vulnerable elders in nursing facilities, and for assuring that facilities comply with health, safety and sanitation standards.

KDADS at last report is over three months behind at 15.1 months. KDADS is consistently running multiple vacancies for surveyors in this key unit. KDADS survey unit is underfunded and understaffed and not meeting its health and safety responsibility. The unit has experienced a higher rate of turnover, which results in less experienced surveyors responsible for citing levels of harm to older residents.

Impact: When elders are at risk of harm or are being harmed by abuse, neglect, exploitation and sub-standard care they endure such treatment for three + months longer than if KDADS was meeting its legal requirements. Understaffing of surveyors, puts elders at risk and in harm's way longer, exposing them to substandard care practices for increasingly longer periods of time.

In March 2016, a 91 year old nursing facility resident with dementia was tased by a sheriff's deputy responding to a call by the nursing facility when the resident refused to go to a medical appointment. The man suffered significant distress and died two months later.

Turnover among surveyors results in inexperience to identify and cite areas of deficient practice. Leaving older adults at risk for harm from abuse or substandard care.

19. Chemical Restraint of Elders – Kansas ranks 50<sup>th</sup> worst in the U.S for the inappropriate use of anti-psychotic drugs on older adults. Anti-psychotic drugs are used to chemically restrain elders with dementia. Anti-psychotic drugs carry a black box warning due to the high danger they pose to older adults and even though there is no approved anti-psychotic drug use for treatment of dementia. The State is not providing leadership for a consistent, focused reduction effort, nor effectively using survey tools and penalties to deter use. KanCare reports no reduction in AP use even though it has been a performance health outcome for nursing facility residents since 2014.

Impact: Serious negative health outcomes for older adults include death, stroke, and falls, creating unnecessary pain and suffering for older adults already challenged with a serious health condition. Costs of unnecessary medications, hospitalizations, therapies, surgeries, and other avoidable health care costs increase overall expenses for Medicaid, Medicare and private insurance, and greatly decrease the quality of life for frail elders. Nursing Facilities performance has worsened in comparison to peers in 50 states.

20. The Medicaid HCBS (but not necessarily Kancare) program is necessary and absolutely vital to the livelihood, health, and independence of my son, who has Muscular Dystrophy and utilizes the PD waiver for 24/7 care. It needs to continue.

However, I am not convinced that having it managed by for-profit Managed Care Organizations (MCO's) is the

most efficient and best use of Medicaid dollars. The current HCBS system, while vital, is also failing my son.

<i>Applications &amp; Renewals Summary</i>	<b>State Response</b>
<p>There was one (1) comment about delays in accessing Waiver services under KanCare.</p>	<p>HCBS waiver eligibility actually involves two types of eligibility. The person must be both functionally eligible for HCBS and financially eligible for Medicaid. This results in additional steps in the eligibility process that can add to the time it takes to begin receiving services. The four entities that must be involved –three performing eligibility steps and one completing a needs assessment – all do their best to be as responsive as they can. The State is committed to working to improve this process so that services can begin more quickly.</p>

**Comments**

1. My name is Michelle Morgan. I’m the director for the Area Agency on Aging here in Hays. We’re also the current ADRC contractor for KanCare also. Just to piggyback on a couple of those comments, just some of the things that that we have seen is that for some of these cases you’re right some of them are very unique and very complex and the toll-free number to the clearinghouse works for a lot of people, but there are some cases that are a little bit more needy, if after so many contacts, if maybe they could be sent back out to the local offices or to some local contact for in person assistance. I know that we’ve had some really, really individual cases come up just with waived customers. It’s been very helpful for us to go back to old TCM staff, or now KDHE staff, who can look to see what the real problem is because our Medicaid system is very unique, it takes a long time to learn it and so having those local people is a huge asset and if something could be worked out so there’s more of that available, I think that would be very helpful to people. The other thing too is what he had talked about HCBS services, about the delay. A lot of times that delay is with that Medicaid processing for people to become financially eligible and back in the old days there used to be a thing I’m sure you remember called expedited service delivery. What was great about it is that a lot of these people on waived services, especially seniors when they call for help they need help right now. Not two months later or 6 months later. Many of these people are very frail and they do pass away fairly quickly, unfortunately. Back then providers used to be able to refer somebody for services and at that time the Area Agencies on Aging provided the case management. We had received training from the SRS staff, I think they were still SRS back at that time not DCF, but we were pretty good at determining whether or not somebody most likely was going to qualify and then if they fell into that criteria that looked like they were, we would be able to: go out do the assessment, the plan of care development, get HCBS Services set up, contact the providers, they would get started, and everybody would get paid. It wouldn’t be, “okay let’s get started”, now we’ve got to wait until all of these pieces are intact. It just worked a lot better because it seems like then, we were meeting the needs of people before they hit the crisis level. If we could just get some of that waiver care out a little bit quicker, I think it would be helpful to the people. It was really just more the financial piece of it. Not the rest of it. It was just getting all of the paperwork filed.

<i>Self-Direction Summary</i>	<b>State Response</b>
<p>There were seven (7) comments related to self-directed service, one (1) relaying the challenges a Direct Support Professional experiences, two (2) related to Night Support, two (2) about challenges with Authenticare, and two (2) related to challenges finding and hiring staff.</p>	<p>Kansas is one of many states that uses Electronic Visit Verification (Authenticare) to ensure that in home services are actually provided. This is a best practice recommended for Medicaid programs to help prevent fraud, waste and abuse. CMS required us to restructure our HCBS waiver service from what was called night or sleep support. This has been replaced with a different service designed to help meet the needs of individuals who need some support during their sleeping hours. For</p>



participants who find it difficult to directly hire their own staff through self-direction, there is also an agency-directed option. Increased rates increase expenditures in KanCare and such increased expenditures must be authorized by the Legislature through the state budget process.

**Comments**

1. As a Direct Support Professional for several people using the I/DD waiver, I want to share the difficulty of using my employers well. The pay rate is low & stagnant, the Authenticare system has frequent problems, IADLS on the Authenticare system don't match IADLS on the PCISP, it is incredibly difficult for me to access my own employee hours through the two FMS agencies I have to have accounts with, both of which outsource direct deposit to Global Cash Card- so I need 2 accounts for that, and the gas required to support my employers' right to be out in the community negate the pay. Every single person I work for is looking for more DSW's. Low reimbursement is driving away your providers. KS Should be addressing the lack of providers which is preventing IDD from accessing services. I see families afraid to appeal reductions in fear of worse cuts.
2. The lady that was asking or saying that was having trouble getting quality care in. I can understand that, we've been through that. The thing of it is, is it's up to the families to find somebody to come in to take care of their family member. If they're working and go to work. It's up to the family members to train these people to take care of your loved one. It's really hard to find quality people because the pay is so low so you're getting people that can't go to work anywhere else to come in and be responsible for your loved one while you're out trying to make a living and it's up to you to train them and they have no healthcare experience at all. Then your child isn't getting proper care, turning, changing, so you end up with bed sores and all other kind of problems, pneumonia, so that's not saving you any money. So if you'd have some training and bring up the pay rate that may save you some money to keep people out of the hospital.
3. Being independent, whether you're on the PD waiver or on the working healthy waiver, how can there be practically no night support? I don't, I find myself in a peculiar situation. I don't have a live in attendant now. So what about nights. I'm not as young as we used to be. I'm been told if you're on the PD waiver or the working healthy waiver there's basically is no night support. Well there is but, it isn't even, I don't even understand how they can call that night support.
4. Ok my issue is about being independent [illegible] the on the pd waiver, or working healthy How can there be practically no night support
5. I'm a head of household family member taking care of a disabled family member in the same household. Authenticare is defective. I am forced to clock in 6 and 7 days a week for every day of the days of KanCare. Even though I successfully clock in and out, I still will not be paid and have to argue with financial management services (FMS) when they claim that it's my fault and then admit that it's their fault. Case workers are abusive towards me just to take care of the family member where all I get are pay cuts and threats over the phone. Case workers for Amerigroup used to have caller blocked ID numbers when they used to call and threaten to cut his disability 4 different ways. Resident doctors are afraid to prescribe things that are going to cost Amerigroup any money because they want to want to graduate. There's a thing called Olmstead Supreme Court decision in Georgia where they can't lock up a disabled in a household or in a closet. When you've got to be head of household taking care of a disabled family member, but you've got to clock in 6 and 7 days a week and even still not get paid; how you think you're going to go take a picnic if you've got to clock in 6 and 7 days a week, 10 and 12 hours apart a day, per day, without any vacation or job benefits of any kind. Now I don't even get overtime, but I still have to clock in 6 and 7 days a week and not get paid for it on top of it.
6. Authenticare takes multiple attempts to do what's needed- kicks you out. #8 as a final number makes for problems as you enter codes. #3 makes this the final number but make sure 3 is not in another code. #3 in upper right corner will not be accidentally hit or read and knock you out.
7. 1. Pay Rate



Currently, the pay rate for direct support workers is on average \$9.75 and no higher than \$10.00 with no healthcare or other benefits. The work involves taking care of personal needs including bathing, toileting, changing catheters, cleaning tracheotomy, change ostomy bags, preparing food, feeding, cleaning etc. Basically, everything we take for granted that we can do for ourselves has to be done by caregivers. This pay is extremely low for the type of work, and it is extremely difficult to impossible to find people who will accept this low wage for the responsibilities. I just learned that McDonald's and FedEx pay \$12.00 an hr.

The FMS provider gets an hourly reimbursement rate that has to be used (but barely covers) for unemployment taxes, workers comp insurance, etc.

The pay is not adequate my son can only attract low quality unreliable workers. He experiences high turnover and people who do not show up. He has a high level of need. The job is complex, requiring intelligent people with critical thinking, spatial reasoning, intuition, and other problem solving skills. People with these skills are typically found in educated fields and require higher pay. My son's life, safety, and health are on the line. It's imperative to have high quality reliable workers. It is simply not a competitive rate that is commensurate with the level of importance of the job and the skill required.

My son has been looking for people for two (2) years and has only been able to hire a few people on and off after much effort and turnover. It has become a full time job and nearly impossible to find good people. Time after time people back out before even starting.

The cost of advertising is approximately \$100 a month. We run around town putting ads in coffee shops and grocery stores.

Agencies are having trouble finding and keeping quality people. My son had an agency and they could not keep his shift covered, and when they did the worker wasn't able to proficiently help (it was too much for them). It is a common problem for consumers to deal with agencies that cannot provide qualified reliable people. Keep in mind that when my son does not know when, or if, a person is going to show up, he is alone and in danger. Plus, he has to train every person and with high turnover, it is a constant challenge. I called every agency on the list for his MCO and no one would provide a caregiver for him. The reason is many are not equipped to provide night support and the type of care he needs, and/or they could not find people to do the work.

These dedicated caregivers deserve and require a competitive pay. According to this comprehensive study by Genworth 2015 Cost of Care Survey, the going rate in Kansas is between \$14 and \$25 and hour. <https://www.homehealthcareagencies.com/resources/home-health-care-costs/>. Keep in mind that encouraging people to live independently and out of nursing homes is much more cost effective. The care is better and consistent when the rate is competitive.

**Solution**

Increase pay to compare with going market rate. And do a financial study on the cost of care givers who work in Nursing Homes providing comparative care. Include benefits and the profit the Homes/Institutions receive. In the past, these studies show it is more cost effective to allow individuals to stay in their own environment.

<i>Network Capacity Summary</i>	<b>State Response</b>
<p>There were nine (9) network capacity comments/questions. Nine (7) expressed concern about a lack of providers and capacity, one (1) related to difficulty finding staff, and one (1) expressing concern that there aren't enough minimum qualifications necessary to become a provider.</p>	<p>The State reviews network adequacy reports from the MCOs on a regular basis and is committed to ensuring that there are sufficient providers to serve KanCare members. State staff are currently working to review, understand and implement new federal managed care regulations specifically addressing network adequacy. The State will continue to hold the MCOs accountable for the adequacy of their provider networks.</p>

**Comments**

1. We have a very limited opportunity to connect with our providers. There is no one able to establish a business and keep it going in our area. My daughter, living in Newton, Kansas, has her independent living counselor coming from Ottawa, Kansas. I know of someone else who is using an agency in Kansas City. That is very difficult to get your care. My daughter is part of Amerigroup. Her transportation is ordered out of St. Louis. Why are we outsourcing? Why is the state of Kansas allowing outsourcing if we're so short on jobs? Why is the KanCare system and Governor Brownback not pushing for more money for these individuals who are care providers so that care organizations at the affiliates of community developmental disability organizations (CDDOs) or affiliates of a working healthy program can continue to stay in business. One of their biggest problems is they get staff, they can't give them a raise, they can't hire people at the right rate; and so those workers walk away and we're left with no one to provide services for individuals who need personal assistant services (PAS) or other services. What is Kansas going to do about that? We're leaving these people out here without services.
2. I really appreciate you coming out here to Western Kansas. I know it's a long trip, four or so hours. I lived in Topeka for five years, I went to Washburn for Law School, I know the distance. The problem I see with the extension is that the provider networks are inadequate. There's a girl [name redacted since not the speaker], for example, she has to go to Wichita to even get something done for her, or garden city, dodge city, liberal to provide services to her. Another issue with the HCBS waiver system is that again the capable person rule needs to be changed. I mean that's just ridiculous. You know what the capable person rule is don't you? You know how hard it is get services on HCBS when you know they don't have, if you guys don't pay very much money for the services. So, the providers don't get, the people in services don't a ton of money, number one. The employees, the people who are providing services don't get enough money. Then number two, on the topic of service providers, they don't have an understanding of what's going on. I mean when we deal with Sunflower or Amerigroup or whatever, they often times don't have an understanding of how hard it is to get people out here in rural Western Kansas. It's hard to find people to provide service out here. You need to up the wages for people who are providing services of the waivers in general because \$10 an hour is not enough. It's just not enough. Nobody wants to work for those kinds of wages. Another thing is the number of hours that people gets on HCBS. She has around 200 hours a month in services in the HCBS program, but under KanCare her hours were cut and cut and cut. She'll tell you how they were cut to as low as 145 hours a month. I know that there's been problems with the state budget and cuts and reduced staffing. I know that we've had some problems with services because of coordination of services is complex and I understand that, but for God's sake could you guys just change the rules for capable person. You guys have the waiver. I don't see why you can't change the rules for capable person. Is it a federal rule? The problem is that we have people who needs services now. I know that there are things you can do. There are administrative laws that people that waivers can get temporary exceptions you can get under the program; I don't know if under HCBS or under Medicaid you could get a temporary exception put in. What I'm saying is there's got to be a way to allow people to have services in their home with a primary caregiver or family member. That's the problem we don't have enough caregivers out here and the caregivers that we have often times we don't want to be cared for by that person. You don't want to be cared for by a person with felonies, you don't want to be cared for by somebody who has problems with... one time we had someone taking care of [participant name redacted since they are not the speaker], we didn't know about it, but this woman was cited for Medicaid fraud in another state, I mean come on... if we don't have the money to pay providers and the people who do the services, then you aren't going to get the services.
3. Our son is served on the IDD waiver and what we're seeing is problems with access to services because of Brownback's reimbursement rate cuts and also because reimbursement rates haven't been increased in almost a decade. It's very hard to find someone to do sedation dentistry for our son, which needs to be done to stay healthy, or even to go to behavioral health therapies. So, the problems that we're having is finding providers. When I talk to numerous office managers, they say it's because of lower reimbursement rates and burdensome paperwork.
4. If your job is to support the IDD waiver, then how do you purpose to move forward with the extension and address the real issues with the IDD waiver such as capacity of providers, dentists, psychiatrists, and licensing?

