

**Kansas Medicaid: Evaluating Program Satisfaction, Access to Care, and Unmet  
Needs of Adults with Serious Mental Illness**

(Contract #FY16-4766)

**Project Final Report**

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## Executive Summary

This project surveyed Kansas Medicaid (KanCare) enrollees with serious mental illness (SMI) about their experiences with the KanCare program. In particular, the project sought to assess participants' overall satisfaction with KanCare, their access to services, and their unmet needs. The authors surveyed a total of 189 KanCare enrollees using services at six Community Mental Health Centers across the state. Overall, 52.9% of respondents reported being in fair to poor health and 73% reported having at least one co-occurring physical health condition.

### Participant Satisfaction with KanCare

- Having affordable coverage for mental and physical health services and prescription medications
- Less worry or increased ease of mind knowing they have coverage
- Coverage protects against large out-of-pocket expenses

### Barriers to Care and Unmet Need

- Expand the range of services covered and/or level of coverage for existing services, especially adult dental coverage, medical supplies and equipment
- Reduce enrollees' out-of-pocket expenses
- Provide assistance understanding the benefits and services available
- Remove barriers to accessing needed medications, such as prior authorization requirements
- Improve transportation services
- Expand provider networks
- Improve communications with managed care organizations (MCOs) and the state

Project results confirmed findings reported by the federal Centers for Medicaid and Medicare Services (CMS) in January 2017 as part of KanCare oversight. For example, respondents reported difficulty obtaining information about their coverage from the MCOs and the state, difficulty obtaining initial or renewed eligibility for KanCare, and problems with provider networks.

Survey findings also have implications for possible Medicaid expansion efforts in Kansas. First, were expansion to be implemented, the state's KanCare eligibility system would need improvements to process the additional applications. Second, many survey participants reported they are unable to access KanCare services due to large spenddowns. These individuals and others might be relieved of a spenddown obligation under Medicaid expansion, potentially improving their access to needed services. At the same time, the state would receive a larger federal match for these Medicaid enrollees.

Finally, survey participants expressed fear about losing their coverage due to health care policy changes at the federal level and budget concerns at the state level. Some shared being worried about losing coverage if they complained to the MCOs or the state, echoing findings about adversarial communications from the state cited by CMS.

## **Purpose of the Project**

The project was designed to evaluate access to care for Kansas Medicaid enrollees with serious mental illness (SMI) and to document their experiences with coverage and areas of unmet need. Project findings could then be used to assess the capacity of Kansas Medicaid to meet the needs of current beneficiaries with SMI and to identify areas of capacity-building needed to support possible Medicaid expansion in the state. Through surveys with enrollees, the project identified components of Medicaid coverage that were perceived by enrollees as most helpful and those needing modification.

## **Background**

Starting in January 2013, the state of Kansas began operating its Medicaid program, called KanCare, under a federal waiver that allowed it to contract administration to three private managed care organizations (MCOs). A potential benefit of managed care is that enrollees may receive assistance in navigating their services and support in accessing preventive care. However, a survey with KanCare enrollees with disabilities in 2013 found that 46% of respondents had experienced at least one problem accessing care or services within four to eight months after the transition to managed care (Hall, Kurth, Chapman & Shireman, 2015). Problem areas included limitations in covered benefits, narrow provider networks, lack of effective communication with managed care organizations, difficulties with care coordination, and issues with non-emergency medical transportation. While 8% of respondents to this survey reported having SMI, no evaluations focusing only on the experiences of people with SMI in KanCare have been conducted. Similarly, little information exists nationally on the outcomes of individuals with SMI in Medicaid managed care. A recent study in Illinois (Owen, Heller, & Bowers, 2016) found that Medicaid enrollees with SMI fared worse than enrollees with other disabilities and had more unmet needs under both fee-for-service Medicaid and Medicaid managed care models.

Given this population's significant health care requirements, historically poorer outcomes, greater unmet needs, and the potential for increased enrollment via Medicaid expansion, more information about specific areas for improvement is needed, both in Kansas and nationally. In addition, during the course of this project, the federal Centers for Medicare and Medicaid Services (CMS) found the KanCare program to be out of compliance with federal requirements and expressed concerns to the state about several aspects of the program. Some project findings directly reflect and inform issues identified by CMS.

## **Methods**

In order to document the experiences of Kansas Medicaid enrollees with SMI, we partnered with six community mental health centers (CMHCs) across the state, in Johnson, Wyandotte, Montgomery, Shawnee, Sedgwick and Barton counties. In consultation with staff from the HCFGKC and these CMHCs, we developed a survey, which was administered in person or over the phone with adult Medicaid beneficiaries with SMI. The survey (see Appendix A)

consisted of demographic items, both closed and open-ended questions to obtain information about respondents' satisfaction and experiences with KanCare, and identify areas of unmet need and suggestions for improvement. Questions from existing federal and state surveys were also included to facilitate comparisons with the general Kansas population. At the request of CMHC Executive Directors we also included a question asking participants for feedback about services and supports they need or wish were available at their local CMHC (see Appendix B). Survey participants were recruited via fliers, newsletter articles, and mailings from the CMHCs that included a toll-free phone number to call to take the survey over the telephone and dates someone would be at their local CMHC to complete surveys in person. A total of 189 individuals from across the six areas completed the survey between October 2016 and February 2017, with a majority completed in person. A table of the distribution of the sample by CMHC location and method of survey completion is provided in Appendix C. The survey was administered by one of the authors either in person or by telephone in order to maximize validity and reliability. This methodology allowed uniform explanation and clarification of questions and terminology (e.g. CMHC caseworker/counselor versus a Care Coordinator from an MCO).

Quantitative data from the surveys was analyzed using SPSS software to investigate factors associated with differing levels of satisfaction and access. Qualitative data from open-ended questions was transcribed and entered into NVivo software for coding and analysis. Responses to open-ended questions were coded for major themes, and quotes were chosen to represent common themes and illustrate important findings.

## **Results**

### Participant characteristics

Sample demographics are provided in Table 1. Respondents ranged in age from 18-83 and were primarily female (68%). More than half (60%) of the sample were white, and less than 10% identified themselves as Hispanic. The most common level of education was a high school diploma or GED. Less than 1 in 6 reported being employed for pay at any level. Participants were geographically located in 10 different Kansas counties.

A majority of respondents were renting a home or apartment. However, it is important to note that 5.3% of the sample identified themselves as homeless, and of the 49 participants who lived with family members without paying rent, in a group home, in a shelter or were homeless, 21 of them indicated this was a temporary living situation. These findings highlight the risk of unstable living conditions among this population, and their experiences provide insight into the additional challenges to receiving and coordinating needed medical care in these circumstances.