5. I've got to tell you, I sat with someone this week who just got her license to do day and residential services. She did her policies, procedures, came up with some antiquated forms and got her license and now she's out there with the wolves. I feel so bad for her because this is the same stuff that we saw years ago. You've got to address capacity, you've got to look at the providers that have been in these services for a long, long, long time that know what they're doing and talk about rates for them. Talk about rate increases instead of letting some beautiful young lady come out there with a license that doesn't what the hell she's going to do with it. She doesn't. She's doesn't. She didn't even know she had to credential. She didn't even know she had to go to KMAP. She doesn't know how to bill, and she's got a license. Wow.
6. Second issue is there's a lack of providers. I've tried to find a psychiatrist for my daughter and can't find one and finally found a nurse practitioner and she left and now doesn't take Medicaid. I'm back where I started. I can't even imagine how people in western Kansas do it because I live in a metropolitan area and I can't find one. So I think something needs to be done about that.
7. I heard you say in your initial introduction you're a finance guy, or somehow involved in finance. I just want to echo the woman's comment over here. Kansas could find themselves in a real jam because it's really only the lack of residential capacity and parental guilt that's keeping people from leaving their homes and going into residential providers because of the hours cut. Just something to consider you could wind up finding yourself where you're actually motivating people to push their children out their home and into res provider situation therefore costing the state of Kansas more money.
8. NETWORK: Currently, we have anecdotal evidence that the HCBS provider network is struggling to remain financially solvent. Reports from KanCare recipients and their family members report problems with finding providers, difficulty with the application process and reductions to their care plans.
9. We also have serious concerns about the strength of the provider network to support additional changes, particularly within home and community-based services (HCBS) providers. The State has not yet provided any data to demonstrate that the health care and HCBS networks are able to meet the expectations of the KanCare demonstration project.

<i>MCO Questions/Comments Summary</i>	<b>State Response</b>
<p>There were seven (7) MCO related comments/questions. Two (2) concerns from parents related to MCO concerns, one (1) related to capacity and provider directories being inaccurate, one (1) related to the waiting list, one (1) concerning MCO referrals to community disability resource organizations, one (1) relating to MCO billing, and one (1) expressing preference to a single source MCO for IDD Waiver recipients.</p>	<p>Please refer to the response above concerning provider network adequacy. Every member of KanCare has the right to file a grievance or appeal. In addition, MCOs are required to maintain a Member Advisory Committee to provide direct input from members about improving customer service and other issues. The federal government requires that Medicaid beneficiaries in managed care programs must have a choice of at least two managed care organizations, so the State could not limit IDD members to a single MCO.</p>

**Comments**

1. I would be interested in seeing the MCO network adequacy reports. The MCO provider directories are not accurate- providers are listed for services they don't provide. I wonder if there is a better way for the state to monitor capacity? Big, big issue impacting capacity is rates. Might have provider agencies but if can't get staff, there's not capacity. Particular areas of shortage are Personal Care Services & overnight services. Are the MCO network adequacy reports public record? How does the state ensure these reports are accurate?
2. Kansas needs to explore a single source payor for IDD services- since Sunflower holds the majority of the members lives- move this direction. It will simplify the process for providers and members.
3. My name is Marilyn Kubler. I'm a parent of a daughter who lives on her own in an apartment and with providers. I'm also a director of an agency, a case management agency, have been for 20 years. I guess the first thing I would like to say is that hope that the extension doesn't get renewed and I hope that going down the road we can carve out KanCare from the MCOs. But my main comment that I wanted to make today is that the waiting list is still 7 years long for IDD. When KanCare was implemented, we were told the waiting list would go down

because this program was more efficient. You have said that we have not had to spend \$1.4B, you said that we've saved \$1.4B by bringing in the insurance companies. Yet the insurance companies profited by \$40M this year on the backs of our most vulnerable people. That \$40M could have been used to take people off of the waiting list. So it seems to me that the only people that really profited from this program have been the stakeholders of these 3 MCOs while our people with disabilities are still waiting at home for services.

4. I'm a parent. I have a few comments in general to say about the situation. I felt that the IDD system worked really well before the MCOs came into being. I see a cash flow problem with the MCOs because the money is not getting to our individuals. Money is not getting to the people; it's getting to the MCOs. There's a conflict of interest in the MCOs deciding services and holding the purse strings. Who gets what moneys, how the money is spent without oversight. So those are my concerns and I'm thinking we need to look again at taking IDD out of the system.
5. I have a couple of issues. One I just have an example of how the MCOs aren't really set up for the IDD population. As a parent I am the guardian of a 24-year-old with developmental disabilities. I have faxed guardianship papers 4 separate times to four different people that I have talked to at United Healthcare because they won't talk to me because I'm not my daughter. So, if I'm in a hurry I've learned that I just need to lie and just say I'm my daughter when I'm on the phone because how do they know, but it's just ridiculous that they can't have some sort of a computer system that when they pull up my daughter's file they see that they have the guardianship papers and they talk to me. They don't even understand dealing with guardians.
6. The lack of referrals from MCOs to community disability organizations such as CILs remains problematic. Topeka Independent Living Resource Center (TILRC) is uniquely situated to assist KanCare consumers with all types of disabilities and of all ages. As a federally funded Center for Independent Living (CIL), it provides assistance with skills building, with learning self care, with locating and securing housing or transportation, with assistance transitioning from a nursing facility or other institution and much more. Despite all of this, referrals to our CIL from KanCare Care Coordinators for these types of traditional CIL services remain practically nil. Care Coordination as it pertains to person-centered HCBS needs to increase interaction with community agencies such as CILs.
7. As a provider, we have worked diligently to navigate the KanCare system and work with each of the three MCOs. To claim that KanCare has improved our system, I cannot say so in good conscience. We've had workers in the MCO system who have been very helpful but overall, working in this system has generally been a frustrating effort. Our billing challenges emerged right out of the chute in 2013 and one would think by 2017, things would be running smoothly. Unfortunately that is not the case. Billing challenges were encountered, were followed up on with the MCOs, and thought to be resolved. Then later, what previously worked, for some unknown reason would no longer work and the process repeats. The billing issue du jour appears to be an on-going battle where providers are required to continually expend time and effort to correct or contest claims as they come through the KanCare/MCO system.

<i>Provider Rate/Reimbursement Summary</i>	<b>State Response</b>
<p>There were five (5) comments/questions related to reimbursement rates. Three (3) related to rates being inadequate, one (1) question regarding when the results of a recent rate study would be shared, one (1) related to difficulty accessing IDD Respite services.</p>	<p>MCOs are required to pay providers at least the rate being paid in the fee for services program, of which HCBS was a part, prior to the implementation of KanCare. Funds for the KanCare program are allocated by the Kansas Legislature, which must pass a balanced budget and cannot deficit spend.</p>
<b>Comments</b>	
<ol style="list-style-type: none"> <li>1. HCBS providers were asked to give financial information so that the state could use an agency to see if providers reimbursement were adequate b/c no raise for so long. When will that results be shared w/ those who submitted?</li> <li>2. Please evaluate the Personal Care Services rate across Waivers. I cannot understand if the service is defined the same or is the same work, why would the rates differ across waivers? The IDD rate for PCS or what has historically been referred to as supportive home care has not seen a rate increase for many many years. System</li> </ol>	

capacity is declining rapidly due to inadequate rates & is or soon will be a crisis to the IDD system.

3. The added benefits for the IDD waiver, you know they're great except that nobody can find respite because the FMS providers won't bill that direction. They don't bill through insurance companies, they bill through Medicaid and an added benefit is not how they bill. So what we find is even though our families are told you can have overnight respite, or whatever the term is at that time, you can't bill it through your FMS provider. You have to bill it through insurance, and that is one more thing that our families don't need to deal with.
4. I've been a provider for HCBS services for 21 years. Prior to that I was an SRS employee as a case manager for the HCBS program. I don't see it getting better with KanCare. One of the issues that I see, we used to have case managers and I think they were contracted through the Area Agency on Aging. Those people knew what was going on in that home; they knew the provider, they knew the worker, they knew scheduling, and all of that. Now we have care coordinators out of the 3 MCOs. You call them and say I need some help finding this resource or this person, and they say, "Well I'll send them a phone number." Well, I wouldn't have called them had the person been able to, by them self, make that call. So, we're losing some of that consistency of care. You know care coordinators are good, but they're doing HCBS, they're doing all the waivers, they're doing nursing homes. You know, how much time can they really give to that HCBS person that's in the home? The extension, I'm glad you're going to get an extension so we don't fall flat on our face out here. You know, 21 years in this, in 2011, I know the system very well. I cover northwest Kansas. So, if I have a little tiny town, Brewster, Kansas, and I have somebody who needs 8 hours. I go to Brewster and I find somebody that can jump through my hoops as an employee, pass criminal background checks through the KBI, and usually within a couple of weeks can get that person services. That's not happening anymore. 2011 with a really good year for my business. We are down 60% since KanCare started. Per the referrals, I got something in the mail a couple of days ago that says, okay now starting July 1<sup>st</sup> I have to do 5 background checks with 4 different companies or agencies. I did myself yesterday. The only record I could get was my record from the DMV. I don't have any speeding tickets. \$8.70. Three of the other ones cost. I do the PD waiver. We get paid \$13.08 an hour as my agency. \$13.08 an hour. I have not had a raise for years. I pay my workers a couple of bucks above minimum wage, but the business still has to cover the business expenses: workman's comp, liability insurance, there's absolutely nothing for travel. Northwest Kansas if you want a job you're going to go where that job is. You know there's no reimbursement for that drive time. After the extension, hopefully when you're renewing the contracts, we need more money. I don't know where your committees come from but I want, so somebody out in western Kansas that's saying what our needs are out here. I understand they can do an HCBS client in Topeka. You walk into the housing and 8 of your clients are right there and at the end of the day you walk out. My clients might be 20 miles away and we might get two in a day just because of where they're at, and reimbursement is just really poor. The national average for just someone to go in and clean your house is \$16 an hour. That's the national average, that's what came up on the Kansas stuff. We're working \$2-\$3 less an hour for an agency to provide a worker than what they can go out and privately get. It gets very frustrating.
5. First of all, I do work with an FMS. We do work with all of the populations. So, I would say there are some significant failings for all of the populations. Our greatest experience, in the numbers we serve, is IDD so I'll speak specifically to that. But at the same time, the clearinghouse does not work properly. People are not being found eligible when they should have been eligible all along. The authorizations are supposed to be pre-authorizations. We are supposed to have them prior to that individual start date. That doesn't happen. Every month we chase them down. The expense for the change in the system has fallen on the individuals. It's fallen on the agencies, the targeted case managers, the families, the people who are not getting the services that they used to. In regards to the value added benefit, that was something that, yes, the MCOs did. Yes, that could be a great benefit for those people who have been approved for those services and their families, but the reality is the expense of that again falls on the other agencies. The systems are not there to bill through the state system. Through Authenticare. That's all separate. It's all manual. It's all outside of the of the \$115 we get. The \$115, the Authenticare system. Everything was supposed to be easier, smoother, less time. We had to add more staff. It doesn't begin to cover it. Every time there are new layers, new background checks that now need to be done every couple years. That's an additional expense; we have to pay for that. Again, paying these individuals the



small amount of money they are to do this kind of work, it's very difficult. You just can't keep them. So then we go through this over and over again. The expense for this has fallen on the agencies, again the people who are trying to provide the service. One particular MCO has done a lot more with capable person. A lot of those individuals have had a significant reduction in the hours that that individual family member had in the past. There's just a lot of issues in the system and doesn't feel like they're being addressed nor do we have any control. Thank you.

<i>Duplication of Service Summary</i>	<b>State Response</b>
<p>There were four (4) comments/questions related to duplication of service, all expressed concern about overlap between Targeted Case Management and Care Coordination and that this creates redundancy in the HCBS system.</p>	<p>MCO Care Coordination is designed to encompass case management; disease management; and, discharge and transition planning. The State requires MCOs to maintain a care management program for members with complex medical and/or behavioral health needs. While targeted case managers provide much assistance to the two populations they serve in KanCare, they cannot see all the physical and behavioral health care provided to a members, nor can they quickly identify gaps in these services to ensure they are met. Targeted case management and care coordination as provided by MCOs are defined differently by the federal government and are not duplicative services.</p>

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. MCOs duplicating what is already done by HCBS TCMS!</li> <li>2. How is ISP/PCP not a duplication of services and double dipping?</li> <li>3. Changes in care coordinators. We have been, between the three organizations, through any number of changes in care coordinators. Our families, the only place they can go is to us because we're the only ones that stick with them, that know them; that understand their problems, their disabilities, their concerns. We have nurses who are working with children with maybe emotional disturbance and autism, and they don't know about autism. They don't begin to understand that. So you are talking about us as targeted case managers (TCMs) dong a whole lot of training two times a year. The BASIS assessment when we invite the care coordinators in and their 6-month visit. They then supposedly know everything there is to know about the individuals that we see monthly if not more often. It's not fair to our individuals to not have somebody that knows who they are.</li> <li>4. Let's talk about the redundancy of the paperwork for the case managers and the care coordinators. You know there's two of us doing the same job. It's not necessary. I'd like to keep my job because the only thing a care coordinator does is come out and do the same thing that the targeted case manager does, but they've got a 42-page document now instead of a 9-page document. The KanCare clearinghouse. The case managers always knew how, they were always able to put their finger on the pulse with their clients with their Medicaid applications, with their obligations, with their plan of cares. We were able to speak to all those things. Now we can't even find out what their status is in Medicaid. We don't even know if they're in the 3-year redetermination, 1-year. Are they closed? What their obligation is? We don't know.</li> </ol>

<i>HCBS Policy Summary</i>	<b>State Response</b>
<p>There were eleven (11) questions/comments related to HCBS policy. Five (5) related to coordination and communication between the state, providers, and MCOs, two (2) related to concerns about the capable person policy, one (1) related to the Crisis Exception policy, one (1) related to the Background Check policy, one (1) related to providing training funds to participants, and one (1) related to the status of the Shared Living policy</p>	<p>To ensure safety and to help prevent fraud waste and abuse, background checks for staff who serve vulnerable populations are important. We agree that training staff is important; unfortunately, federal Medicaid funds, through provider reimbursement rates, cannot be used directly for training. Crisis exceptions are just that - exceptions for people who are in crisis, so there must be some documentation that supports the need for an exception. Any concerns about how a provider of IDD services is</p>



performing should be raised with KDADS so that staff there can investigate the issue.

**Comments**

1. The crisis request and exception process. Help us with that. I mean, it's so stringent. We've got folks out there that don't meet the state's definition of crisis but they need funding so they don't have to go into institutions or PTRFs; or, when they do come out we can get them personal care services inside their home. Now, with the new regulations that came out in January, we've got to have police reports. We've got to have them doing dangerous things. So, I've been working with someone for months trying to get a crisis request and it's ridiculous. This poor guy. I'm just shaking my head.
2. Some of the families on my caseload are caring for their adult child at their home. As a case manager, I've witnessed the most amazing selflessness that these folks have gone through for years, and years, and years. I'm talking total support. It seems like there's this bias and I don't know if it's with KanCare or with the state that these parents should not be getting reimbursed for caring for their adult child. I would like to see some of these guys higher up trade places for 24-hours with some of the sacrifices these families have made. It's like phenomenal. It's amazing. I've never seen such saints in my life. For them to have hours taken away because it's an IADL. You know, come on. The state is like shooting themselves in the foot because there're going to make it so difficult for these families that they're going to have to have residential care, and of course we don't have any residential care openings because of that capacity issue. That's going to cost the state lots and lots more money. They really need to think about this. It's wrong.
3. Capable person rule
4. You say that KDADS and KDHE are working on things. It seems to me like the MCOs are giving out information that's in conflict with KDADS. Sometimes they're giving information out ahead of time that we find out from KDADS is not necessarily true. Is KDADS or KDHE trying to talk to the MCOs and say, "Hey wait a minute here. Let's talk about this before you send this information out." Because it's very confusing, especially on the provider side. I can't imagine what it's like confusing the people actually receiving the services.
5. Ex. Recent Amerigroup memo on background check policy directly conflicts w/ 1/24/17 "memo" from KDADS staff. Background check policy not available on KDADS or KDHE website yet providers are expected to follow it.
6. Your answer to my question earlier about policies having the state and the MCOs logos on there. Why should the MCOs logos be on State policies? CDDOs are contractors also. We have to enforce certain things and we don't get to put our logos on state policies.
7. Why do the MCOs have to notify the community of the policies? Why can't they come straight from KDADS that way we are told officially because we were told several years ago, providers, the state has to make the policies not contractors?
8. There seems to be a disconnect between policies that KDADS are putting out and the interpretive guidelines from the MCO's this needs to be addressed and the memos from the MCO's should correspond w/ the policies.
9. There has been a freeze on the shared living model until a manual of policies & procedures is adopted. There has been a draft manual for about 2 yrs. I wish you would get a manual so other agencies can do shared living. I had a problem with an agency that does shared living & was told by the CDDO that the agency could do what they wanted because there were no rules adopted.
10. 2. Background Checks  
In addition to a Kansas Bureau of Investigation (KBI) criminal check, it is now (since January 1st, 2017) required to also have Department of Children and Families (DCF) Adult Abuse and Neglect and Child Abuse and neglect registry checks done, as well as some other checks. These DCF checks create an undue burden on both the consumer and FMS financially.

The KBI check is immediate.

The DCF checks take up to three (3) weeks each. It is a manual process that has proven to be unnecessary and inefficient. The DCF check is based on an internal investigation and may not result in the person being charged

with a crime. The law says a person with a criminal background cannot receive funds from the Kansas taxpayer. Therefore, if a person who is investigated, and not charged with a crime, should be free to be hired. When a person is investigated, and charged with a crime, the KBI check identifies the person. The three (3) week delay is extremely limiting as many potential hires find higher paying jobs while waiting. Many workers are out of work and need to start working immediately, and will take another job. It is important to start the working relationship as soon as possible. Plus, he is usually short of workers, and needs them to start immediately. He has no one otherwise. Waiting means he doesn't know if they will be available once the background check comes back, and has to start the process over. His disability does not go away while these checks are taking place and he is left without care. This is dangerous and a threat to his life.

Currently, these background checks are mandatory, and there is no way for him to refuse/waive any checks. And there is no procedure in place to be able to hire someone on a "conditional" basis until the background check comes back.

The State is charging the Financial Management Service (FMS) providers for every background check. FMS receives \$115 a month per consumer to cover all costs related to services provided. Some FMS providers are passing the background check fees onto the consumer at, my son was asked to pay \$35 per background check (this is not the full price of the check). My son has experienced hiring three (3) or more people in a month, and had to have more background checks ordered when people drop-out/change-mind and/or do not show up for work after accepting the job and filling out paperwork. People are finding other employment during the three week wait period. Some FMS pass the cost on to the employee and reduce their first paycheck. The scope of work for FMS involves administering extremely rigorous payroll rules, (extensive new hire package) imposed by the State of Kansas, and comply with IRS requirements etc. Processing pay checks for up to eight people when my son is fully staffed is part of the expenses of the \$115 monthly reimbursement. This is prohibitive to conducting business and many FMS have gone out of business. Due to the high turnover in employees these companies loose money in this process. This caused my son to have to change payroll agency several times, and adds to an already stressful lifestyle.

**Solution**

One, create a system where background checks provide immediate results.

And Secondly, if the DCF background check is not considered unconstitutional and/or violates privacy act, require the potential employee sign a waiver for any pay received if the background check comes back negative. This would weed out potential employees who know they have a record, and allow for the consumer to have their daily needs met. In the case of my son, these are life sustaining needs.

**11. 4. Training**

Training (specific to the consumer) for workers is extremely important, yet unpaid. A current worker needs to be able to train the new worker; therefore the current worker is the one being paid. This is very specific to the consumer's needs, not generalized training. For my son, it takes between 3 to 10 hrs (depending on the person's ability to learn) of training to get someone proficient in helping him.

Currently my son asks new hires to complete training unpaid. According to Federal Law, he should be paying for training. However, he has no choice, as he can not possibly pay for training all incoming hires, especially when there is such high turnover and lack of retention due to low wages (see section 1 above.)

**Solution**

Provide funds to access for training. This puts the burden of prohibitive laws and restrictive regulations on the State not the consumer and worker.

<i>HCBS Care Coordination Summary</i>	<b>State Response</b>
There were five (5) comments related to care	The State is continuing to have conversations with the

<p>coordination, all expressing concern about turnover, redundancy, lack of flexibility, and that care coordinators asked people to sign blank or incomplete forms.</p>	<p>MCOs about care coordination turnover and the steps they are taking to improve care coordinator turnover rates. Signing blank or incomplete forms is not acceptable and this issue is addressed in the State’s corrective action plan submitted to CMS on 2.17.17.</p>
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**Comments**

1. Now I think the other thing is that I’m a proud member of an organization called Families for KanCare Reform. We conducted or commission study that was done among targeted case managers (TCMs) throughout the state of Kansas in early December. The feedback that we had from that survey basically validates what we have experienced as parents. The high turnover rates that occur among care coordinators that have resulted in poor service. Some of the numbers I can tell is, for examples, we had half of the respondents said that between 6 and 14 of their clients had different care coordinators during the year. 4/10 of these targeted case managers (TCMs) said they did not know the care coordinators (CCs) that were assigned to their case, caseloads. Nearly half of the targeted case managers (TCMs) said care coordinators (CCs) do not show up at meetings. We said that between 4 and 10 of the targeted case managers (TCMs) said their care coordinators (CC) had asked their clients or authorized representatives to sign blank integrated service plans (ISPs) or other documents to be filled out at a later date. That is not quality by anyone’s measure. So, those are my concerns and I just wanted to have the opportunity to share them here. If there’s anyone in this room that would like to become part of Families for KanCare Reform come and talk to me after this meeting, thank you.
2. The other thing I want to talk about is the low quality of experience that my families are getting because of KanCare. One because of the constant turnover of the care coordinators. That’s a very big source of frustration for my clients and their families to be dealing with a new person at least once a year, sometimes multiple times a year. Also it’s very frustrating these care coordinators come in with a very low level of understanding of the IDD population and how to interact with them and their families. A lot of times we’re dealing with nurses. They’re equipped to come in and help an elderly person interact with elderly persons not with a 30-year-old person that has a cognitive impairment. The other thing that I want to say is I just had a client bend my ear for 30 minutes after a combined BASIS and ISP meeting and I had to explain to her, comfort her, or just listen to her vent about the fact that she has to have this stranger come into her house and ask her these uncomfortable questions. Now we’re used to the BASIS people but now we’ve got this revolving door of care coordinators coming into these people’s lives and it doesn’t sit well with a lot of these folks that we serve to new faces coming in, and new faces that come in and treat the situation very much like a clinical situation. Like there’s not a human being with feeling and emotions on the other end of all these questions and at the other end of this experience. They come into it very clinical, just kind of treating it like a tumor that you would talk about in the 3<sup>rd</sup> person versus a live human being that we’re interacting with and talking about live and asking questions of on a live basis. So I feel like really, at the end of the day, KanCare was very much about the appearance of doing things, the appearance of checking boxes. It is very much lacking the substance of doing things, very much lacking the substance of providing a quality experience, because I feel like again the overall umbrella we’re up against is a state that doesn’t want to help people that need help. KanCare has been a very effective tool at making sure people cannot access that help and I really hate to see us renew it, but I feel like we’re just equipping a very bad attitude by our state at the moment.
3. I’m the parent of 29-year-old on the IDD waiver who also has complex medical needs. I’m also a physician so I also have a unique perspective on the quality of the care coordinators and the MCOs and the service they’re providing. We are now on our third MCO for my son. With the last MCO, we had five care coordinators in one year. I didn’t even know who the last two were. The only time the most recent one appeared was at a meeting because the I’s had to be dotted and the T’s crossed. She knew nothing about my son. The only thing they know about my son is from the 4-page report I hand to every person that has anything to do with him that details his medical, physical, developmental, diagnosis, and needs. So, from my perspective, there’s nothing about the MCOs that have been of any benefit to my son, and obviously we’ve have to change 3 times. We’ll see if the 3<sup>rd</sup> time we get any better care coordination. I don’t feel the care coordinators have any medical knowledge, or I

don't know what their training is, but it appears to me to be next to none. So even when provided the information, I don't think they even know how to interpret it; or what it means for his quality of life, what it means for his long-term healthcare needs, long-term disability needs. They don't have a fund of knowledge that is any way is helpful to this population. His case manager, who has known him for over 8 years, or 10 years, or I don't know – I've lost track. She does, because she's lived it with us for that long. I think there is a huge redundancy with the care coordinators and the case managers. Our population is much better served with the case managers.

4. Inadequate care coordination also remains an issue for HCBS within KanCare. TILRC continues to receive reports that consumers do not know their care coordinator, that any contact with a Care Coordinator is infrequent, and that there is too much turn-over. Coordination of HCBS for many consumers necessitates more frequent contact and assistance than is currently the case with KanCare. After all, living a full, rewarding, person-centered life is the point of HCBS. Too much emphasis appears to occur around health-related appointments and needs. The heart of person-centered planning and service delivery is concerted efforts toward making all of an individual's goals and dreams in life a reality. Otherwise, "person-centered" becomes just another piece of current jargon. The Care Coordinator should be the hub around which revolves a host of community supports, services and events that may interest a given individual.

5. 3. Lack of Flexibility

Every time a consumer makes a change in hours between Agency hire and Direct hire workers, the Individual Service Plan (ISP) has to be changed. They have to provide the exact hours the Agency will provide vs. Self Direct hours. When the agency fails to send someone and the consumer's direct hire person works as emergency back up, the direct hire cannot be paid. In situations where a direct hire worker leaves or the situation changes suddenly, the agency cannot take on those hours without a change in the plan. The MCO requests a week notice to make the changes. The case manager has to make the changes in the system as well as all the paperwork, which has to be faxed to the agency and the FMS provider. It has to show up in the Authenticare system first. This lag in time is a hardship and could cost lives. It has been my son's experience with several agencies that they take their time in responding, then sending someone out for intake, and finding people for your case which has taken three or more weeks.

Possible Solutions

- Provide accessible case managers/social workers with knowledge of healthcare industry and needs of consumers, not corporate data managers.
- Require MCO's to vet and monitor the Agencies that sign on to provide caregivers. The system has to become more responsive either via electronic means or emergency practices in place.
- Allow consumer hours to be interchangeable between self-direct and agency direct. As long as no more hours are billed than what the consumer has on his plan, then it shouldn't matter which agency(s) or FMS provider bill.

*Wait List Summary*

There were nine (9) comments about the waiting lists. Five (5) comments expressed thoughts that KanCare savings or MCO profit should be used to reduce waiting lists, three (3) technical questions about why there is a waiting list, wait times, and the number of people waiting, and one (1) commented how the wait list might be addressed.

**State Response**

HCBS is not an entitlement and certain waivers that provide essentially life-long services are more expensive per person than others. These waivers tend to have waiting lists since the State cannot add people to these waivers without available funding. The State has used savings from KanCare to remove people from HCBS waiver waiting lists and will continue to do so.

**Comments**

1. I moved here in August from Colorado and I was on their Medicaid program because of my disability, not because of the amount of money that I make. Once I was approved for that, which is the same kind of program for home and community based services, I was immediately given services. Immediately. The next week there was someone in my home to help me. I'm on a waiting list [PD waiver] here. Why?

2. Are you supposed to be using some of the money you're saving to move people off of the IDD waiting list?
3. How many people have been removed from the waiting list from the cost savings that KanCare has provided? Including the IDD and physically disabled (PD).
4. How many are currently on those waiting lists?
5. With all the money that you guys say you're making through having KanCare, we were promised that you would be moving people off the waiting lists. I have not heard any news about that. I would like some information about that.
6. Roxanne Hidaka, I've been a case manager and in the service delivery system for almost 25 years. I will say that Medicaid for IDD individuals in the state of Kansas has worked well until the MCOs took over 4 years ago. I piggy back off of \$1.4B in savings. I can't imagine where that money is. That waiting list should actually be 0. And I'm not real good with math, but I'm thinking it might be enough to serve everybody on the waiting list.
7. If you want to keep talking about how you're going to help the IDD waiver, let's look at the wait list. There's seven years of people still waiting on the wait list and people still coming on every day. I've got people just coming on to my caseload that got an application for services in January 2017, November of 2016; so it's going to grow.
8. And then the waiting list. I was wondering if there could be some sort of requirement in the new contract for the MCOs that they put some sort of percentage of their profits towards eliminating the wait list for our people?
9. While the IDD Waiver continues to serve many individuals well, the waiting list for IDD services remains a chronic problem. Little progress has been made under a managed care model. A multi-year plan should be developed to tackle this longstanding barrier to services for thousands of the IDD population forced to wait for years to be served. This plan should be developed with input and oversight by people with disabilities, including intellectual and developmental disabilities, family members, providers and advocates. Based on the timeliness of the plan, there should be a special appropriation each year that would incrementally reduced the size of the waiting list until it has been eliminated. Services of current consumers of any HCBS program should **not** be reduced just to free up money to pay for reducing the IDD Waiver waiting list. New funding should be appropriated for this endeavor.

*Service Allocation Summary*

There were five (5) comments related to service allocation, four (4) shared reductions in hours/service and one (1) expressing not being allocated enough service units to carry out needed activities (for example, the time it takes to support someone bathing).

**State Response**

The State encourages any KanCare member who believes he or she has had an unfair reduction in service hours to follow the robust appeals and State Fair Hearings process.

**Comments**

1. 40% cut in hours
2. 207 ↓ 149 hours
3. Since we're kind of getting off of extending the contract, because let's face it, it's going to happen. We're not dumb. We didn't come to this point... But, we are, my family, is one of those families whose had services cut 50% because my daughter lives at home with a 65-year-old mother and a 69-year-old father. She's 38 years old. All of a sudden, what Sunflower said was, "[Your daughter] qualifies for sleep cycle support or enhanced care services but mom and dad, you can't provide that service any longer." Let me tell you, we provided that service for 20 years when it paid \$20/night. When it went to paying an hourly rate, suddenly mom and dad couldn't do it anymore and that is the best example of the state of Kansas saving money on the back of my disabled adult child, because that is strictly a financial decision. I currently do have an appeal with Sunflower, which is interesting because they called me in for an informal meeting. Like I said earlier, when I said Susan Jarsulic, everybody says, "Oh God, not her again." Which is basically what I got from Sunflower, but that's okay because I fight for my daughter and I fight for the 10 people at my day program. But those are the things... I guess why is it necessary to make life a living hell? I have a lot of other things I want to do besides do things like this on a Friday afternoon, and I'm sure ya'll do too. You wouldn't have to be here if things were like we had wished for and hoped for. The other day on my Facebook thing it came up one of those memory things that said, "4 years ago



you wrote this letter about KanCare.” I’m like, “Oh my God” I can’t believe it’s been 4 years. We’ve survived so far, but this is the first time that my daughter’s services have been cut. I will also say that when [another commenter] spoke earlier about the conflict of interest with the MCOs making those decisions. January 4<sup>th</sup>, I’m sitting in a meeting with the Sunflower care coordinator and [commenter’s daughter]’s targeted case manager and she does this assessment, the meeting’s over and the care coordinator stands up and says, you know, “[The commenter’s daughter] no longer qualifies for sleep cycle support.” Boom! Just like that. I said, “Well, you better send me a notice of action then”. So this has been dragging on for what, 2 months now? I went to the Disability Rights Center; didn’t even bother to call the ombudsman. Went to the Disability Rights Center and have attorney there who’s helping me. But, like I said, I have other things that I would like to do with my life besides have to fight this, but I’m not giving up because the most important person is my daughter. It just, it makes me so mad that we all begged to keep the IDD population out of KanCare and yet here we are.

4. Between special ed and old, we have me. So, medical model. I just cannot tell you how difficult that is for many of our individuals to be able to cope with; their families, everyone else. They are not all medical model. They don’t fall into that. 15 minutes for a bath. For some of our individuals is 30, and then everybody goes, “well, but really you only get 15.” So that is an issue.
5. As a provider, we have also observed MCO decision contrary to the needs of person with IDD, causing great concern. One most recent MCO action pertained to communication about an individual with IDD and in their message wrote they (MCO) will be ‘titrating down the high functioning individuals in order to reach their required residential days to ensure their quality of life.’ That communication continued, ‘Individuals requiring very minimal hands on assistance will be decreased by titration.’ This matter is currently being challenged. The presumption that higher-functioning people can be titrated off services seems to me to offers an insight about not only the lack of understanding of LTSS for people with IDD but also insight into what I believe is an embedded motivation to save money. The level of service and support for these individuals, would appear as assumed by the MCO, not really needed. The MCO communication continued, if during the titration, the person’s quality of life begins to decline, the MCO would meet and re-evaluate. LTSS for people with IDD have been developed over time and implemented to meet the person’s needs. As most recently seen, under this model, a weaning of paid supports has commenced, based presumably on the above mentioned belief that they are somehow unnecessary. The stated fear by parents and advocates that KanCare would disrupt services for vulnerable people has sadly become reality.

<i>IDD Carve Out Summary</i>	<b>State Response</b>
There were six (6) comments that IDD should be carved out of KanCare.	Thank you for the comments.