Slightly more than half of the sample were dually eligible for Medicare and Medicaid and just over a quarter (27.1%) had to meet a spenddown obligation for Medicaid. Of those with a spenddown, 71.1% were able to meet their spenddown at least once in the last year. With regard to MCO representation, slightly more than one-third of the sample belonged to Sunflower, one-third belonged to Amerigroup, and just over one-quarter belonged to United.

Approximately 5% of the sample could not identify which MCO they had for their Medicaid coverage.

All respondents had a SMI diagnosis. Respondents were asked to report the specific condition they considered to be their primary condition first. Using this method, the most frequently reported primary mental illness was schizophrenia, followed by bipolar disorder and depression. Slightly more than half (51.9%) reported having more than one mental health condition. Respondents reported having average of 14.96 days of poor mental health during the last 30 days, compared to 3.2 days for the general Kansas population (RWJF, 2017). Overall, more than one-third of participants reported having more than 15 days of poor mental health during the past month.

Overall, 52.9% of respondents reported being in fair or poor health (compared to 15% of the state’s general population; RWJF, 2017), indicating that this is a population that strongly needs access to health care. Similarly, 73% of respondents reported having one or more chronic physical health conditions in addition to their mental illness. Approximately 1 in 5 respondents had not had a physical exam in the past 12 months. In addition, 55% were current users of tobacco, compared to 18% of the general population (RWJF, 2017). These findings underscore the significant needs and importance of access to care for this population of Medicaid beneficiaries with SMI.

CMHC staff were consulted regarding the representativeness of the sample and reported that the demographics reflect the Medicaid population they serve. No significant differences in participant experiences with KanCare were found on the basis of age, gender, primary diagnosis, geographic location, or MCO.

Table 1. Participant Demographics (n=189)

Demographic Category	n	%
<b>Gender</b>		
Female	129	68.3
Male	60	31.7
<b>Age</b> Range = 18-83   Mean = 45.05 (SD=12.53)		
<b>Race</b>		
White	112	59.7
Black	39	20.6
Multi-racial	17	9.0
American Indian	9	4.8
Pacific Islander	1	0.5
Asian	1	0.5
Other	1	0.5
Prefer not to answer	9	4.8
<b>Hispanic/Latino(a)</b>	17	9.0

(table continues)

<b>Demographic Category</b>	<b>n</b>	<b>%</b>
<b>Education Level</b>		
Less than high school	32	16.9
High school diploma or GED	73	38.6
Some college	57	30.2
2- or 4-year degree	25	13.2
Graduate degree	2	1.1
<b>Employed for pay</b>	26	13.8
<b>County of Residence</b>		
Shawnee	39	20.6
Sedgwick	37	19.6
Wyandotte	33	17.5
Johnson	32	16.9
Montgomery	27	14.3
Barton	10	5.3
Chautauqua	4	2.1
Cowley	3	1.6
Pawnee	2	1.1
Rice	2	1.1
<b>Living Situation</b>		
Rents home/apartment	115	60.8
Lives with family without paying rent*	31	16.4
Owens home/apartment	21	11.1
Group home*	8	4.2
Homeless or living in shelter*	10	5.3
Renting a room in a house	4	2.1
*Live with family, in a group home or shelter or homeless (n=49) <b>Is this living arrangement temporary or long-term?</b>	28 long-term 21 temporary	57.1 42.9
<b>Medicaid/Medicare dual-eligibles</b>	95	50.3
<b>Has Medicaid spenddown</b>	42	27.1
<b>Mental health condition (primary)</b>		
Schizophrenia	59	31.2
Bi-polar	43	22.8
Depression	32	16.9
PTSD	26	13.8
Anxiety	14	7.4
ADHD	8	4.2
Other (anger, mood, paranoia)	3	1.6
Prefer not to answer	4	2.1
<b>Reports &gt; 1 mental health condition</b>	98	51.9
<b>Report &gt; 15 days of poor mental health out of last 30</b>	69	36.5

(table continues)

Demographic Category	n	%
<b>Has physical health condition (comorbidity)</b>	138	73.0
Musculoskeletal	29	21.0
Diabetes	27	19.6
Cardiovascular	19	13.8
Respiratory	12	8.7
Other	12	8.7
Neurological (includes Traumatic Brain Injury)	11	8.0
Gastrointestinal	8	5.8
Cancer	6	4.3
Intellectual/Cognitive	6	4.3
Visual Impairment or Blind	3	2.2
Chronic Pain	3	2.2
Prefer not to answer	2	1.5
<b>Reports &gt; 1 physical health condition</b>	66	47.8
<b>Report Fair or Poor Health</b>	100	52.9
<b>Has <u>not</u> seen a doctor for physical exam in the last year</b>	34	18.0
<b>MCO</b>		
Sunflower	68	36.0
Amerigroup	64	33.9
United	48	25.4
Don't know	9	4.8
<b>Currently Smokes or Uses Tobacco Products</b>	104	55.0
<b>Of non-smokers, those who smoked in the past (n=85)</b>	29	28.2

### Satisfaction with KanCare

The survey included a question asking respondents to rate their KanCare health plan on a scale of 0 to 10, with 0 being the worst plan possible and 10 being the best plan possible. Overall, the average score for this question was 7.3. When asked what they like most about their health plan, the four most frequent types of responses included having coverage for mental and physical health services, the fact that out-of-pocket expenses were low and affordable, that it covers prescription medications, and that they simply had less worry or increased ease of mind knowing they had coverage. When asked about specific services that were most helpful, coverage for prescriptions and mental health care were emphasized the most. CMHC services and transportation were also specifically mentioned by a number of respondents. These positive findings seem somewhat in contrast with the numerous, often serious, problems with coverage identified by participants and described below. However, participants also expressed a gratitude for having any coverage at all and a fear of losing the coverage due to state budget concerns or Medicaid policy changes. Several spoke about having KanCare within the context of their own or others' experiences having no health insurance at all

(i.e. “It is better than having nothing.”). It should also be noted that participants were overwhelmingly happy with the care, services and support they receive from their CMHCs. Survey respondents offered many examples of instances where CMHC staff spent hours of time assisting participants with navigating KanCare benefits and serving as an intermediary between the participant and the MCO or the state to advocate for specific services on a case-by-case basis.

### Participants’ Satisfaction with KanCare

“[KanCare] covers what Medicare doesn't. It's very helpful, care would cost me a fortune otherwise.”

“Being able to go to the doctor. If I didn't have KanCare I'd be in the emergency room all the time.”

“They [MCO staff] are very friendly with customer service and they've been very friendly to me over the phone and I see a counselor twice a month, a social worker, and they've covered that... And when you go to a wellness visit you get points on your account for gift cards and that's been kind of a cool added feature that I wasn't expecting.”

“Being able now to have a counselor and go to a doctor. Until getting this I hadn't gone in years.”

“They [MCO] saved my life. I got a blood sugar test when I first got [MCO]. I didn't know I had a problem, they found it and now I've worked on it and it went down. I didn't end up getting diabetes. I probably would have too or lost my feet or something without even knowing my sugar was high.”

“I used to have a care coordinator to assist with making appointments and making sure I stayed on meds and got to the doctors. That was helpful.”

“Having KanCare made me able to go to a counselor. I couldn't afford to go before and in the last several months I've gotten stabilized and now have a stable place to live, too.”

“No worry about going to doctors, especially a therapist. I am now off meds because I can see my therapist at the mental health center regularly.”

“Diabetic support such as a newsletter with tips, the nurse line I can call with questions, and testing supplies; not quite the kind I was used to, but they cover them.”

“I'm able to get a lot of help, which I have needed lately...Not being in crisis now feels so great. I'm glad I had coverage so I didn't have to worry about that in addition to everything else.”

“...being able to see the doctor when I've needed to. I have family that have no insurance and they don't go to the doctor.”

“I have less fear because I know I have insurance if something goes really wrong.”

Unmet Needs and Barriers to Care

More than half of the sample mentioned barriers to care that were related to the range of services that are covered or the level of coverage for existing services. Another common category of response was related to the first, suggesting that financial aspects of KanCare need to be improved so that enrollees are not required to pay as much out-of-pocket in order to access needed care. These financial concerns were raised throughout participant responses and not dependent upon questions, consequently they are included throughout the findings related to the services and support that are reported as needing improvement in the following sections.

Specific services and supports that participants reported as unmet needs or barriers to care fell into the following categories: information and communication, prescription drug coverage, dental care, non-emergency medical transportation, provider networks, and care coordination. Each of these topics is covered in more detail below with quotes from participants included under each topic.

**Information and Communication.** Many respondents’ comments centered around being unable to fully understand their coverage and needing more or better help understanding it than is currently offered. In general, health insurance literacy was quite low and for some KanCare was their first experience with an insurance company. Enrollees reported extreme confusion about what services are covered and which providers are in network and frustration at not being able to obtain that information in a timely and accessible manner. Several pointed out that the information booklet was overwhelming or unreadable to them and that it wasn’t updated frequently enough. In trying to find accurate and up-to-date information, respondents frequently reported difficulty reaching someone by phone, getting inconsistent or inaccurate information, or being directed to the website. This was especially problematic for those without internet access. The lack of knowledge and assistance was a significant barrier to navigating the health care system and accessing needed services. As a result, participants were not aware of covered services, could not identify how to access needed services, or experienced large bills or denial of claims or recommended treatments without fully understanding why. Perhaps related to this area, respondents also frequently cited a need for improved customer service from both the state Medicaid agency and the three MCOs. These communication issues were cited by CMS as an area of non-compliance for the KanCare program and will be discussed further below.

**Information & Communication**

“They don't ever explain anything to you, tell you why something isn't covered or even tell you what you are eligible for never happens. I don't even try to get things anymore. I am completely confused about KanCare, I get things in the mail and I don't understand them. I don't even try to get supplies because no one really knows what is available. The people at

[MCO] don't know. Having someone who really understands the program and knows what you qualify for and can help you, I need that. I think I qualify for some at home care, but I've never been able to figure it out. I've mostly just given up...The stress of figuring it out or fighting with them, it only aggravates my mental illness. I basically have just given up and I don't even want to mess with Medicaid anymore and doctors they don't want to either they just decide not to take KanCare, not to mess with it.”

“Calling [MCO] is a nightmare. You never get through, you're on hold. I finally gave up altogether and went to my CMHC to ask questions. My kid also has KanCare though and the number you call for them is different and they are so helpful. Same company, totally different experiences.”

“The information book they send is so thick plus I can't read it with my vision issues, even with my glasses and magnifier it is difficult. No one seems to know if they have a large print version, they tell me to look on the website, but I don't have a computer and I can barely see anything on my phone.”

**Prescriptions.** Although respondents cited prescription drug coverage as an important and appreciated aspect of KanCare coverage, they also noted significant problems with it. Overall, 32% of survey participants reported being unable to obtain at least one prescription medication. The most frequently cited problem was denial of coverage due to a medication not being in the plan's formulary. Others reported having to wait long periods of time for prior authorization before being able to access a medication. Still others reported that the out-of-pocket costs were too high. Although we did not specifically ask for consequences related to problems accessing medications, nearly 1 in every 6 respondents (15.9%) described not taking prescribed medications, not taking them as recommended, relying on samples, or using leftovers.

### Prescriptions

“I had to switch ADHD meds because the one I was on that was working became generic so [MCO] said I had to take that, but it didn't work. And the other options that are covered don't work so now I just don't take it. This makes it harder to figure everything out too. I can't focus.”

“My concern is step therapy for prescriptions. That has affected mental health as well as physical health, it is not favorable at all. Things need to be better at the time when people are especially vulnerable - at initial diagnosis, when they need the most support and effective treatment and when either being delayed with pre-authorizations or given a lesser effective treatment that just continues to compound their condition... With mental health medications as well as probably with other things – cancer treatments or others – it is feasible that they can get worse with the first treatment if it is lesser effective. So consequently, they can reject it because they don't think it is working and so decide they

don't want to take any treatment. It is very important when confidence is low or they are in crisis, to be able to treat them effectively and treat them quickly.”

“Pre-authorization is a problem. It took three weeks the first time my medication was prescribed and is now down to about five days. So the authorization time went down, but waiting has still adversely affected me—especially anxiety when I have run out.”

“One [prescription] I just couldn't get and for another [the doctor] had to adjust how it was written. Originally I had 50 milligrams two times per day, but they would only cover 100 milligrams one time per day, so I have to cut them in half, but the pills are not scored so the dosage is never exact.”

**Dental care.** As part of the transition to KanCare, the state required that contracting MCOs cover dental cleanings and screenings (once or twice per year, depending on the MCO). Any needed services beyond these for adults, however, are not covered. We asked survey participants whether they had seen a dentist in the last year and, if not, why. Overall, more than half had not seen a dentist (59.3%). Most said they did not want to pay the out-of-pocket costs associated with treatment. Others reported avoiding the dentist because they were unsure of their coverage or had a general fear of going to the dentist. Almost 15% reported having no teeth and over one-third of them reported needing dentures but being unable to afford them. Participants also shared that the medications they take for their mental health conditions often result in dry mouth, which can lead to serious dental problems.

#### Dental Care

“Meds make my mouth very dry. I have no saliva so food gets trapped. My teeth are starting to fall out and cleaning is not enough. They pay for having teeth pulled, but not [treatment].”

“I just don't want to go and find out I have cavities or issues that I can't pay for. I would just worry about it if I knew something was wrong.”

“I have false teeth and need new ones but the dentist who takes my [MCO] card is over 100 miles away. I don't want to deal with it and I'm not sure [MCO] would pay for them anyway.”