**Comments**

1. Carve OUT I/DD!!!!
2. Unless there’s specific goals and outcomes for extending KanCare to address those things that I listed do you really think that the IDD waiver can be served by you, by KanCare, effectively again or should it be carved out?
3. I also just want to say that before KanCare went into effect we went up to Topeka and lobbied hard. I drug my poor son around the capitol multiple times trying to keep IDD services out of KanCare. The message I got, unfortunately, from legislators and administrators was that our fears were ridiculous and we were being very negative; this would be great. Virtually every fear that we had at that time has come to fruition. Sometimes the people at the state want to think they know what’s better for us. You know what, we know what’s better for our children and it would be really valuable if the state would listen and learn.
4. I would like to say that environmentally, when an MCO sends us a 42-page document and we have to print that out, we are wasting resources. I don’t know, that might pay for somebody to get maybe get some more hours or maybe serve somebody on the waiting list. Those, that’s pretty much what I have to say today. I feel that the IDD population does not fit into the KanCare system. They’re a little different because really they’re not sick. They’re actually well taken care of by their residential providers, their day service providers, and their families. The other waivers, I’m not sure. I’ve been an IDD case manager for almost 25 years so I know the IDD system. So I would like to see the IDD population carved out of KanCare.



5. Finally, there have been literally thousands of comments urging the state to remove I/DD from managed care since prior to its inception. These comments come from those who receive the services, their families and their providers. We ask you to revisit the appropriateness of I/DD LTSS in managed care and remove these services from the KanCare 2.0 RFP.
6. If KanCare is renewed, it would be best if the IDD population were pulled out. There is plenty of information citing that this system is not working for them, their families, their workers, etc. Kansas needs to set up a system that does not have a long waiting period for IDD services.

*Experiences & Examples from HCBS Stakeholders*

**State Response**

Four (4) commenters shared experiences as HCBS recipients in KanCare.

Thank you for your comments.

**Comments**

1. I'm going to have one question for you Mr. Randol [State Medicaid Director]. Should we by some grace of God be successful in getting the Legislature to agree to carve us out, or carve IDD out of KanCare, would you and Dr. Mosier support that?
2. Susan Jarsulic, which probably everybody here knows. I just want to give you a firsthand look at the IDD population. I have a day program; we serve 10 individuals with severe disabilities. Everybody there is a tier 1, the most severe. Most of them are in wheelchairs. We, of course, haven't had a pay raise in 10 years, we're still struggling by. Two weeks ago, one of the clients who started with me the very first day, she passed away. Her memorial service was held at our day service. I had case managers there, I had people who had worked with her in the past who had known her for the 15 years that she came to our day service program. What I didn't have was anybody from her MCO. The care coordinator didn't show up. And to me, that's one thing she should have showed up for. That's just a small little glimpse into of the life that we live every day. These people that come to my day program they have become part of our family. [Another person the room] over there, is one of my clients at Dreams Work. Like I tell my families at Dreams Work, KanCare is somewhat transparent to you because you just, you come to meetings at Dreams Work. We're a mom & pop operation and when I say mom & pop, that's exactly what I mean, we're small. With clients with these severe needs, I can only serve 10 people. For us, all the meetings, all the stuff everybody has talked about, it makes it so we don't have time to do what we need to do for our clients; the actual hands on. I want you to have that snapshot of what life is like for us.
3. Hi my name is Robert. I'm here with my son. I'm a parent and a co-guardian with my wife. My son is 36 years old. He's been in the system many years. It just seems like when KanCare took over about 4 years ago everything started becoming such a hassle and it is almost adversarial it seemed like. We just had to fight and trying to draft for anything we could and then once you had something you had to try to hang onto it. It doesn't seem to be getting any better when they keep coming things like capable person terminology. We want options for our son. We don't want to just have residential settings available. We feel that he could live on his own with my life and I. I have a job outside the home, but I'm lucky enough to work and spend about 50% of my work time at the house and can help with some physical situations. We get along fine and we do have a good day program that helps us that he can go for 5 hours a day. They haven't been able to get an increase in their funding in years and most of the time they're looking at a 5% reduction in monies that they get. There's also something that I think has been talked about, about making it work related. My son going to have to be trained to do a job. We're not, we do want him to have to do that. We like a social program that he could go to. So I guess one of my questions would be, keep the options available so that they're not forced to have to do one thing or another, to keep the services if they want to stay in the home. Provide some money, lawyer services, don't make providers do things they're not set, designed to do. If it's working for the clients that's I think what we all want and what's best for them. That's all I have. I'll let that go. I think it needs to be carved out. There's correlation between our kids, our young adults that have long term disabilities versus people who have regular medical needs so there's really, I just don't see the purpose of this.
4. I just wanted to piggyback what [another commenter] said over here, back there. I've been a targeted case manager and assistive technology person through KU. I've worked with individuals for about 20 years, since

Kindergarten. I thought I'd put a little humor into this, we're getting way too serious here. You know, we're spending quite a bit of time training our care coordinators. These are good people, the MCO's, you know they're out there, they're doing their job, they're just messengers. But I'm telling you, I'm going to piggyback on what [2 other commenters] have said, I've had a 4<sup>th</sup> care coordinator this year for an individual. They are IDD. They have to get to know a brand new person, they have trust a brand new person, when we spend a lot of time training them on stranger danger and not letting strangers into their home. And then all of a sudden it's "knock, knock, knock". "Hi, my name is Judy. I'm with United Healthcare." My targeted case manager doesn't know who you are. They're not contacting us. I mean, we've tried developing good relationships and good business partnerships with the MCOs, so they do contact us and let us know they're going to be contacting someone who's their own guardian and has a cognitive disability, and they're a stranger. They expect to be let into the home or their phone call answered. When it's one person in 4 months, and then another person in 5 months, and another person in 6 months. Then they're calling us and there's talking about capable person again and they haven't read up on the rules or the regs and we're starting all over again. And is that a good use of home and community based service time when we could be spending time getting these people services in the community after they get out of their day service program? Helping them get to church, helping their residential providers find activities rather than spending most of our time administratively? Retraining care coordinators? It is a duplication of services. IDD is a home and community based service with Article 63 being our lifeline to telling us how we're supposed to run our services for individuals with intellectual/developmental disabilities. We are the only waiver requires targeted case management because they are a very vulnerable population who are not sick and do not meet the medical model. These individuals need HCBS targeted case managers to advocate for them, to protect them, to help their day and res providers navigate through the system. Especially with the changes happening. It's like I wake up and it's Tuesday, and something's changed in Topeka. We are constantly going under changes, billing changes, massive updates. The administrative time taking us away from individuals is unbelievable, and then we get a new care coordinator. I'm asking you to carve it out. Then we'll leave you guys alone, okay. Thank you.

## Provider Reimbursement & Program Funding

**There were ten (10) comments regarding provider reimbursement and KanCare funding. Seven (7) about reimbursement and rates and three (3) about KanCare funding.**

<i>Provider Reimbursement/Rates Summary</i>	<b>State Response</b>
There were seven (7) comments about reimbursement and rates. Four (4) were about the impact of current rates, one (1) about rate cuts, and two (2) related to payment of providers.	Although the Governor’s budget requests funding for state programs, ultimately, funding for these programs, including KanCare, is allocated by the Legislature. By law, the budget must be balanced so that expenditures equal the revenue available. Kansas cannot deficit spend as the federal government can.

### Comments

1. Providers not getting paid. – Dr. Krug
2. KanCare needs to pay for providers and needs a current and correct list of providers.
3. Access to services and reimbursements rates, are we going to see an increase in reimbursement rates so we are going to be able to access services?
4. Will there be increases in reimbursement rates?
5. Savings due to DECREASED services offered + NO RATE INCREASE.
6. We do in-home care and I also have a home plus in Osborne County. We are the only facility in the county other than nursing homes. It's been a successful business. We have a town of a hundred people. We are, for a home plus that was built for 5, they changed the regs, I increased it to 8. They changed the regs again to where we can have 12, my five room home cannot hold 12 people. Right now I've got 8 residents, six of them are on Medicaid. The case managers do their best to help us get as many hours, because we put those hours in and sometimes we don't realize what we can do to get the hours. I sent my taxes in here just the other day. My facility lost \$26,000. The year before it was \$21,000. I am married to a farmer who does not give up, next year is going to be better. How can next year be better? I have no savings; I've lost all that. I'm getting to the age where I can't do too much more work. Physically I want to retire. Everybody else has retirements, I don't. I'm taking care of my elderly people. What do we do? I mean logically I should have closed that door a long time ago, but where are those people going to go? And then on the other side, I've got a home care service I have advertised. We've got a reputation out here of not paying. We don't make enough money, so I can advertise in 'til I'm blue in the face and no one's going to apply. I don't even get calls anymore because they don't want to work for me, because I don't pay enough. I'm an RN and I get paid \$13 an hour. That's an insult, but I'm still doing it. So, I increased my area; took on the DD waiver, boy I love those people, I love them all. So I'm doing, more work, putting more mileage on my car, I don't get reimbursed for that. We are required, every now and then, we have to do more. Like she said, we have to do more background checks now. If we had somebody for 3 years now, it'll be time to do a background check again. Sometimes it takes three or four hirings to get somebody that'll even stay six months. So, we run ourselves poor just doing background checks and TB skin tests, and all of the other things that we do. My office help spends most of her time making calls and waiting and waiting and I'm paying her. I'm only getting paid \$13 an hour for all these people. I just got a text a while ago and it says, "Hey Donna, I was wondering if you have any more clients. I'm not making much money anymore when people cancel and when I lost [a client]. My checks used to be around \$650 a month and now they're only around \$450 or so." Then a couple of days ago I got one, "Hey, you might be getting a reference check call. I hope that's okay." Which means I've got an excellent worker here and I'm going to lose her. Then I'm going to hire somebody, it doesn't work out, so I'll hire somebody else, and if that doesn't work out I'll hire somebody else, and maybe find another caregiver. There aren't very many people going to call. I've had an ad on Nex-Tech in one area for someone, I've had him since 2015, and his brother to go on the job no phone calls, nothing, and that looks bad on me because I can't find a worker and I don't know what to do.
7. Payment [illegible]

<i>Program Funding Summary</i>	<b>State Response</b>
There were three (3) questions/comments, one (1), asked twice by the same person, asking whether KDHE has requested additional funds for KanCare, and one (1) commenting on the budget in relation to population growth.	Although the Governor’s budget requests funding for state programs, ultimately, funding for these programs, including KanCare, is allocated by the Legislature. By law, the budget must be balanced so that expenditures equal the revenue available. Kansas cannot deficit spend as the federal government can.
<b>Comments</b>	
<ol style="list-style-type: none"><li>1. How many times have you asked for [the Kansas legislature] to increase the money?</li><li>2. How many times have you asked for [the Kansas legislature] to increase the money? (asked twice)</li><li>3. Funding: The Governor’s Budget Recommendation held funding flat for 4 years FY 2014 through 2017 for HCBS/FE, before the 4% Medicaid cut. During the same timeframe, the Kansas older adult population will increase by 19%.</li></ol>	

## Corrective Action Plan

**There were ten (10) comments regarding Kansas' letters from the Centers for Medicare and Medicaid (CMS) and the Corrective Action Plan. Two (2) about Kansas' response to CMS' letters, two (2) regarding barriers to extending KanCare, and six (6) questions/comments about the corrective action plan.**

### *Kansas' Response to CMS' Letter(s) Summary*

There were two (2) questions/comments about Kansas' response to CMS' letters. One (1) asked for more information related to person centered planning and employment barriers. One (1) relayed opinion that the tour was in response to CMS' letters.

### **State Response**

The purpose of the public comment meetings held in March 2017 was to collect input from stakeholders about the one-year extension request for the 1115 demonstration. It is true that there are federal regulations about public comment for 1115 demonstrations (including holding a minimum of two meetings). It is the State's intent to always meet those requirements and go beyond them.

### **Comments**

1. I have a question again about the response you had to the letter in January. Two particular topics. One was person centered support plans, and the other was on the barriers to employment and what you have found to be the barriers and how you're dealing with that.
2. And part of this is that's not true, and the only thing, I don't mean to be (?), but the only reason we're all here together now is because CMS came out and said you guys better get your act together. Otherwise nobody was paying attention to what we've been going through for the last year to two years. The only reason all you all are out here, even though you've been out for 175 meetings previous to, the only reason that any of this is even coming to a head now is because you're having to reapply and you're having to go through all this corrective action. Part of it was that you guys weren't overseeing these MCOs, nobody was overseeing what United, what Sunflower or Americorp was doing, and that's in that report. So it does come back to you guys for stuff like this, because nobody was looking into it. It's all well and good that you guys are putting these actions into place, and I applaud you for that; however, you're only doing it because you're under the gun and CMS is watching you.

### *Possible Barriers to Extension Summary*

There were two (2) comments about barriers to extending KanCare, one (1) question about potential barriers, one (1) opinion that the CMS letters were related to administrative issues because that's what they're limited to addressing.

### **State Response**

CMS can review anything related to the 1115 demonstration or any of the 1915(c) waivers, including health and safety, quality and person-centered planning. Their review included numerous documents and four days on-site with State staff and at the three MCOs. As noted in the letter denying the State's original request to extend the 1115, part of the reason for the denial was that the State's application did not meet the format and content requirements. The State submitted a Corrective Action Plan in response to CMS concerns on 2.17.17 and is awaiting CMS's response.

### **Comments**

1. Besides everything I've heard here today, what were some of those issues, because there were issues at first that made them say that they weren't going to do that?
2. The other thing that I just want to point out is that I was at some of those meetings with CMS and I also read the documentation CMS put out and said the things they found and what they wanted addressed. One view of that could be it was very one, ticky-tacky. It was very administrative; it was very bureaucratic. I think that was what CMS was constrained to. I think they can't really challenge you on what the experience was like in the meetings, what the attitude is like from the people performing the work. So, all they can do is attack the administrative details and challenge you for not doing something that was in a contract. But, what I believe CMS saw that concerned them as much as anything, based on the meetings I was in, was the attitude that they saw Kansas

using. I felt CMS was almost, kind of, an advocate for the disabled population against the state of Kansas and kind of took the approach of, “Well, we’re going to use all of this administrative things almost like a lawyer would. We’re going to use all of these ticky-tacky details to really justify why we’re not happy with Kansas, but we actually have real moral and ethical concerns underlying all of those ticky-tacky reasons.”

<i>Corrective Action Plan Questions &amp; Comments Summary</i>	<b>State Response</b>
<p>There were six (6) corrective action plan questions/comments. Three (3) people asked if and where the corrective action plan and related data can be viewed, one (1) asked what the major concerns of CMS are, one (1) referenced an instance where the plan may not have been followed by an MCO, and one (1) asked about the timelines of the corrective action and KanCare extension.</p>	<p>CMS asked the State to submit a corrective action plan related to oversight by KDHE of the management of HCBS by KDADS. The issues CMS raised were not specific to each MCO. That corrective action plan was submitted to CMS on 2.17.17. The State has already taken steps to implement some portions of the plan and is awaiting CMS approval of the plan. The extension, if granted, would run from 1.1.18 through 12.31.18.</p>

<b>Comments</b>
<ol style="list-style-type: none"> <li>1. Can you talk a little bit about what their [the Centers for Medicare and Medicaid Services (CMS’)] major concerns were and corrective action the state is going to be taking on those?</li> <li>2. Where can we find, if it’s put together, the corrective action plan you that you have implemented once CMS denied your application?</li> <li>3. On your corrective action plan that you’ve submitted, is there someplace we can go to see the corrective action plan and where would we access that? You said earlier there is a timeframe for the applications that you must meet; what is that timeframe?</li> <li>4. My question was when you, it sounds like you are going to be identifying the data that CMS had asked for, will those results be posted for providers or for clients to see? Will they be posted specifically for each MCO? I’m specifically asking about whatever the data was that CMS said you all weren’t collecting or providing to them.</li> <li>5. I just have one more thing and that is, I reviewed both the CMS report that went to KDADS and KDHE and I also took a look at the response back to CMS. I thought it was interesting that all of the due dates for action are 10/31 and 12/31 of this year. Which basically gets us through this extension that you guys are asking for, right? Because the extension is good through the end of this year, or next year?</li> <li>6. CMS was clear in its Jan 2017 letter that no services should be denied during the ongoing process of corrective actions, yet service are being denied: Amerigroup approved 31 units of residential services 12/16 after assessment update, then Jan 2017 he was notified that units would be changed to 11 per month starting 2/28/17. Appeal was denied by Amerigroup.</li> </ol>



## Dental Coverage

*There were three (3) comments/questions about dental care coverage, summarized below.*

<i>Summary</i>	<b>State Response</b>
There were three (3) comments/questions about dental care, two (2) were related to why coverage is limited to cleanings and extractions. One (1) commenter shared information about services that are deemed medically necessary, in response to a previous question.	KanCare does not cover adult dental services, except for emergency extractions. The MCOs all offer value-added adult dental cleanings, at no cost to the State. Coverage of new services with significant fiscal impact must be approved by the Legislature through the appropriations process.

### Comments

1. I have a question about Medicaid and KanCare. Why does it not cover completely dentists? Because when I go to the dentist they say just the cleaning is covered they not cover cavities and deep cleaning and other stuff. That's my questions. [rephrased by facilitator] Why does KanCare only cover dental cleanings and other dental services?
2. I just want to make a comment. A while ago you said Medicaid doesn't cover dental. However, they do. If your primary physician and dentist say that it is a detriment to your health, they will go ahead and do the dental work and pay for it.
3. Why don't is not KanCare is not covere dantice complete

## Individual Situations

*There were Five (5) comments regarding commenters' individual experiences with KanCare, summarized below.*

Summary	State Response
<p>Five (5) commenters shared their individual situations. One (1) was related to how KanCare and Veteran's benefits connect, one (1) related to provider referrals, one (1) shared their difficulty navigating multiple systems, one (1) related to transportation and access to services, and one (1) related to the individual's spenddown.</p>	<p>The State requires MCOs to maintain current and accurate provider lists. Website listings will be more up to date than printed lists. Receiving VA benefits does not prevent one from being eligible for Medicaid, but could result in a spenddown. Spenddowns occur when income is too high and participants must spend some of their income on medical expenses before Medicaid will cover care.</p>

### Comments

1. My mother is on KanCare and my father was a veteran. When I went to have the doctor fill out some of the papers for her, she didn't hesitate at all to do it. She did indicate that my mother wouldn't get any assistance from the Veteran's Administration (VA) because she's on the KanCare program. Why?
2. My name is [redacted], and I have background in human services. I have been, in the past, I worked for seven years as an IL counselor for the PD waiver. I do agree that the consistency of care has been lost. Before, I was the one that went to the assessment, I was the one that looked at resources for them, I was the one that got their care started, I was the one that talked to the person at SRS/DCF to get services started. I can agree also on the provider list; it needs definite improvement. There are a lot of doctors on there that have never been on KanCare that they have on the list. For example, someone mentioned earlier, we were talking about dentists, I had to get my tooth drilled so I had to go to a KanCare provider, here in Hays, and they put on a temporary crown well then I was eating a caramel and I pulled it off. So I had to go back, I had to go back to have them put it back on. I said can you put this back on to the hygienist. She looks at it and she wasn't the same one that was there when the dentist cracked my tooth the first time. But she said, "Oh man, I don't think we have anything to put it on." Anyway, to make a long story short, I was referred to some doctor in Wichita, an oral surgeon, and I found that he wasn't even on the dang list. Is there some way when providers, if they're going to refer you to somebody, to refer you to somebody that's actually on KanCare? Because I even asked her, she says, "Well here. You go to this guy, he's in Wichita." And I said, "Well, is he on KanCare?" "I don't know." Really? Why would I go to somebody that's not on KanCare?
3. Why do you consider... like I've got a retirement account that I cannot take out until I'm 65. I got on disability and I'm approved for Medicaid, but my spenddown is a \$11,000 spenddown. It's because my previous year, I earned a little bit of money and the retirement, the co-op retirement. I can't touch that co-op retirement. So is KanCare going to take into consideration that? What's my spenddown going to be next year? Is it going to go down or the same?
4. Driving between Kansas and Missouri because the person I'm taking care of can't get transportation in the state of Kansas to your medical appointments. So I'm having to drive to my VA appointments in Missouri, drive back here to Kansas, drive her to her appointments, and then turn around and drive back to Missouri for my VA appointments. Also, for some reason, this thing does not provide a program for those who have a fall down risk. She is a fall down risk and cannot get the button that says I've fallen down and can't get up.
5. I have been to several of the "State" staff meetings. My (2) son's and daughter both have tried to receive the Medicaid of Ks – help with No help what so ever. I have asked many questions about the "State of Kansas KanCare Program and just yesterday talking to KanCare employees about a 72 year old man – he has Medicare and Wellcare but KanCare Reps would not take his brother off legal documentation and sending copies to him – Federal HIPPA Violation – federal not State.  
My (2) sons and daughter have gone to all Social Security (Federal) and ring to get them disability or at least SSI for at least a Medicaid Card – Federal appts state 'Yes', but Ks statues states 'No' and they have paid into Federal and State all their life and now Ks states 'No' we will not help. Plus (1) son has the program and does not even stand behind the laws of KanCare to protect him. The mileage statements Logisticare – AZ and OK – only states

do not apply to KS. I take my son to 62pt.s in Wichita and all over the State and to Dr. appts. I do (his Mother) I am on disability myself and have spent hours and of my own dollars taking to appts. The last 3-4 years and never received a dime. The Program is and always will be a scam!

Staff employees only listen to who they feel can contribute not the elderly and the middle aged that need the help. Social Security is Federal and the hospitals- doctors and the education is for them. The money is not for the patients. I know – my family has gone through all the politicians and reps. And all are still not Federal Compliant. I can prove all. The mistakes- the cover-ups and the lies the KanCare staff still tell. No Ins – No Care. ER and jail-time in Cowley County if not paid.

State Staff need to educate themselves before trying to tell the people especially coming to Cowley County. My son cannot attend because most of the people that truly needed the help have now lost vehicles – houses and the self-worth they use to have. Sending this back because of the mother of (3) – all have lost everything they ever owned and loved, but suicide has never entered their mind only staying alive.

Need to practice what you Preach. Federal is not State.

(1)Federal Law – (2) State Law – and (3) Local Law

Cowley County lives by local law. Good luck but this is one person that have been at the meetings and the Staff were rude and ignorant of (1) person that have ask questions and ignored. Plus files and files and files of the True Medical records and most of the hospitals in Wichita and surrounding areas are not Federal HIPPA Compliant.

## American Health Care Act (AHCA)

*There were five (5) comments regarding the American Health Care Act (AHCA). Two (2) comments regarding the security of participants' Medicaid, three (3) reflecting concerns about funding.*

<i>Uncertainty of Loss of Benefits Summary</i>	<b>State Response</b>
Two (2) of the comments indicated uncertainty that the AHCA might create an unstable Medicaid environment and participants might suddenly lose their Medicaid benefits.	The AHCA was not passed and nothing has occurred to indicate that Medicaid participants will suddenly lose their benefits.

### Comments

1. I have questions in regards with what we're hearing in the news about the AHCA repealing the ACA replacing with the AHCA. They're talking block grants instead of per capita. And it's disproportionately shifted to the rural areas which in modern times and in medical systems, if a person has a heart attack or anything that is beyond their control it can bankrupt somebody very easily. I heard on the Whitehouse press briefing today, there was a question to Sean Spicer about Kansas, that Kansas is just now just expanding Medicaid. It's confusing as to why wasn't it done before? Why isn't it being done now? What's going to prevent the rug from being yanked out from under all of us?
2. Everybody in America is asking themselves, how do we know what we're discussing here now is not going to be moot 3 months from now. They're talking about passing the AHCA Thursday. We have no guarantees that the rug is not going to be pulled out from anybody on KanCare, Medicaid, everything. It's very scary for us.

<i>Funding Changes Summary</i>	<b>State Response</b>
Three (3) commenters identified potential funding changes through the AHCA, particularly block grant funding, as a potential barrier to Kansas' ability to provide adequate Medicaid services.	As noted above, the AHCA was not passed and nothing has yet changed in how the federal government will participate with states in covering the costs of Medicaid services.

### Comments

1. Just to follow-up on what that gentleman down there brought up about the AHCA and the per capita cap system, better than a block grant, but either way you slice it we're going to get less money for Medicaid services if we go to that kind of system from the current entitlement system that we have. One thing that you can count on with the AHCA is states that have done the expansion are going to get a bigger slice of the Medicaid pie than states that didn't. If it's something that concerns, you need to contacting you people in Congress and letting them know.
2. I have researched all of the proposed changes to Medicaid. Even though President Trump said he wasn't going to change it, he's going to anyway. My concern is this, I realize they have not come up with a healthcare bill yet that they can take before the house or senate, either one. I realize they're in the middle of trying to get it done. If these proposed policies come up, am I to worry about whether if my Medicaid is going to continue for the next year until we can re-figure it out until then? I'm a disabled old man and believe me this isn't a freeing windfall that I'm getting. I've seen some the ideas are crazy. Medicaid people. You have to put a certain amount of money back into some sort of healthcare thing or something. I'm going to tell you what, it hurts me to even get a dollar out of my check. I only make \$733/mo. That's not much to live on. So, my biggest question is once the federal government comes up with their plan or whatever, are they going to instantly put it into effect and Kansas just has to go along with the block grants, whatever they're going to give?
3. If federal gov. goes to block grants instead of current funding way, what programs will be most at risk?

## KanCare Renewal / KanCare 2.0

*There were thirteen (13) comments/questions related to KanCare renewal, summarized below.*

Summary	State Response
<p>There were thirteen (13) comments/questions related to KanCare renewal. Five (5) were questions and comments about what changes or new services may be offered, including suggestions to increase dental services, services for adults with mental illness, policies around spenddowns, and general questions about what changes may occur. There were two (2) technical questions about what happens to KanCare in a new state administration, and how long the renewal will be. Two (2) comment was a concern about renewal when there are outstanding concerns. One (1) comment was in support of KanCare renewal, two (2) were in opposition, and one (1) suggested a renewal should not be allowed until existing issues with KanCare are resolved.</p>	<p>The State is focused on obtaining approval for the one-year extension of KanCare. There will be a separate public input process for KanCare renewal. The State will seek input about new services, processes and policies for the demonstration renewal as required by federal regulation. The renewal approval would allow the demonstration to continue for five years, from 1.1.19 through 12.31.23. That period would be under a new Governor.</p>

**Comments**

1. So then, this [KanCare 2.0] would come under a new governor of Kansas, is that not correct? So is the governor now going to have anything now or will it rely on the new governor of 2018? If there are substantive changes to KanCare 2.0, whatever those might be, and they require a significant amount of funding does that require the legislature to give us more money?
2. Question is, I understand that KanCare is not going to be renewed. It has to go through this process because it had problems. Is that correct?
3. In the renewal process, is there any consideration for HCBS to be available to those who are chronically mentally ill. Because Many of those folks do not need, while they are getting therapy and medications, they problems that are cause them problem are their home living environment, keeping it clean and neat, passing the section 8 housing, having somebody who can come in and do it. Is there any consideration because you're already providing medical care, to expand that to provide HCBS services to that special needs?
4. When you do KanCare 2.0 maybe do some dental benefits. That would be great.
5. I know this is an extension meeting but I wanted to ask about the renewal. In the new request is the state planning to test a new hypothesis or test the same thing? Does the state intend to integrate or block grant our program?
6. I guess this goes to the renewal part of KanCare. There's a fairly new policy that for people that don't meet their 6-month spenddown they get kicked off the program. With the system that we have now, with the capitated rate the MCOs get paid the same amount every month whether they provide a lot of services for people or they provide zero services for people. The state doesn't want to pay them to provide no services for people, which I get, but that's a big problem for the consumers. I know that people can reapply when they have a major health expense that's going to qualify to where they would be able to meet that spenddown. You know, a person that's rolling to the hospital in the ambulance isn't going to be asking the EMT, "Hey can you help me log on to KanCare.gov so I can reenroll in KanCare." This issue is particularly important when you go back to what the issue that [a previous commenter] brought up earlier under what they're talking about with the new proposed healthcare, what the AHCA, having people having to renew every 6 months instead of once a year, but along with that they're saying that people will no longer and be able to go back be able to bill for medical expenses in prior three months before they get back on KanCare and that's going to be a huge problem for people if that happens. Seems to me a better way to deal with that issue is when it's time to rewrite the contracts tell the MCOs we're going to pay you your capitated rate when you provide services for people, but if you're not doing anything, you're not going to get paid that month instead of just booting people off the program and making them constantly reapply when major health expenses come up in their lives.
7. Talking about the extension that's going to go out through all of 18. What's the new deal that's going to come in? Is it going to be like a 5-year program? A 2-year program? How long is this Kansas 2.0?

8. If CMS approves KanCare 2.0 what improvements, what changes do we expect to see?
9. Doesn't it seem to be an issue if CMS is so displeased with the way the system is going with KanCare is going that seems to be a genuine issue that we need to be looking at rather than "oh they didn't like something" so we're going to "turn in a new term paper"?
10. I am writing to express my support for KanCare renewal and expansion. Working with MCOS has proven to be more efficient in terms of fiscal responsibility as well as improved patient outcomes.
11. I believe that not renewing KanCare and getting away from the privatized system would be the best. It seems to have worked a lot better than the system now. I have been involved in the Foster Child system as a consumer, advisory board member, and a social worker working for one of the companies.
12. Privatization does not work. The companies bid low so they can get the contracts and then they cut back on the services. Some companies could not even meet their requirements the first year of their contracts because they did not bid high enough. So the foster children and families suffered and still suffer. It is the same with KanCare.
13. Adding program changes on top of a system that is struggling to put will continue to put the health and well-being of thousands of older Kansans and persons with disabilities at risk. An extension is necessary to address the serious compliance issues outlined by CMS. The KanCare program should not be renewed until the problems that currently plague the KanCare program are resolved.



## General Questions & Comments

*There were Nine (9) general questions and three (3) comments regarding individualized topics. This category is formatted to allow the state to respond to each individual question due to their unique nature and acknowledge the comments the same as other comments.*

Questions	State Response
<p>1. I have a question about the ombudsman office here in Wichita? Where is it located here in Wichita?</p>	<p>WSU Community Engagement Institute helps support the KanCare Ombudsman’s volunteer program. That office is located at 238 N. Mead, Wichita.</p>
<p>2. The other is, how can you characterize the KanCare Ombudsman as being independent if that person is an employee? I have one example. When I called and I asked a question, I was told that the ombudsman just tells us to go somewhere else like the Disability Rights Center and that was really no help at all. Overall, an ombudsman that is an employee of the very organization that we are having trouble with is not empowered to help us.</p>	<p>The KanCare Ombudsman is located in the Kansas Department of Aging and Disability Services, but operates independently from the department.</p>
<p>3. Do you know if the Kansas Estate Recovery Contractor is still in operation?</p>	<p>Yes, Kansas still contracts with an entity to handle estate recoveries.</p>
<p>4. If a person is only getting MediKan, medications aren’t covered unless it’s life sustaining. Why is that?</p>	<p>MediKan is a state-funded program that provides a time-limited benefit to participants who have a level of disability that does not quite meet Social Security Disability criteria. It covers some mental health services and medications for mental health.</p>
<p>5. I want to be clear on it, Medicaid and KanCare are 2 different programs, right?</p>	<p>KanCare is Medicaid in Kansas.</p>
<p>6. Are they going to pass KanCare expansion?</p>	<p>As of 5.3.17, Medicaid (KanCare) expansion was passed by the Legislature, but vetoed by Governor Brownback.</p>
<p>7. You said earlier that the feds pay \$0.55 out of the dollar and Kansas pays \$0.45. Can you tell us something about what the requirements that the federal government has in terms of what they require KanCare to do here in Kansas?</p>	<p>The federal government requires any state participating Medicaid to cover a certain core set of services and allows us to cover other optional services, including through HCBS waivers. We must comply with federal Medicaid regulations and federal Medicaid managed care regulations, as well as the requirements laid out in our Special Terms and Conditions, located here: <a href="http://www.kancare.ks.gov/docs/default-source/about-kancare/history-of-kancare/1115-history-documents/kancare_stcs_idd_amendment_01_29_14.pdf?sfvrsn=5">http://www.kancare.ks.gov/docs/default-source/about-kancare/history-of-kancare/1115-history-documents/kancare_stcs_idd_amendment_01_29_14.pdf?sfvrsn=5</a></p>
<p>8. I just wanted to comment, when the lady over there was talking about, from Colorado and how their care was so much better than Kansas. I was watching on a program and Kansas is the worst in the United States and it was also on the news they were talking over in Australia and they were comparing it and our, it’s worse than Cuba and Thailand. And how come it’s so different from state to state? I’m kind of concerned we’re worse than third</p>	<p>Medicaid is a federal-state partnership, so each state’s Medicaid program differs to some degree, but all Medicaid programs are required to cover the same core set of services and maintain program integrity units.</p>