“I need a dentist and I'm not sure what to do. I need dentures as my teeth are all rotted and it is hard to eat.”

“I have impacted wisdom teeth, but they won't cover it. My mouth hurts a lot every day.”

**Transportation.** Non-emergency medical transportation (NEMT) is a federally required benefit for Medicaid beneficiaries that is often essential to their ability to access needed services. In this population, many individuals do not have a car or cannot drive due to medication side effects and cannot use public transportation due to anxiety, memory loss, lack

of availability, or costs. In fact, one in twelve respondents reported that NEMT was one of the KanCare services that they liked most or found most beneficial. Conversely, many respondents were not aware that transportation was available to them and noted lack of transportation as a barrier to getting needed medical care. Overall, 38.6% of survey participants had used NEMT provided by one of the MCOs. Among these respondents, 37.7% reported no problems, but others reported substantial problems. These problems included canceled or late rides, policies that prohibited children from riding with the parent, and drivers who smoked or were rude. In addition, MCOs require enrollees to book their transportation three days in advance, which is often impossible for an urgent need or an appointment that has been re-scheduled by the provider. Respondents reported having missed appointments due to these problems. It is important to note that each MCO may have contracts with different transportation providers.

### Transportation

“I don't have transportation. This appointment today at [CMHC] is the first one I have had in years and I walked several miles to get here.”

“[MCO] kept cancelling my rides an hour before my appointments so now I'm using what the CMHC provides.”

“Transportation will take you somewhere, but you have to wait all day, hours to be picked up.”

“Hated it. They use Yellow Cab and they are always late, cab is full of cigarette smoke, and you wait over an hour to get picked up too.”

“Twice they have forgotten to pick me up and [I] have missed appointments because of it.”

**Medical supplies/equipment.** Even though the project focused on people with serious mental illness, more than three-quarters (75.7%) of survey respondents reported needing some sort of medical equipment or supplies. Of these, 27.3% were unable to access a variety of needed medical supplies or equipment. The most frequently reported unmet need was for CPAP machines for sleep apnea, a serious medical condition that if not properly treated can lead to other serious health complications. Others needed various orthopedic devices such as crutches, walkers, canes, braces, or scooters. Diabetic supplies such as testing strips, glucose meters, and shoes were also mentioned.

### Medical Supplies/Equipment

“It has been a few years since I got diabetic shoes. I have been fighting for over a year to get [MCO] to cover them...and I'm trying to get a manual wheelchair, and I need to do a 24-hour oxygen test because [MCO] wants to take my oxygen away.”

"I needed a CPAP machine and my doctor wanted me to get a nebulizer. We really had to jump through a lot of hoops in order to get equipment like that. The nebulizer I did not get, but we found a company that will give you a [CPAP] machine, a once in a lifetime thing, and all you have to do is pay the shipping. So I got that through them not KanCare. I think if my doctor orders it and says I need it then I should get it."

"I need more powerful glasses way more often than they allow. I would think since they are necessary for me to function they could make an exception or something. I end up just using my magnifier, but that doesn't help me with TV or when I'm out and about."

"I had difficulty getting a walker or even a cane. I ended up borrowing this cane from my sister-in-law."

"The machine they cover for diabetes blood testing is weird and doesn't always work, but they told me I can't get a new one. I keep trying, sometimes I get a good reading."

"They [MCO] will not pay for a portable oxygen concentrator that I need to be able to go for walks. I need to get exercise to control my diabetes."

**Physician visits/provider networks.** One of the promises of managed care for improved population health is an emphasis on preventive care. We asked survey participants if they had seen their primary care physician for a check-up in the last 12 months, and 81.9% reported they had. Among those who had not, the most frequently cited reason was a limited provider network/difficulty finding a primary care physician who accepted KanCare. We also asked participants if they had been unable to see any particular types of providers and why. Overall, almost a fourth of respondents (24.3%) reported a problem seeing a particular type of provider, again mainly due to difficulty finding one who accepted KanCare. The second most frequently reported reason for not seeing a particular provider was not having met one's spenddown obligation to be eligible for Medicaid services. Provider types respondents frequently reporting difficulty seeing included mental health providers, pain specialists, orthopedic surgeons, and podiatrists. Network adequacy was similarly cited by CMS as an area of non-compliance for the KanCare program and will be discussed further below.

#### Physician visits/provider networks

"It is difficult to find therapists with expertise in those with autism who also have mental illness - these types of therapists typically have higher fees and the Medicaid reimbursement isn't enough for them to be able to accept it, but having people with this experience and knowledge is crucial."

"I've seen my doctors, but used my Medicare and paid the 20%, they bill me for it and I pay when I can because my doctor I've seen for a long time isn't in the KanCare network."

“More mental health providers need to take it. You'd think in a city of this size, there would be more psychiatrists but you really end up having to go to [CMHC], which is fine but I'd like more choice.”

“My doctor [PCP] wanted me to see a pulmonologist, but the one he referred me to wouldn't take my KanCare and I didn't know who else to go to. I don't have money or phone to search around for one, so I didn't go.”

“My mental health therapist doesn't take KanCare so I pay \$50 out-of-pocket per appointment.”

**MCO Care Coordination.** KanCare managed care organizations have the potential to improve outcomes for enrollees by helping them to manage their care and utilize appropriate services. The MCO care coordination provision of KanCare was described in the state's request for proposals from insurers: “the contractor [MCO] shall be responsible for care coordination and establish a set of Member-centered, goal-oriented, culturally relevant and logical steps to ensure that a Member receives needed services in a supportive, effective, efficient, timely and cost-effective manner. Case management, disease management, discharge and transition planning are elements of care coordination for Members across all providers and settings” (pg. 71, KDOA, 2011). More specifically, subsections of the care coordination provision also state that the MCO is required to provide: “...a person or entity formally designated as primarily responsible for coordinating health care services furnished to the enrollee” and “monitoring Members with ongoing medical or behavioral health conditions” (pg. 72, KDOA, 2011). We have found that in some instances people with chronic conditions may be assigned a person who serves as Care Coordinator to meet these provisions. However, the assignment of a specific individual at the MCO who serves in this capacity for members isn't consistent across or within MCOs. In light of this ambiguity, the survey asked respondents if they have worked with an MCO Care Coordinator. Less than one-fifth (18.5%) of survey respondents reported having worked with a Care Coordinator and another 6.9% were unsure if they had an MCO Care Coordinator or not. Many of those who had a Care Coordinator, currently or in the past, reported that he or she helped with logistics such as appointments, medications, transportation, and equipment. Others said the Coordinator provided needed information and support. At the same time, more than a quarter of people (28.6%) who had experience with a Coordinator reported problems, including staff turnover, lack of or discontinued contact, and not returning calls. When asked what the Coordinator could do better to meet their needs, survey participants suggested more frequent contacts/resumption of frequent contacts, providing more information on benefits/resources, and returning calls/being easier to contact.

#### MCO Care Coordination

“I used to have an [MCO] Care Coordinator, but about 2 months ago he called and said they

weren't going to be providing that anymore, I don't know why. They really helped me keep everything straight. They even made some appointments for me and made sure I got there. Sometimes it all becomes too overwhelming for me with my PTSD and this guy helped a lot.”

“I wish she [Care Coordinator] would start calling again, I don't know why they stopped.”

“My Care Coordinator could actually answer my questions when I have them. Or even tell me she needs to find out the answer and get back to me and then actually get back to me. Mostly if she could help me be able to get my over-the-counter vitamins and meds right now that would be great.”

“Someone needs to let me know if I still have [a Care Coordinator]. I did change my phone number, but I told them.”

### Suggestions for Improving KanCare

The survey included a specific question, “what suggestions do you have for improving the services and supports available through your health plan?” In addition, throughout the survey when respondents answered other questions about their experiences and identified barriers to care, many also made specific suggestions for improving KanCare. Specific suggestions were grouped into broader categories, however some issues and suggestions cut across categories. Table 2 provides a count of the number of participants who made specific types of suggestions and/or described a negative experience that could be avoided or alleviated by making improvements. Quotes were chosen as examples of suggestions within each category.

**Expand covered services.** This category includes respondents who mentioned specific health-related services and supplies that they needed that were not being covered and/or made suggestions that services be expanded. These recommendations were in some cases related to the individualized needs of the respondent (e.g., remove limits on physical therapy). However, a majority of respondents in this category (57.1%) noted that adult dental care that goes beyond basic cleaning and covers procedures like fillings and dentures was especially needed.

**Reduce financial barriers to needed services.** Responses in this category include financial barriers to needed services and participants’ recommendations primarily related to reducing out-of-pocket costs, such as lowering co-pays and out-of-pocket costs for particular covered services or eliminating spenddowns. More than 60% of responses in this category were not from individuals with a spenddown obligation, therefore suggestions are not limited to those experiencing difficulty as a result of spenddown.

**Provide assistance understanding benefits.** A number of respondents reported not understanding how their KanCare health insurance worked and said they needed more help than was currently being provided. Respondents stated the importance of having a better understanding of what is available to them under their plan, why treatments ordered by their doctor were not approved, the differences between the three MCO plans, what is covered by Medicare versus Medicaid, and how a spenddown works and how to know when it is

met. Current methods to inform them of their benefits were criticized and recommendations to address these problems frequently involved providing an easy-to-contact person or navigator who could help them with their specific needs and more importantly explain this complicated system in a way they could understand.

**Improve transportation.** All suggested improvements to transportation were placed in this category, even though some of them related to expanding coverage or changing policies/procedures. Participants wanted flexibility or reasonable exceptions to policies such as how many days in advance transportation needed to be scheduled and who could accompany someone using the KanCare provided transportation services. Reducing wait times before and after appointments was also suggested frequently. Participants also believe contracted transportation providers should be more professional by being on time and not being rude.

**Remove barriers to accessing needed medications.** Suggestions in this category included removing limits on medications, expanding covered medications, reducing out-of-pocket costs, streamlining or eliminating prior-authorization requirements, and not requiring the use of less effective generic drugs.

**Expand provider networks.** Many of the suggestions for improving access to needed health care services included expanding the number of providers. While some recommended broadening the network in general, others had specific types of providers that were not in network at all or needed to be more proximate geographically. A few explicitly suggested treating providers better or increasing incentives for doctors to accept Medicaid.

**Improve customer service.** These suggestions were often linked to the MCOs not being responsive and sometimes even offensive in interactions with KanCare beneficiaries. Having live people to answer the phone, calling people back in a reasonable time frame, and not treating clients as enemies were mentioned. Suggestions also related to improving the consistency and accuracy of information provided by MCO representatives.

**MCO care coordination.** Respondents were specifically asked if they had a care coordinator assigned to them from their MCO, and if they did what that person could do better to meet their needs. Participants wanted a consistent care coordinator who was knowledgeable about their needs and could suggest services and supports that could benefit them, and who would stay in touch.

Table 2. Barriers and suggestions for improving KanCare

% <sup>n</sup> *	Category/Theme	Suggestions
52% (n=98)	Expand covered services	<p>“Need to offer comprehensive dental services, not just extractions. People need teeth. We need to have an affordable dental plan.”</p> <p>“Really need adult dental care covered, not just cleaning. I know the condition of my teeth contributes to my poor health, most definitely.”</p> <p>“Having to wait 4 years for an eye exam and new prescription [glasses] is too long, especially for those with cataracts that isn't good.”</p> <p>“If a test or procedure is needed and the doctor ordered it, pay for it.”</p> <p>“My suggestion would be for them to provide for the needs of the patient without having to jump through hoops, like with my CPAP. I mean, if a doctor says I need it that should be good enough... For the nebulizer, I had to try a spacer on my inhaler for a while to see how that works and then if it doesn't work I can get a nebulizer. With the CPAP machine, you have to have a sleep study done and KanCare won't pay for the sleep study in order to get a CPAP. I would have to pay for the study out of my own pocket and I can't afford that.”</p>
37% (n=70)	Financial barriers to needed services	<p>“I haven't gone to my doctor or counselor because I haven't met my spenddown. I can get prescriptions because Medicare covers them, but I can't go to a doctor to get prescriptions because I can't pay out-of-pocket up front for the office visit. The way I get my inhalers is to call pharmaceutical companies and get low cost or free samples from them once in a while when I can. I did go to my counselor at [CHMC] once and had to pay \$90 for a one-hour session. I haven't been able to do that again.”</p> <p>“Medication co-pays could be less, sometimes I just can't pay them. I know they aren't much, but I just couldn't. One of them I just didn't take and others I used leftovers I had in the cabinet.”</p> <p>“Cover needed services. I needed a dermatologist to remove cancerous growth and [MCO] wouldn't cover it. I found this out after the appointment and can't pay.”</p> <p>“Eliminate spenddown to get rides. I miss a lot of appointments not having transportation because the spenddown not yet met.”</p>

(table continues)