<p>world countries as far as that. Why is there such a difference? Why do other states get better care than Kansas people?</p>	
<p>9. I believe it was in California, so it may not have anything to do with anybody, but they brought out that one insurance company was making people on paper seem to be sicker than what they really are. It gives a negative response as to people that, I don't know about anybody else but I'd rather have a job than be in the situation I am now. Is that being heard louder than those of us that are maybe short on provision in the home? I didn't know, I think that's a small percentage of what's really going on but I think it kind of hurts the rest of us.</p>	<p>Medicaid has some very stringent program integrity standards to prevent fraud, waste, and abuse. Anyone with evidence of fraud or abuse can report it to the Medicaid Fraud Control Unit in the Kansas Attorney General's Office by calling 1-866-551-6328 or (785) 368-6220.</p>
<p><i>Comments</i></p>	<p><b>State Response</b></p>
<p>1. KanCare EXPENSIVE to providers.</p>	<p>Thank you for your comment.</p>
<p>2. I don't know if it's KanCare or who. I do appreciate the health that I do get in my home. I would hate to go to a rest home. I actually thought about ending my life if that's how it goes. Then I had a change in health. I came with a disease and my case manager was there to help with providing some other services that were needed desperately.</p>	<p>The state appreciates your comment and is pleased to know you are getting the help you need.</p>
<p>3. We need expansion, especially with the uncertainty of a workable system. To merely renew will determine that many will be left out of the system and continue the financial burden on rural providers for necessary care.</p>	<p>Extension or renewal of the 1115 demonstration (KanCare) is not connected to whether or not the Kansas expands Medicaid. The 1115 (KanCare) is how Kansas delivers Medicaid services.</p>

## Written Letters

**From:** Christie Appelhanz  
**To:** [KanCare Renewal](#)  
**Subject:** KanCare Renewal -- Public Comments  
**Date:** Tuesday, March 21, 2017 3:28:45 PM

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March 21, 2017  
KanCare Renewal  
c/o Becky Ross, KDHE-Division of Health Care Finance  
900 SW Jackson, LSOB – 9<sup>th</sup> Floor  
Topeka, Kansas 66612

Dear Ms. Ross,

Thank you for the opportunity to provide comments regarding the proposed one-year extension of the KanCare program on behalf of the Children's Alliance of Kansas, the only association in the state representing private, non-profit, child welfare agencies. Under federal statute, children receiving Title IV-E foster care and adoption assistance are categorically eligible for Medicaid. These children and adolescents represent a population with unique health care needs who depend on Medicaid for an array of physical, behavioral, and social treatments.

As an extension to KanCare is considered, we urge you to use this as an opportunity to address critical issues facing the program. There has been an eligibility backlog for nearly a year and a half, concerns about the adequacy of provider networks as a result of burdensome administrative processes and denial rates, and the lack of appeal processes for both providers and consumers. In addition, outside factors -- including record numbers of children in foster care and cuts to community-based services -- are providing unsustainable pressure on the KanCare program. Changes such as uniform paperwork and procedures for each of the MCOs could significantly improve the program.

While we are hopeful the Kansas Legislature will restore the four percent Medicaid reimbursement rate reduction this session, currently it is impacting access to care for our state's most vulnerable youth and has placed additional burdens on the already stressed child welfare system. The result has been agencies scaling back operations and questioning whether they can afford to continue participating in a program that pays less than the cost of providing care.

Child welfare agencies are important health care providers who respectfully ask that if KanCare is extended, it is also improved. The health care needs of children in child welfare are vast and often compounded by their circumstances. Ensuring access to stable health care services is good policy that is in the best interest of all Kansans.

Sincerely,

**Christie Appelhanz**  
Executive Director  
Children's Alliance of Kansas  
627 SW Topeka Blvd.  
Topeka, KS 66603  
office: (785) 246-9381  
mobile: (785) 554-1835



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**From:** KanCare Renewal  
**To:** [wescrenshawphd@fpskansas.com](mailto:wescrenshawphd@fpskansas.com); [KanCare Renewal](#)  
**Cc:** [Sloan Tom](#); [Anthony.Hensley@senate.ks.gov](mailto:Anthony.Hensley@senate.ks.gov)  
**Subject:** RE: Public Hearings  
**Date:** Monday, March 13, 2017 10:52:57 AM

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You may attend any or all of these public hearings. We do not require registration or "getting on the agenda." Everyone who attends can share their questions and concerns both verbally and in writing.

**From:** [wescrenshawphd@fpskansas.com](mailto:wescrenshawphd@fpskansas.com) [mailto:[wescrenshawphd@fpskansas.com](mailto:wescrenshawphd@fpskansas.com)]

**Sent:** Thursday, March 09, 2017 8:41 PM

**To:** KanCare Renewal

**Cc:** Sloan Tom ; [Anthony.Hensley@senate.ks.gov](mailto:Anthony.Hensley@senate.ks.gov)

**Subject:** Public Hearings

KDADS Colleagues:

As the owner of a practice that takes KanCare, and as a former Medicaid provider since 1992, I would like to appear at the public hearing, preferably on March 21, but I would travel to Wichita to take part if I can only appear on the 20th.

Please advise how this is arranged, or if it is arranged in advance. I have not been passionate enough about anything before to appear, and it is clear that this was unfortunate now that Kansas is in such a situation with KanCare.

I can provide a unique prospective on how things have been for providers recently, how they were under KHS and how they were under the original system in the 1990s. Moreover, we have hand-to-hand and face-to-face experience with all aspects of KanCare and have since it's inception under the three MCOs. And I would gladly face off against any of their staff in a discussion of our experiences, particularly over the last 9 months.

Please advise.

Wes Crenshaw, PhD ABPP CST  
Family Psychological Services, LLC  
2601 W 6th ST STE A  
Lawrence, KS 66049-4319  
Ph: 785-371-1414  
Kansas City: 913-888-8967

Email: [wescrenshawphd@fpskansas.com](mailto:wescrenshawphd@fpskansas.com)

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making elder care better every day

March 27, 2017

Thank you for the opportunity to submit comments regarding a one-year extension for renewing the KanCare 1115 waiver demonstration grant. The KanCare demonstration waiver has not effectively or efficiently served Kansans who are Medicaid eligible, nor has it served as a model worthy of replication by other states considering similar undertakings. If CMS deems it appropriate to continue the KanCare demonstration waiver, Kansas Advocates for Better Care would support a one year extension for the demonstration project and respectfully request that: 1) CMS maintain active oversight of the areas defined for correction in its letters to Kansas of December 2016 and January 2017; 2) CMS maintain active oversight of the state's implementation of an approved correction plan; 3) CMS require an aggressive correction in the state's grossly delayed Medicaid eligibility determination process; 4) CMS include special terms and conditions for the extension which require a fully independent and functional, legally based ombuds program for Medicaid beneficiaries, preferably housed outside of state agencies.

**HEALTH:** While the State recently pointed to an increased number of well-child visits, improved treatment of alcohol/drug addiction and better diabetes care as measures of KanCare's effectiveness, the State provided no improvements on the health outcome measure related to the reduction in the misuse of anti-psychotic drugs on older adults with dementia. KanCare was to reduce use by 10% annually beginning in 2014 and going forward. The improvements referenced by the State represent very limited measures of medical/healthcare metrics, and cannot be used to evaluate the effectiveness of and access to long term supports and services which serve frail elders and beneficiaries under the other six Home and Community Based Services waivers.

**NETWORK:** Currently, we have anecdotal evidence that the HCBS provider network is struggling to remain financially solvent. Reports from KanCare recipients and their family members report problems with finding providers, difficulty with the application process and reductions to their care plans.

**DATA:** In its Jan. 27 letter to Secretary Mosier, CMS pointed to limited evidence of data, reports and performance information that contribute to program evaluation and continuous improvement of the program's operation. Additionally, CMS cites whole sections of the KanCare 372 report that are absent data, including sections measuring the health and welfare of recipients and qualified providers.

Incomplete and unavailable data has plagued our ability to evaluate the effectiveness of KanCare programs and the strength of the long term supports and services provider network under the seven HCBS waivers. As we move toward renewal of KanCare, it is imperative to look at meaningful measures to identify gaps in the system, develop solutions, and provide better care for older adults and persons with disabilities being served by the waivers.

KABC continues to ask the State to address and resolve the following problems for the benefit of all older adults, including those who receive care through the KanCare program:

913 Tennessee Suite 2 Lawrence, Kansas 66044-6904  
phone: 785.842.3088 fax: 785.749.0029 toll-free: 800.525.1782 e-mail: [info@kabc.org](mailto:info@kabc.org) website: [www.kabc.org](http://www.kabc.org)

## **KDADS Oversight of Health Standards and Protection of Vulnerable Elders in Nursing Facilities**

*Adequately fund and fill survey/inspection positions to assure KDADS can achieve its oversight and protection functions for frail elders in nursing facilities within state required timeframes. Provide oversight for KDADS inspection timeliness.*

**Survey/Inspection Deficit** – KDADS is lagging 3+ months behind in meeting its statutory requirement to inspect all Kansas nursing homes every 12 months (average). There are 350 nursing facilities and a similar number of assisted type residential care facilities. KDADS is responsible for conducting survey/inspection and for assuring the protection of vulnerable elders in nursing facilities, and for assuring that facilities comply with health, safety and sanitation standards.

KDADS at last report is over three months behind at 15.1 months. KDADS is consistently running multiple vacancies for surveyors in this key unit. KDADS survey unit is underfunded and understaffed and not meeting its health and safety responsibility. The unit has experienced a higher rate of turnover, which results in less experienced surveyors responsible for citing levels of harm to older residents.

**Impact:** When elders are at risk of harm or are being harmed by abuse, neglect, exploitation and sub-standard care they endure such treatment for three + months longer than if KDADS was meeting its legal requirements. Understaffing of surveyors, puts elders at risk and in harm's way longer, exposing them to substandard care practices for increasingly longer periods of time.

In March 2016, a 91 year old nursing facility resident with dementia was tased by a sheriff's deputy responding to a call by the nursing facility when the resident refused to go to a medical appointment. The man suffered significant distress and died two months later.

Turnover among surveyors results in inexperience to identify and cite areas of deficient practice. Leaving older adults at risk for harm from abuse or substandard care.

**Chemical Restraint of Elders** – Kansas ranks 50<sup>th</sup> worst in the U.S for the inappropriate use of anti-psychotic drugs on older adults. Anti-psychotic drugs are used to chemically restrain elders with dementia. Anti-psychotic drugs carry a black box warning due to the high danger they pose to older adults and even though there is no approved anti-psychotic drug use for treatment of dementia. The State is not providing leadership for a consistent, focused reduction effort, nor effectively using survey tools and penalties to deter use. KanCare reports no reduction in AP use even though it has been a performance health outcome for nursing facility residents since 2014.

**Impact:** Serious negative health outcomes for older adults include death, stroke, and falls, creating unnecessary pain and suffering for older adults already challenged with a serious health condition. Costs of unnecessary medications, hospitalizations, therapies, surgeries, and other avoidable health care costs increase overall expenses for Medicaid, Medicare and private insurance, and greatly decrease the quality of life for frail elders. Nursing Facilities performance has worsened in comparison to peers in 50 states.

### **Access Deficits for Elders to Long-Term Care Supports and Services:**

Access to Home and Community Based Services/Frail Elder– HCBS-FE Medicaid Waiver:

*Fund HCBS/FE to address current needs and increasing older adult population demographic statewide.*

913 Tennessee Suite 2 Lawrence, Kansas 66044-6904

phone: 785.842.3088 fax: 785.749.0029 toll-free: 800.525.1782 e-mail: [info@kabc.org](mailto:info@kabc.org) website: [www.kabc.org](http://www.kabc.org)



**Funding:** The Governor's Budget Recommendation held funding flat for 4 years FY 2014 through 2017 for HCBS/FE, before the 4% Medicaid cut. During the same timeframe, the Kansas older adult population will increase by 19%.

Access to Home Based Services backlog of Medicaid Eligibility:

***Assure funding and procedures are in place to accomplish processing of Medicaid applications in required 45 days.***

**Backlog:** Increasingly frail older adults are waiting 6 months and longer for eligibility determinations and entry to the KanCare program placing them at risk of serious injury and illness. Hospitals report difficulties in identifying nursing facilities which will accept Medicaid pending older adults ready for discharge from the hospital setting. Nursing homes report the inability to "float" the cost of care for older adults with pending Medicaid applications. Older adults and family members are increasingly reporting an inability to locate nursing facilities which will accept Medicaid pending individuals unless that individual can show up to six months of financial resources to pay privately. Older adults are going without HCBS services, as there is no retro-activity of reimbursement for waiver services.

**Impact:** Increased risk of harm to older adults unable to access services at home or in a facility. Force older adults to consider geographic displacement in order to access care, separating them from their families and support networks. Increased cost for hospital stays which are longer than is needed for care required. Increased unwillingness for nursing facilities to accept older adults who have pending Medicaid. Before moving forward, advocates and policy-makers must have a thorough review and analysis is critical to improving KanCare's HCBS waiver services as well as the medical care provided.

The HCBS network has never stabilized after the move to managed care. In response to the compliance issues noted by CMS, the State has slowly begun addressing problems within KanCare, but there is not currently a stable, adequate network. Older adults need a stable, reliable provider network, as do others who use long-term care waiver services. Such a network would be confirmed through data that demonstrates that the health care and HCBS provider networks are strong and that KanCare is meeting its original goals.

The waiver extension gives the State time to address KanCare's compliance issues. If CMS approves the extension, we are asking CMS to provide for consistent oversight of the State's efforts to reduce the risk of harm to frail elders and all Medicaid recipients. Further we ask that CMS to direct the state to work more closely with all stakeholders (not only providers and state agency staff) to assess the program and identify gaps in services to improve the health and well-being and outcomes for frail elders and of all KanCare recipients.

Mitzi E. McFatrach, Executive Director - On behalf of Board of Directors and Members

KABC is a not-for-profit organization whose mission is to improve the quality of long-term care for elders in all settings – nursing and assisted facilities and in-home. KABC is not a provider of government funded services. For 40 years KABC's role has been as a resource and advocate for older adults and families and as a resource to policy makers on aging and quality care issues. KABC provides consumer education information and tracks and reports on quality care performance issues.

913 Tennessee Suite 2 Lawrence, Kansas 66044-6904  
phone: 785.842.3088 fax: 785.749.0029 toll-free: 800.525.1782 e-mail: info@kabc.org website: www.kabc.org

**From:** Mariette Jongenelen-Ryer (Maria)  
**To:** [KanCare Renewal](#)  
**Date:** Tuesday, March 21, 2017 12:08:34 PM

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CMS was clear in its Jan 2017 letter that no services should be denied during the ongoing process of corrective actions, yet service are being denied:

Amerigroup approved 31 units of residential services 12/16 after assessment update, then Jan 2017 he was notified that units would be changed to 11 per month starting 2/28/17. Appeal was denied by Amerigroup.

[Kdhe.kancarer renewal@ks.gov](mailto:Kdhe.kancarer renewal@ks.gov):

Mariette Jongenelen Ryer  
Arrowhead West, Inc.  
613 N Ridge Road  
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**From:** Maureen G  
**To:** [KanCare Renewal](#)  
**Subject:** Letter of support for KanCare renewal and expansion  
**Date:** Tuesday, March 28, 2017 12:03:56 PM

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I am writing to express my support for KanCare renewal and expansion. Working with MCOS has proven to be more efficient in terms of fiscal responsibility as well as improved patient outcomes. My only concern is with the inefficient delivery of services by the KanCare Clearinghouse. Long wait times on the phone and timely response to beneficiary inquiries. It also takes an unreasonable amount of time to see updates in coding changes in KMAP for HCBS and Nursing Facility beneficiaries. This can delay delivery of services due to ineligibility as well as delay payment room providers. Thank you for considering my comments.