% <sup>n</sup> *	Category/Theme	Suggestions
34% (n=65)	Assistance understanding benefits	<p>“Tell me more about it. I know to give my card at appointments, but are there things I can get covered that I don't know about? I never really had insurance before KanCare, so I'm not sure how it works.”</p> <p>“Make us more aware of what's available. I honestly don't read the book. I read at a third grade level and the book is too complicated, so I don't try. And no one tells you.”</p> <p>“When you first get it [KanCare] they should let you know what you have, what is covered. They give you a book, but many of us with disabilities can't sit down and read a book like that or retain what it says in there. They should have someone call and let you know these things when you are new.”</p> <p>“I suggest that KanCare or the MCOs make an informational video about the plans so people can more easily learn what is available, just a general outline of the plans and rules that is simple but comprehensive. They could even mail out DVDs or check them out from somewhere and have it online too for those that do have internet access.”</p> <p>“Have a comparison of KanCare plans that is easy to use and understand. Better yet, have them all cover the same things. I had to switch to another MCO to get the doctor I have gone to for a long time, but then found out this company doesn't cover the smoking patches. Why aren't the plans more similar?”</p>
31% (n=58)	Transportation	<p>“It works pretty well. Although calling in advance can be a problem sometimes. If you have an emergency and get to the hospital either by ambulance or someone taking you, you can't get home. They need three days advance notice to get you a ride so you get stuck at the hospital.”</p> <p>“Transportation they could improve a lot. A lot of people I talk to to schedule are coming from the Missouri side and the call center is in Florida. They need a call center that is here and knows the area (it would be great if they could make it local and keep business in Kansas, I'd apply for that job). We depend on transportation to be on time and courteous - many of us need the transportation because we aren't allowed to drive because of our condition or meds, because of seizures or getting dizzy for example.”</p> <p>“When I could use it they ran late a lot. Now I don't use it. I can't use it because they changed their policy. They only allow 1 adult and 1 kid in the taxi. I have 2 younger kids, one with autism, I can't leave them home alone.”</p>

(table continues)

%,n*	Category/Theme	Suggestions
31% (n=58)	Medications	<p>“Shorten the length of time to get approval for certain meds or make it so a pre-approval is not needed every time. It is something I have been using for a long time, they know I need it.”</p> <p>“Help me be able to get my over the counter vitamins and all meds right now, that would be great. I take lots of meds, including over the counter, and with all my conditions it is a delicate balance. If I can't keep the med regimen I have, I'm going to end up back in the hospital or nursing home. And this only costs the state more money.”</p> <p>“Expand the pharmaceuticals available. To get one med I'm going to have to pay out-of-pocket since they just stopped [January 2017] paying for it.”</p> <p>“If someone runs out of meds or needs to get prior authorization, you call [MCO] and wait, this could be faster. Sometimes I go without meds for three days.”</p>
28% (n=53)	Expansion of provider network	<p>“More doctors need to take it [KanCare}, especially specialists like podiatry and chiropractors because there are none of those that will take it. They just need a better network with more doctors so I don't have to wait so long to see someone.”</p> <p>“Something to attract more providers, those that are well-trained and experienced would probably not take Medicaid because of how they're reimbursed.”</p> <p>“I wish it [KanCare] was more appealing for doctors to sign up and take it. If it wasn't for the CMHC I would not probably see a therapist because there are so few out here in my area and they don't want to mess with KanCare.”</p>
18% (n=34)	Customer service	<p>“Improve communication – I've waited hours to hear back or been disconnected while talking to [MCO]. And notify a person when insurance is cut off or if spenddown is not met. I need stability in a health plan, something I can rely on.”</p> <p>“If you leave a message, call people back. And I wish they would stop telling people - the recording when you call [MCO] does this too - to go online to find your answers. I don't have a computer or internet access. I can't just go online.”</p> <p>“The smoking cessation program is good and has been helping my husband and me, except the coaches they have. They call you and if you aren't right there and you call them back you get put on hold for a long time or you get transferred and hung up on and can't actually reach your coach very easily. Also, if you need to get more patches you have to call and have the same issues reaching someone.”</p>

(table continues)

%,n*	Category/Theme	Suggestions
	Customer service, cont.	<p>“Update information more often—the book of providers is outdated and not everyone has internet to look up doctors on their own.”</p> <p>“I wish real people, live people would answer the MCO phone. I understand they are busy, lots of people are calling, but 4 days to wait for a call back is frustrating.”</p> <p>“They should have left Medicaid alone. If it wasn’t for my case manager here [CMHC] I would be alone in this Medicaid business. Before I could call SRS and they could tell me things or help me out, but the people you call at [MCO] don’t seem to know or you get different answers from different people when asking the same question.”</p>
14% (n=27)	MCO Care Coordination	<p>“I’d like the Care Coordinator at [MCO] to go back to calling me again. I have tried calling them, but I couldn't remember her name so I didn't know who to ask for. They said they would check my file and get back to me, but no one has yet.”</p> <p>“Contact me more frequently. Have had issues with hearing back when I call and leave message it takes a week or two, then I have to talk to supervisor to get [Care Coordinator] to call back. Hope new person they just gave me is better.”</p> <p>“I don’t know what the Care Coordinator I have is supposed to do, should I call her? It isn’t clear to me what they are there for except to make sure I get paperwork in and remind me about getting my pay stubs in when I used to work.”</p> <p>“...they should have kept Health Homes. They did away with that. But then they said I should still have a case manager with [MCO] and they gave me the number. So I called them when Health Homes went away. They never called me back. I think just being more honest and saying if you're going to help people, that’s what you do, [here’s] what you're going to have as a customer. So it's kind of disappointing.”</p>

\*Note: The number of individuals expressing a suggestion that falls into each category. Categories are not mutually exclusive.

## Findings related to CMS concerns about KanCare

As noted, officials at the federal Centers for Medicare and Medicaid Services (CMS) have recently notified the Kansas Medicaid agency of several significant deficiencies with the KanCare program and have found it to be in noncompliance with federal regulations (Scott, J., CMS 2017 January 13; Scott, J., CMS 2017 January 20). In a letter dated January 13, 2017, CMS noted that feedback at multiple stakeholder meetings indicated “an inability to obtain clear and consistent information from the State and MCOs, making it difficult for KanCare enrollees to navigate their benefits” (p. 3). Survey participants noted the same issues regarding lack of timely and useful information and the resulting difficulty of using KanCare services.

Similarly, in this same letter CMS noted a lack of reliable data to determine whether KanCare provider networks are sufficient to meet the needs of beneficiaries. Based on feedback from our survey respondents and discussed above, this project demonstrates that limited provider networks are resulting in real barriers to both primary and specialty care.

Finally, in a letter dated January 20, 2017, CMS noted deficiencies in the state’s eligibility and enrollment processes for Medicaid, which violated federal requirements. Several survey participants shared stories of problems obtaining or maintaining eligibility in a timely manner, such as:

I have a lot of issues with KanCare, it’s a mess. The plan itself and [MCO] is fine, but it took over a year for the state to actually approve. KDADS is totally incompetent. They ask you for something, you get it to them and then they are so very slow to respond. Sometimes each request they had for clarification would take 2 months. So many hoops to jumps through and they would lose things we sent in and ask me to send again, over and over. While waiting for approval I incurred huge credit card debt paying for medications and assistance at home. I know I’m going to die before that debt is paid off.

## Findings related to possible Medicaid expansion in Kansas

The survey did not contain any questions specifically regarding Medicaid expansion, but many of the barriers and needs they reported would likely need to be addressed if the state chooses to participate in Medicaid expansion. Although we surveyed individuals with SMI, the majority also experienced chronic health conditions, so their experiences can inform broader expansion issues related to coverage gaps for both mental and physical health care services.

One issue identified in the survey that would need to be addressed for Medicaid expansion to work well for potential enrollees is problems with the state’s eligibility system. As detailed above, one survey respondent reported that it took more than a year to finally be approved for services. Others shared experiences of being told repeatedly that their applications were “in process,” as they continued to accrue more and more medical debt. Medicaid expansion would open KanCare to tens of thousands more applicants, so the eligibility system would be further stressed if not improved beforehand.

As noted, more than a quarter of survey participants have a spenddown requirement for Medicaid services. For individuals who have recently qualified for Social Security Disability Insurance and are in their 24-month wait for Medicare, Medicaid expansion coverage could be especially beneficial. For these individuals, a spenddown process would no longer be necessary and they would have immediate and full access to Medicaid services. At the same time, the state would receive a higher federal match rate – 95% currently for the expansion population versus the 54.7% match Kansas currently receives for the categorically eligible population. Finally, implementing Medicaid expansion would allow participants to have earnings up to 138% of federal poverty level and maintain eligibility for Medicaid. A recent study demonstrated higher levels of employment among people with disabilities in Medicaid expansion states (Hall, Shartzter, Kurth & Thomas, 2017).

### Participant Fears

Finally, as noted earlier, many participants expressed fears or worries about their coverage through KanCare. These concerns fell into two broad categories. First, participants expressed a general uneasiness about the future funding of KanCare in Kansas and health care overall at the federal level. Many cited instances of staff losses at CMHCs and how those losses had affected the quality of services in general and their personal relationships with staff in particular. They worried that future cuts might result in the complete loss of coverage. As one participant stated, “I just don't want the state to get rid of it altogether. You hear all the stuff about the budget and Kansas being in such bad shape, I'm afraid they are going to cut us all loose to fend for ourselves. If I didn't have my meds it would be bad.”

Second, participants shared being worried about being penalized for “making waves” and others expressed having given up on trying to get needed services because they fear having their coverage taken away. In one of its letters to the state (January 13), CMS noted that KanCare stakeholders reported “adversarial” communication from the state. Such communications may have contributed to the fears and worries expressed by participants. In addition, concerns about losing coverage seemed to have the effect of making participants appreciate the coverage they have despite the numerous problems they reported with it. In turn, their overall ratings of their health plans may have been inflated.

Finally, the survey included items to determine KanCare participants’ knowledge about filing a grievance if they have concerns about their health plan or MCO. Just over half (55%) of respondents were aware they could file a grievance, but of those who knew about filing grievances, only 42.3% understood how to go about doing so. This lack of knowledge about filing grievances is important to note in light of the fears participants expressed and their reported barriers to care and unmet needs. Further, based upon the fears expressed, it is unclear whether participants would feel comfortable actually filing a grievance, even when they encounter problems.

## Discussion

Based on these findings, it is clear that KanCare coverage is critical to supporting the health and well-being of Kansans with SMI. The participants in our survey were appreciative of the coverage and the security of knowing that they are protected against catastrophic medical costs. At the same time, they reported numerous areas where KanCare coverage could be improved to better meet their physical and mental health care needs. In many instances, gaps in coverage seem to be “penny wise and pound foolish.” For example, lack of coverage for dental services caused more than half of our participants to forego care in the last year. Given the strong relationship between oral health and other medical conditions including heart disease, diabetes and stroke, it seems that covering dental care beyond cleanings could result in significant long-term gains in health in addition to cost savings. These benefits are multiplied in a population with high rates of smoking and use of psychotropic medications that can cause numerous oral health problems. Similarly, coverage for CPAP devices for sleep apnea could offset spending on obesity-related problems and heart disease over time. Problems accessing prescribed medications were also frequently reported. As noted by participants, inability to obtain needed drugs can result in exacerbations of illnesses and, potentially, hospitalizations. Finally, problems with transportation also have the potential to disrupt care and result in longer-term health problems for participants.

Many of the survey participants who had worked with a Care Coordinator through the MCOs reported positive experiences. To the extent that Care Coordinators can assist enrollees in navigating their coverage and utilizing and understanding benefits, their expanded use could address some of the problems identified by survey participants. The particular challenges of the population, such as unstable living conditions, lack of access to the internet, and difficulty processing and understanding information, make individualized support by a qualified professional especially important in accessing appropriate care and other necessary services.

Findings from our surveys also affirmed issues identified by CMS in its correspondence with state Medicaid officials. Survey participants reported great difficulty in obtaining accurate and timely information about their coverage from either the MCOs or the state. Survey respondents identified lack of internet access, difficulty with the printed materials, and inability to reach a person on the phone as some of the specific barriers in accessing coverage information. In turn, they encountered difficulties in locating providers to treat their health conditions. Network adequacy was also a barrier to care reported by many participants and cited by CMS. Addressing these problems, and problems with the state’s eligibility system, will be critical in making coverage more responsive to the needs of not only Kansans with SMI, but all Kansans enrolled in Medicaid now and in the future.

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## **APPENDIX A: Survey Instrument**

### **Section 1**

**The first questions I have are to get to know a little bit about you.**

Overall, would you say your health is...

- excellent    very good    good    fair    poor    don't know/no response

Are you...

- female    male

What is your age? \_\_\_\_\_

Which one or more of the following is your race?

- Native American or Alaska native
- Native Hawaiian or pacific islander
- Asian
- Black/African American
- White, Caucasian
- Don't know/prefer not to answer

Are you of Hispanic or Latino(a) origin or descent?

- Yes    No    Don't know/prefer not to answer

Which county do you live in?

- |                                  |                                 |
|----------------------------------|---------------------------------|
| <input type="radio"/> Barton     | <input type="radio"/> Rice      |
| <input type="radio"/> Chautauqua | <input type="radio"/> Sedgwick  |
| <input type="radio"/> Cowley     | <input type="radio"/> Shawnee   |
| <input type="radio"/> Elk        | <input type="radio"/> Stafford  |
| <input type="radio"/> Johnson    | <input type="radio"/> Wilson    |
| <input type="radio"/> Montgomery | <input type="radio"/> Wyandotte |
| <input type="radio"/> Pawnee     |                                 |

Do you have any other type of health care coverage or insurance besides Medicaid (KanCare), such as Medicare, Tricare or private insurance?

- No    Yes – What type of coverage or insurance is it?

What is the highest grade or level of education you have completed?

- |  |   |
|--|---|
| <input type="radio"/> less than high school      | <input type="radio"/> 4 year degree                   |
| <input type="radio"/> high school diploma or GED | <input type="radio"/> graduate degree or higher       |
| <input type="radio"/> some college               | <input type="radio"/> don't know/prefer not to answer |
| <input type="radio"/> 2 year degree              |   |

What is your current living situation?