Maureen Griese RN  
Manhattan KS

**From:** Evelyn Maxwell  
**To:** [KanCare Renewal](#)  
**Subject:** Expansion  
**Date:** Saturday, March 18, 2017 10:05:24 AM

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We need expansion, especially with the uncertainty of a workable system. To merely renew will determine that many will be left out of the system and continue the financial burden on rural providers for necessary care.

Sent from my iPhone



**From:** Jerry Michaud  
**To:** [KanCare Renewal](#)  
**Subject:** Public Comment on KanCare Renewal  
**Date:** Friday, March 24, 2017 4:56:12 PM

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KanCare Renewal  
c/o Becky Ross,  
KDHE-Division of Health Care Finance  
900 SW Jackson, LSOB – 9 th Floor  
Topeka, Kansas, 66612

Dear Becky Ross,

My comments relate to KanCare and the renewal process. This model was implemented in January 2013 and in looking back, there were expectations and promises made about the KanCare Model and what it would accomplish. KanCare covers approximately 400,000 Enrollees, however, my comments pertain to a much narrower subset - the community system serving people with Intellectual and Developmental Disabilities (IDD) and specifically those person's Long Term Service and Support (LTSS).

Publicly stated concern at the start of KanCare related to Medicaid spending and how it had grown to unsustainable levels. I believe it is vital to understand and differentiate between all Medicaid dollars spent, and those specifically spent on community services for persons with IDD and LTSS for people with IDD. A couple of observations are noteworthy regarding spending on LTSS for persons with IDD. In the years leading up to KanCare, IDD LTSS funding had been held flat (since July 2008). Flat funding cannot cause a 'growth in spending'. From 2013 to present, those same rates paid for IDD LTSS have remained flat. As a side note, overall funding for these community services has actually gone the other direction since KanCare began.

As a provider, we have worked diligently to navigate the KanCare system and work with each of the three MCOs. To claim that KanCare has improved our system, I cannot say so in good conscience. We've had workers in the MCO system who have been very helpful but overall, working in this system has generally been a frustrating effort. Our billing challenges emerged right out of the chute in 2013 and one would think by 2017, things would be running smoothly. Unfortunately that is not the case. Billing challenges were encountered, were followed up on with the MCOs, and thought to be resolved. Then later, what previously worked, for some unknown reason would no longer work and the process repeats. The billing issue du jour appears to be an on-going battle where providers are required to continually expend time and effort to correct or contest claims as they come through the KanCare/MCO system.

As a provider, we have also observed MCO decision contrary to the needs of person with IDD, causing great concern. One most recent MCO action pertained to communication about an individual with IDD and in their message wrote they (MCO) will be 'titrating down the high functioning individuals in order to reach their required residential days to ensure their quality of life.' That communication continued, 'Individuals requiring very minimal hands on assistance will be decreased by titration.' This matter is currently being challenged. The presumption that higher-functioning people can be titrated off services seems to me to offers an insight about not only the lack of understanding of LTSS for people with IDD but also

insight into what I believe is an embedded motivation to save money. The level of service and support for these individuals, would appear as assumed by the MCO, not really needed. The MCO communication continued, if during the titration, the person's quality of life begins to decline, the MCO would meet and re-evaluate. LTSS for people with IDD have been developed over time and implemented to meet the person's needs. As most recently seen, under this model, a weaning of paid supports has commenced, based presumably on the above mentioned belief that they are somehow unnecessary. The stated fear by parents and advocates that KanCare would disrupt services for vulnerable people has sadly become reality.

Prior to KanCare beginning in Kansas, we expressed our concern and belief that the LTSS for people were not a good fit within the KanCare model. Since then, we have worked to make the best of a difficult situation. I cannot speak to the savings that may have occurred outside the LTSS community services we provide. I can say the IDD - LTSS system today has not been strengthened by KanCare. In fact, it has been made more difficult and the negative implications are real for both providers and for the individual with IDD. A vital link to these individuals and their ultimate success in the community, is through the supports they are provided by community service providers.

The promise that we would have better outcomes and savings under KanCare, 'without any cuts in services or rates paid to Medicaid providers' simply is not accurate. I can appreciate the desire to have every element of Medicaid included in KanCare, however, the LTSS for people with IDD remains the round peg that continues to be forced into a square opening.

Respectfully submitted,

Gerard L. Michaud  
DSNWK - Hays

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**A CALL TO ACTION:** Let us reunite by strengthening and supporting each other, and forging out solutions for the fulfillment of our Mission.

**Our Mission:** We advocate with persons with disabilities and those who care about them, by planning and supporting a life of dignity, interdependence, and personal satisfaction in the community.

**Core Values:** Good Stewardship makes good sense; Good enough is not good enough; Everyone is important; We lead by example; Work should be rewarding and fun; Openness and honesty are best practices.

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**An independent voice for  
those served by KanCare.**

Barb Conant / 785 383-4272  
baconant@hotmail.com

Sean Gatewood / 785 230-5355  
seangatewood@outlook.com

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March 27, 2017

Thank you for the opportunity to offer comments regarding the request by the State of Kansas to extend its Medicaid KanCare 1115 demonstration project for a year. The KanCare Advocates Network (KAN) supports an extension of the existing KanCare program for a year, or until the current problems are resolved and the CMS compliance issues have been satisfactorily addressed.

KAN is a coalition of advocates whose collective interests include issues impacting children and adults who are served by KanCare under the Kansas Medicaid program. KAN has tracked the obstacles encountered by beneficiaries and the financial strain KanCare has placed on providers of services of both long term supports and services and medical care. To further document those issues, we hosted 3 public forums across the state in May, July and October and heard from at least 500 individuals, families and providers.

Since KanCare began, we have consistently heard from consumers and families across all waivers who struggle with finding and coordinating services to help them with their activities of daily living. This anecdotal evidence has been confirmed by the CMS audits which found serious compliance issues around plans of care, documentation, care coordination and eligibility determinations.

The State is in the very early stages of addressing the problems identified in the CMS compliance audits. Many of the problems are technical in nature and will require the State to commit significant staff and resources to fix them. Few of these fixes can be accomplished quickly and without the input of stakeholders and advocates.

KAN has been consistent in our message that the following problems must be resolved before subjecting KanCare members to more change. We have repeatedly opposed all actions to eliminate the current HCBS Kansas waivers until KanCare problems have been resolved and details of the any major program changes are made public.

The backlog issues, including problems within the KEES program, have impacted the health and well-being of thousands of Kansans waiting for home and community based services or nursing home care. Not only does the backlog need to be eliminated, we must be sure that it doesn't reoccur.



We also have serious concerns about the strength of the provider network to support additional changes, particularly within home and community-based services (HCBS) providers. The State has not yet provided any data to demonstrate that the health care and HCBS networks are able to meet the expectations of the KanCare demonstration project.

Adding program changes on top of a system that is struggling to put will continue to put the health and well-being of thousands of older Kansans and persons with disabilities at risk. An extension is necessary to address the serious compliance issues outlined by CMS. The KanCare program should not be renewed until the problems that currently plague the KanCare program are resolved.

**From:** Charlene Sims  
**To:** [KanCare Renewal](#)  
**Subject:** KanCare renewal comments  
**Date:** Monday, March 27, 2017 2:52:28 PM

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Here are my questions/comments/thoughts after attending the KanCare meeting at Olathe on Friday.

- I believe that not renewing KanCare and getting away from the privatized system would be the best. It seems to have worked a lot better than the system now. I have been involved in the Foster Child system as a consumer, advisory board member, and a social worker working for one of the companies.

Privatization does not work. The companies bid low so they can get the contracts and then they cut back on the services. Some companies could not even meet their requirements the first year of their contracts because they did not bid high enough. So the foster children and families suffered and still suffer. It is the same with KanCare.

- If KanCare is renewed, it would be best if the IDD population were pulled out. There is plenty of information citing that this system is not working for them, their families, their workers, etc. Kansas needs to set up a system that does not have a long waiting period for IDD services.

- If KanCare is renewed, applications and renewals need to be handled in a timely manner for all populations. My experience right now is with my mother who is in a nursing facility. My understanding is that the wait time for new applications is much too long.

My mother started in KanCare, I believe about 2012. It was very easy to apply, renew, and get information through the local DCF office.

When my mother moved from assisted living last August to a nursing facility, both the nursing facility and I notified the clearinghouse. Neither one of us received information but the nursing facility took the amount of my mother's obligation from the KanCare website.

To make a long story short, my mother underpaid at the nursing facility and now owes money for her obligation. When the nursing



facility bookkeeper finally was able to get through to the clearinghouse, we both received two envelopes with three letters stating three different obligations that had been determined. We think we are working on the correct one now. There is no excuse for this.

- If KanCare is renewed, the Clearinghouse needs new administration. Someone should be responsible for situations like the above.

Other problems are – my mother received a letter November (her regular time for renewal) which started out “Your request for medical assistance is INCOMPLETE. You will be DENIED if the following information is not received by 11/21/2016.”

I called immediately and asked if I had received a previous letter. The person that I talked with was apologetic and said everything was fine just send in the information. She even gave me a short extension because my mother’s bank statement for December was needed.

The next week I received another letter stating that her obligation would be starting January 2017. I called and asked if I still needed to send in all of the information, which I was waiting for. They said go ahead and that her caseworker would be contacting me. That never happened. According to them, the information on the letter was probably not correct because it had no basis for its determination and to just wait to talk with a caseworker.

So I sent in the information, and even added to it weekly with faxes of changes that would occur to her insurance, etc. in January. Still no one contacted me.

Finally on Feb. 1, the nursing facility and I received all of the letters mentioned above.

The last time I talked with someone there, they said they were filing a complaint/appeal (?) for me since my mother had not been notified of the amount of her obligation. I have never heard anything about it.

This is not good management. My mother now owes about \$1,300 in back payments because the information on the website was not correct.

- One more thing, the Clearinghouse phone system is very difficult to maneuver. The first options that are given are very easy to maneuver but the next options are very, very, hard to hear. I have complained about this every time I called. People with hearing difficulties as most elderly have might very likely give up. Good for Kansas, huh?

Then after you finally push a number, a recording comes on that says you must make a choice but then it says continue to hold. What sense does this make?

- Once again, if KanCare is renewed and Kansas really wants to take care of its elderly and disabled, new management is needed at the Clearinghouse. Someone needs to be accountable. These problems are unacceptable. I do want to say that every person that I talked to there was very nice and often apologetic.

Charlene Sims

913-898-6595

**JOHNSON COUNTY**  
KANSAS  
**Developmental Supports**

March 24, 2017

To: Dr. Susan Mosier, Secretary for Kansas Department of Health and Environment  
Tim Keck, Secretary for Kansas Department for Aging and Disability Services

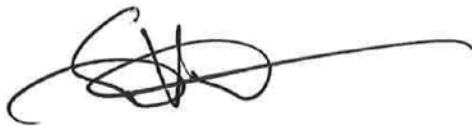
Re: Comments on KanCare Renewal

Thank you for the opportunity to comment on the State of Kansas's proposed extension of the KanCare program. This extension period could be a beneficial time for KDHE and CMS to evaluate the components to be included in the KanCare 2.0 RFP. During KanCare 1.0, we have learned that managed care simply does not work well with long-term supports and services.

As there was no true pilot or test period for LTSS for I/DD in KanCare, we have treated KanCare 1.0 as such. What we have learned is this, managed care for LTSS has been an exercise in managing costs. This is one of the most significant flaws in this program. It is impossible to keep the same rates that have been in place for nearly a decade and assume they can be squeezed to get more out of them. It simply doesn't work. An environment where three managed care organizations show a \$40 million profit while Medicaid providers experience a four percent cut and HCBS providers are cut through policy changes is not only not conducive for quality services but is in fact placing the system in crisis.

As a statewide system we have seen increased bureaucracy without the additional benefits promised prior to KanCare 1.0. Two key elements stressed prior to KanCare 1.0 were the assumption that those with I/DD would see increased employment opportunities in the community and have increased access to behavioral health services. Managed care has not brought additional expertise in either of these of areas or even a basic understanding of LTSS.

Finally, there have been literally thousands of comments urging the state to remove I/DD from managed care since prior to its inception. These comments come from those who receive the services, their families and their providers. We ask you to revisit the appropriateness of I/DD LTSS in managed care and remove these services from the KanCare 2.0 RFP.



Chad VonAhnen  
Executive Director  
Johnson County Developmental Supports

cc: James G. Scott, CMS Associate Regional Administrator for Kansas City

Chad VonAhnen  
Executive Director

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Lenexa, KS 66219-1223  
jocogov.org

**From:** Shari Wright  
**To:** [KanCare Renewal](#)  
**Subject:** KanCare renewal  
**Date:** Thursday, March 23, 2017 10:03:59 AM

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I will start with the obvious conclusion. Whatever you do do not renew this contract. This process is the biggest joke. It must be brought back in to the regional DFS offices like before.

I can speak from experience. I started the process for my elderly, disabled father right before the move to KanCare happened. I spoke to a very capable knowledgeable person in a local office. Then before the original application was completed KanCare took over.

My only choice was to then deal with an office in Topeka. Many complicated documents were necessary with proof of various items necessary. Not trusting that a mailed application would work, I drove to Topeka and went through the application carefully with a staff person. It seemed to go well. Then I waited. And waited. After several months something came back that completely misstated my fathers income. I had to make several calls to straighten it out.

Again something came back that was still wrong. He had been accepted but the income amounts were still wrong. I faxed back additional proof. And never heard back despite repeated calls.

Then this November we received a renewal request and were told we had two weeks to apply or be denied. Again I drove all the paperwork to Topeka and was told everything was in order (although the ongoing mistake in income was still not rectified.) Then I waited and waited. We called every week and were told things were in process.

Over three months later we received a letter saying the application was incomplete and would be denied if we didn't respond in a week. The missing item was a February bank statement. For an application that was due in November and which, when made in November, we included a November bank statement. Just let that sink in.

I could go on and on but the bottom line is that it is clear the sole purpose of the KanCare process is to keep putting up barriers until someone gives up or they can otherwise be denied. And my story is just one in thousands.

Stop this charade. End KanCare. Bring the process back to local offices. Expand Medicaid. Do what is right for the thousands of hard working Kansans who now need help at the end of a long tax paying life.

Shari Wright  
Lenexa Kansas resident

Sent from my iPhone

Kansas Medical Assistance Program  
Office of the Fiscal Agent  
P.O. Box 3571  
Topeka, KS 66601-3571

RE: KanCare Medicaid Program  
RE: State Staff\* Kansas versus Federal

I have been to several of the “State” staff meetings. My (2) son’s and daughter both have tried to receive the Medicaid of Ks – help with No help what so ever. I have asked many questions about the “State of Kansas KanCare Program and just yesterday talking to KanCare employees about a 72 year old man – he has Medicare and Wellcare but KanCare Reps would not take his brother off legal documentation and sending copies to him – Federal HIPPA Violation – federal not State.

My (2) sons and daughter have gone to all Social Security (Federal) and ring to get them disability or at least SSI for at least a Medicaid Card – Federal appts state ‘Yes’, but Ks statues states ‘No’ and they have paid into Federal and State all their life and now Ks states ‘No’ we will not help. Plus (1) son has the program and does not even stand behind the laws of KanCare to protect him. The mileage statements Logisticare – AZ and OK – only states do not apply to KS. I take my son to appt.s in Wichita and all over the State and to Dr. appts. I do (his Mother) I am on disability myself and have spent hours and of my own dollars taking to appts. The last 3-4 years and never received a dime. The Program is and always will be a scam!

Staff employees only listen to who they feel can contribute not the elderly and the middle aged that need the help. Social Security is Federal and the hospitals- doctors and the education is for them. The money is not for the patients. I know – my family has gone through all the politicians and reps. and all are still not Federal Compliant. I can prove all. The mistakes- the cover-ups and the lies the KanCare staff still tell. No Ins – No Care. ER and jail-time in Cowley County if not paid.

State Staff need to educate themselves before trying to tell the people especially coming to Cowley County. My son cannot attend because most of the people that truly needed the help have now lost vehicles – houses and the self-worth they use to have. Sending this back because of the mother of (3) – all have lost everything they ever owned and loved, but suicide has never entered their mind only staying alive.

Need to practice what you Preach. Federal is not State.

(1)Federal Law – (2) State Law – and (3) Local Law

Cowley County lives by local law. Good luck but this is one person that have been at the meetings and the Staff were rude and ignorant of (1) person that have ask questions and ignored. Plus files and files and files of the True Medical records and most of the hospitals in Wichita and surrounding areas are not Federal HIPPA Compliant.

Charrie Ivie – Jenkins

March 23, 2017  
Jan Gallagher  
2301 W. 105th St.  
Leawood, KS 66206  
913 381 5706

KDHE Kancare Extension Committee

The Medicaid HCBS (but not necessarily Kancare) program is necessary and absolutely vital to the livelihood, health, and independence of my son, who has Muscular Dystrophy and utilizes the PD waiver for 24/7 care. It needs to continue.

However, I am not convinced that having it managed by for-profit Managed Care Organizations (MCO's) is the most efficient and best use of Medicaid dollars. The current HCBS system, while vital, is also failing my son.

I have outlined below the main policies and procedures in place that make it extremely difficult for my son to get the help he needs to live independently.

### **1. Pay Rate**

Currently, the pay rate for direct support workers is on average \$9.75 and no higher than \$10.00 with no healthcare or other benefits. The work involves taking care of personal needs including bathing, toileting, changing catheters, cleaning tracheotomy, change ostomy bags, preparing food, feeding, cleaning etc. Basically, everything we take for granted that we can do for ourselves has to be done by caregivers. This pay is extremely low for the type of work, and it is extremely difficult to impossible to find people who will accept this low wage for the responsibilities. I just learned that McDonald's and FedEx pay \$12.00 an hr.

The FMS provider gets an hourly reimbursement rate that has to be used (but barely covers) for unemployment taxes, workers comp insurance, etc.

The pay is not adequate my son can only attract low quality unreliable workers. He experiences high turnover and people who do not show up. He has a high level of need. The job is complex, requiring intelligent people with critical thinking, spatial reasoning, intuition, and other problem solving skills. People with these skills are typically found in educated fields and require higher pay. My son's life, safety, and health are on the line. It's imperative to have high quality reliable workers. It is simply not a competitive rate that is commensurate with the level of importance of the job and the skill required.

My son has been looking for people for two (2) years and has only been able to hire a few people on and off after much effort and turnover. It has become a full time job and nearly impossible to find good people. Time after time people back out before even starting.

The cost of advertising is approximately \$100 a month. We run around town putting ads in coffee shops and grocery stores.

Agencies are having trouble finding and keeping quality people. My son had an agency and they could not keep his shift covered, and when they did the worker wasn't able to proficiently help (it was too much for them). It is a common problem for consumers to deal with agencies that cannot provide qualified reliable people. Keep in mind that when my son does not know when, or if, a person is going to show up, he is alone and in danger. Plus, he has to train every person and with high turnover, it is a constant challenge. I called every agency on the list for his MCO and no one would provide a caregiver for him. The reason is many are not equipped to provide



night support and the type of care he needs, and/or they could not find people to do the work.

These dedicated caregivers deserve and require a competitive pay. According to this comprehensive study by [Genworth 2015 Cost of Care Survey](#), the going rate in Kansas is between \$14 and \$25 and hour. <https://www.homehealthcareagencies.com/resources/home-health-care-costs/>. Keep in mind that encouraging people to live independently and out of nursing homes is much more cost effective. The care is better and consistent when the rate is competitive.

### **Solution**

Increase pay to compare with going market rate. And do a financial study on the cost of care givers who work in Nursing Homes providing comparative care. Include benefits and the profit the Homes/Institutions receive. In the past, these studies show it is more cost effective to allow individuals to stay in their own environment.

### **2. Background Checks**

In addition to a Kansas Bureau of Investigation (KBI) criminal check, it is now (since January 1<sup>st</sup>, 2017) required to also have Department of Children and Families (DCF) Adult Abuse and Neglect and Child Abuse and neglect registry checks done, as well as some other checks. These DCF checks create an undue burden on both the consumer and FMS financially.

The KBI check is immediate.

The DCF checks take up to three (3) weeks each. It is a manual process that has proven to be unnecessary and inefficient. The DCF check is based on an internal investigation and may not result in the person being charged with a crime. The law says a person with a criminal background cannot receive funds from the Kansas taxpayer. Therefore, if a person who is investigated, and not charged with a crime, should be free to be hired. When a person is investigated, and charged with a crime, the KBI check identifies the person. The three (3) week delay is extremely limiting as many potential hires find higher paying jobs while waiting. Many workers are out of work and need to start working immediately, and will take another job. It is important to start the working relationship as soon as possible. Plus, he is usually short of workers, and needs them to start immediately. He has no one otherwise. Waiting means he doesn't know if they will be available once the background check comes back, and has to start the process over. His disability does not go away while these checks are taking place and he is left without care. This is dangerous and a threat to his life.

Currently, these background checks are mandatory, and there is no way for him to refuse/waive any checks. And there is no procedure in place to be able to hire someone on a "conditional" basis until the background check comes back.

The State is charging the Financial Management Service (FMS) providers for every background check. FMS receives \$115 a month per consumer to cover all costs related to services provided. Some FMS providers are passing the background check fees onto the consumer at, my son was asked to pay \$35 per background check (this is not the full price of the check). My son has experienced hiring three (3) or more people in a month, and had to have more background checks ordered when people drop-out/change-mind and/or do not show up for work after accepting the job and filling out paperwork. People are finding other employment during the three week wait period. Some FMS pass the cost on to the employee and reduce their first paycheck. The scope of work for FMS involves administering extremely rigorous payroll rules, (extensive new hire package) imposed by the State of Kansas, and comply with IRS requirements etc. Processing pay checks for up to eight people

when my son is fully staffed is part of the expenses of the \$115 monthly reimbursement. This is prohibitive to conducting business and many FMS have gone out of business. Due to the high turnover in employees these companies lose money in this process. This caused my son to have to change payroll agency several times, and adds to an already stressful lifestyle.

### **Solution**

One, create a system where background checks provide immediate results.

And Secondly, if the DCF background check is not considered unconstitutional and/or violates privacy act, require the potential employee sign a waiver for any pay received if the background check comes back negative. This would weed out potential employees who know they have a record, and allow for the consumer to have their daily needs met. In the case of my son, these are life sustaining needs.

### **3. Lack of Flexibility**

Every time a consumer makes a change in hours between Agency hire and Direct hire workers, the Individual Service Plan (ISP) has to be changed. They have to provide the exact hours the Agency will provide vs. Self Direct hours. When the agency fails to send someone and the consumer's direct hire person works as emergency back up, the direct hire cannot be paid. In situations where a direct hire worker leaves or the situation changes suddenly, the agency cannot take on those hours without a change in the plan. The MCO requests a week notice to make the changes. The case manager has to make the changes in the system as well as all the paperwork, which has to be faxed to the agency and the FMS provider. It has to show up in the Authenticare system first. This lag in time is a hardship and could cost lives. It has been my son's experience with several agencies that they take their time in responding, then sending someone out for intake, and finding people for your case which has taken three or more weeks.

### **Possible Solutions**

- Provide accessible case managers/social workers with knowledge of healthcare industry and needs of consumers, not corporate data managers.
- Require MCO's to vet and monitor the Agencies that sign on to provide caregivers. The system has to become more responsive either via electronic means or emergency practices in place.
- Allow consumer hours to be interchangeable between self-direct and agency direct. As long as no more hours are billed than what the consumer has on his plan, then it shouldn't matter which agency(s) or FMS provider bill.

### **4. Training**

Training (specific to the consumer) for workers is extremely important, yet unpaid. A current worker needs to be able to train the new worker; therefore the current worker is the one being paid. This is very specific to the consumer's needs, not generalized training. For my son, it takes between 3 to 10 hrs (depending on the person's ability to learn) of training to get someone proficient in helping him.

Currently my son asks new hires to complete training unpaid. According to Federal Law, he should be paying for training. However, he has no choice, as he can not possibly pay for training all incoming hires, especially when there is such high turnover and lack of retention due to low wages (see section 1 above.)

### **Solution**

Provide funds to access for training. This puts the burden of prohibitive laws and restrictive regulations on the State not the consumer and worker.

### **5. Lack of Emergency or Extraordinary Help/Procedures**

Currently, there are no procedures in place when there is an emergency.

What does a consumer do when they can't find anyone to work, or agency hire workers fail to show up to work?  
The consumer is alone and unsafe.

What is the process when the consumer does not want to go to the nursing home and has a right not to be, but there are no services available to fill in the gap of services?

What happens when a consumer contacts Nursing homes and they say the case is not within their scope of work (or case is too difficult or costly)?

What does a consumer do when they know the Nursing homes won't be able to keep them safe?

We have experienced these situations and asked these questions of the MCO and State officials, but no one has provided an answer.

### **Solution**

Qualified case managers with access to resources need to be available. It is critical to share of information between agencies, and have access to emergency funds during critical situations.

Paying a going rate, would be the solution because the consumer could retain workers and reduce turnover.

I appreciate that no adverse changes are being proposed, however, there are problems with the program as it currently stands, and I implore you to consider making changes to the program, in order to make it truly and fully meet the needs of Kansans like my son. His life and independence depends on it.

Jan Gallagher

March 20, 2017

Comments Related to the One Year Extension of KanCare

Mike Oxford, Exec. Dir.  
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## Overview

The Topeka Independent Living Resource Center (TILRC) is federally funded Center for Independent Living (CIL) and is a civil and human rights organization. Our mission is to advocate for justice, equality and essential services for a fully integrated and accessible society for all people with disabilities. TILRC has been providing cross-age, cross-disability advocacy and services for over 30 years to people with disabilities. Our agency has been particularly interested in and committed to assuring that people who require long term services and supports have access to information, services and supports that offer choices; choices that promote freedom, independent lifestyles and dignity, including the dignity of risk. TILRC is overseen, managed and operated by people with disabilities.

The basic premise of the one year extension of KanCare appears to be continuing for one more year to do the same as currently is the case. This seems to be a matter of practicality. It may not make sense to consider significant changes for just a short extension. Increased access to, and use of, primary health care while decreasing use of the emergency room has been reported as has overall improved coordination of health care services. Improved health outcomes at a lower cost is one of the benefits that can occur with a managed care service delivery model.

## Quality Measures, Metrics & Reporting

Questions remain, however, about the efficacy of the managed care model vis-à-vis home and community based services and supports. Available research seems to indicate that some advances in measures of quality may obtain with managed home and community based services and supports (HCBS), but cost savings concomitant with advances in quality are uncertain according to the limited evidence that exists. Topeka Independent Living Resource Center continues to have concerns with KanCare as it pertains to home and community services and supports.

Reports from KDADS/KDH&E on increases in quality and on cost savings metrics have been about provision of managed acute and chronic health services of KanCare. However, managed HCBS remains a cipher. KanCare needs to develop and adopt and benchmark clear quality performance measures for HCBS and begin reporting on them To the general public. Over this next year a workgroup made up of people with disabilities of all ages, including consumers of services, providers, advocates and academics needs to be appointed to develop standards and measures of quality of HCBS for KanCare. Such measures need to include, for example, community integration and inclusion, independence, self-care, improved health and well-being, employment, and overall satisfaction. Clear information and reporting about quality measures and metrics would go a long way toward fostering better understanding about how KanCare is working for those served through HCBS.

In late 2016, the National Quality Forum published a report on quality measures for HCBS. This report represents the product of two years of work that included top researchers and thinkers representing universities, state government,

the aging community, the disability community, and the HCBS workforce in the area of home and community-based long term services and supports. This document should form the basis for KanCare HCBS quality measures and related metrics and would provide a great starting place from which a workgroup on managed HCBS quality could begin. The link to the NQF document is below:

[http://www.qualityforum.org/Publications/2016/09/Quality\\_in\\_Home\\_and\\_Community-Based\\_Services\\_to\\_Support\\_Community\\_Living\\_Addressing\\_Gaps\\_in\\_Performance\\_Measurement.aspx](http://www.qualityforum.org/Publications/2016/09/Quality_in_Home_and_Community-Based_Services_to_Support_Community_Living_Addressing_Gaps_in_Performance_Measurement.aspx)

## HCBS Care Coordination

Inadequate care coordination also remains an issue for HCBS within KanCare. TILRC continues to receive reports that consumers do not know their care coordinator, that any contact with a Care Coordinator is infrequent, and that there is too much turn-over. Coordination of HCBS for many consumers necessitates more frequent contact and assistance than is currently the case with KanCare. After all, living a full, rewarding, person-centered life is the point of HCBS. Too much emphasis appears to occur around health-related appointments and needs. The heart of person-centered planning and service delivery is concerted efforts toward making all of an individual's goals and dreams in life a reality. Otherwise, "person-centered" becomes just another piece of current jargon. The Care Coordinator should be the hub around which revolves a host of community supports, services and events that may interest a given individual.

## Referrals to CILs

The lack of referrals from MCOs to community disability organizations such as CILs remains problematic. Topeka Independent Living Resource Center (TILRC) is uniquely situated to assist KanCare consumers with all types of disabilities and of all ages. As a federally funded Center for Independent Living (CIL), it provides assistance with skills building, with learning self care, with locating and securing housing or transportation, with assistance transitioning from a nursing facility or other institution and much more. Despite all of this, referrals to our CIL from KanCare Care Coordinators for these types of traditional CIL services remain practically nil. Care Coordination as it pertains to person-centered HCBS needs to increase interaction with community agencies such as CILs.

## IDD waiting list

While the IDD Waiver continues to serve many individuals well, the waiting list for IDD services remains a chronic problem. Little progress has been made under a managed care model. A multi-year plan should be developed to tackle this longstanding barrier to services for thousands of the IDD population forced to wait for years to be served. This plan should be developed with input and oversight by people with disabilities, including intellectual and developmental disabilities, family members, providers and advocates. Based on the timeliness of the plan, there should be a special appropriation each year that would incrementally reduced the size of the waiting list until it has been eliminated. Services of current consumers of any HCBS program should **not** be reduced just to free up money to pay for reducing the IDD Waiver waiting list. New funding should be appropriated for this endeavor.

## PD Waiver Average Per Capita Expenditures

The Physical Disability (PD) Waiver continues to serve many individuals in a satisfactory manner. TILRC has received reports of unnecessarily deep cuts to service plans, however. It also appears that based on the current census and the current budget figures for this program, the PD Waiver has had its average per capita costs significantly reduced. For years prior to KanCare's commencing, the average per capita expenditure was about \$22,000 for the PD Waiver. It appears that the average per capita expenditure is now about \$17,000. It is true that averages do not tell the tale of what individual expenditures may be. However, this much of a reduction in overall per capita spending for PD Waiver services causes concern about support for those with the most significant needs. A question must be raised as to

whether individuals with high service needs that are over the cost cap are unnecessarily ending up in nursing facilities. This question is of particular concern because national research indicates that working age individuals with physical disabilities are one of the fastest growing cohorts of nursing facility admissions. A related concern is that numbers of individuals transitioning from nursing facilities to their own homes have plummeted. Is the civil right to community integration and independence being compromised by KanCare's cost containment motives?

### **Money Follows the Person**

The loss of Money Follows the Person (MFP) may very well be a catastrophic loss of basic liberties and civil rights for institutionalized individuals and those at imminent risk of being institutionalized. The number of individuals transitioning from nursing facilities appears to be less than half of the number from the prior year. Care Coordinators and state program partners often impose special terms and conditions on people seeking to leave institutions, treating community integration as a privilege, not a right. Very few agencies take referrals and provide the hands-on, direct assistance and support to individuals that is necessary to effectuate successful transitions. A significant issue is that an agency must expend its own resources and then pursue reimbursement from the MCOs; a process that is time-consuming and never results in being reimbursed for all of the expenses. These costs must be covered if the twin goals of cost-savings from use of HCBS instead of institutions and increased independence and life-satisfaction for people with disabilities are to be realized.

TILRC is appreciative of the earnest offer of KDADS staff to work on structuring a state MFP program to continue transition efforts post-federal MFP. The plummeting numbers served while there are substantial federal resources is cause for grave concern, however, and indicate there are current problems that must be addressed. In a similar vein, the apparent significant reduction in total financial resources available per capita in the PD Waiver is also of concern and raises a question of correlation between reduced MFP numbers and reduced per capita expenditures.

TILRC appreciates the opportunity to provide comments and looks forward to continuing a productive relationship with KanCare and the state agencies that oversee it.