- own home/apartment
- rent home/apartment
- live with family or friends without paying rent
- renting a room in a house
- group home or facility
- shelter
- homeless
- other
- don't know/prefer not to answer

Is this a temporary or long-term/permanent living arrangement?

- temporary
- long-term
- don't know/prefer not to answer

Do you currently smoke cigarettes or use tobacco products?

- Yes
- No
- don't know/prefer not to answer

Have you smoked in the past?

- Yes
- No

Are you currently working at a job for pay?

- Yes
- No
- don't know/prefer not to answer

Have you had a physical exam or medical check-up in the last 12 months?

- Yes
- No
- don't know/prefer not to answer

Thinking about your mental health, which includes stress, depression, anxiety and problems with emotions, for how many days during the past 30 days was your mental health NOT good?

- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- 11
- 12
- 13
- 14
- 15
- 16
- 17
- 18
- 19
- 20
- 21
- 22
- 23
- 24
- 25
- 26
- 27
- 28
- 29
- 30

What is your mental health condition? If you have more than one, please give your main one first.

Do you have other conditions or disabilities?

- Yes
- No
- don't know/prefer not to answer

What are they? If you have more than one disability or health condition please give your main one first.

## Section 2

**These next questions ask about your experience with your Medicaid (KanCare) health plan.**

1. Which Managed Care Organization (MCO) or company do you have for your KanCare health plan? ([MCO name])
  - Sunflower
  - United
  - Amerigroup
  - don't know/no response
  
2. How many months or years in a row have you been in your current MCO health plan?
  - less than 6 months
  - 6 months to 1 year
  - 1 – 2 years
  - 2 – 3 years
  - don't know/no response
  
3. Did you have a different KanCare health plan previously, before choosing [MCO name]?
  - Yes
  - No
  - don't know/prefer not to answer
  
4. Did you have to meet a spenddown for your KanCare/Medicaid services?
  - Yes
  - No
  - don't know/prefer not to answer
  
5. In the past 12 months have you been able to meet your spenddown in order to get your mental health counseling or treatment paid for by your MCO health plan?
  - Never met spenddown in past 12 months
  - Yes, met SOME of the time
  - Yes, met ALL of the time
  - Don't know/no response
  
6. What do you like most about your MCO health plan?
  
7. What services or supports that your health plan provides do you find most helpful or beneficial?
  
8. In the last 12 months, how much of a problem was it to get the mental health counseling or treatment you thought you need?
  - not a problem
  - a small problem
  - a big problem
  - don't know/no response
  
9. In the past 12 months, did you look for any information about counseling or treatment that was available and/or covered by your MCO health plan in written material or on the internet?
  - Yes
  - No
  - don't know/prefer not to answer



20. With your [MCO name] plan have you been able to see your psychiatrist, counselor, therapist or other mental health provider(s) when you needed to?  
 Yes       No       don't know/prefer not to answer
21. You said you have not been able to see your Primary Care doctor or mental health providers when you needed to, what have the problems been?
22. In the past 12 months, have you been unable to get any prescriptions because of [MCO name]?  
 Yes       No       NA no prescriptions needed       don't know/prefer not to answer
23. Please explain why you have not been able to get prescriptions.
24. Have you seen a dentist in the last 12 months?  
 Yes       No       don't know/prefer not to answer
25. Explain why you have not seen a dentist.
26. Are there any doctors, therapists, specialists or other providers you need to see who are not in the network for [MCO name]??  
 Yes       No       don't know/prefer not to answer
27. What have you needed and why were you unable to get these services?
28. Are there any other types of medical services or equipment (e.g. specialists, medical supplies, etc.) that you have needed but have been unable to get in the past 12 months?  
 Yes       No       don't know/prefer not to answer
29. What have you needed and why were you unable to get these services?
30. In the past 12 months, has anyone provided transportation to you for medical or counseling appointments? (KanCare provided or CMHC provided, not family/friends...)  
 Yes       No       don't know/prefer not to answer
31. Was the transportation provided by your mental health center or [MCO name]??  
 mental health center     my health plan     both     don't know/prefer not to answer

32. Has it worked well and what issues have you had with the transportation provided?

33. Using a number from 0 – 10, where 0 is the worst health plan possible and 10 is the best health plan possible, what number would you use to rate your MCO health plan?

- 0       1       2       3       4       5  
 6       7       8       9       10

34. What suggestions do you have for improving the services and supports available through [MCO name]?

35. Are you aware that you can file a grievance if you have concerns about [MCO name]??

- Yes       No       don't know/prefer not to answer

36. Do you know how to file a grievance about your health plan?

- Yes       No       don't know/prefer not to answer

37. If care coordination like you have received through the Health Home program was made available again would you use it? (explain HH: Having a coordinator to help you understand your health care and who could go with you to appointments)

- Yes       No       don't know/prefer not to answer

38. What services do you need or wish were available to you at your mental health center?

39. Is there anything else you would like to tell us about your experiences with KanCare that we didn't ask you about or didn't discuss already?

## Appendix B

### Participant responses to the question: “What services do you need or wish were available to you at your mental health center?”

Responses to this survey item have been categorized into the following topical areas: suggestions for additional services; case management; doctors, psychologists and therapists; groups, classes and activities; other support services; scheduling and appointments; and other comments. In addition to this list, these comments were broken out by each individual site and provided to each CMHC Executive Director.

#### **Suggestions for Additional Services**

- A dentist on site, not just for cleanings but that could do work.
- Dentist and eye doctor at the CMHC.
- If I could get all the meds I need here at [CMHC name] instead of having to go to three different pharmacies. I can only get my psych meds here, why can't the pain doctor and my PCP just call other prescriptions in here?
- Prescriptions, wish I could get them here more locally or at the center. I take a lot of meds and sometimes have to go to another town, about an hour away to get my other prescriptions.
- Increase number of doctors and have services for kids here too.
- Maybe some counseling in regard to overeating or being overweight.
- There's no place here for blood draws.
- Wish there was more care for people like me, those with more physical health conditions need more help.

#### **Case Management**

- Allow for more than an hour of CM daily. Seems like they are only allowed to spend that much time with you.
- More case managers maybe. I used to have one that was good, but she left and now I haven't really gotten one on a regular basis again.
- Maybe more time with my case manager. I know they do all they can, but some months I need more help with things than others and she's really the only one I can turn to who will help and answer my questions. The only one who I feel supports me in all kinds of ways. I'm grateful to [CMHC name], so grateful.

- I need a case manager. I have been trying to get one to meet with me.
- Case manager has very limited time to spend with me, wish she had more time to spend helping me.
- Good question, I don't always agree with everything they do. I know with the large case loads they have, there was a while there where my case manager didn't get in touch with me and if I needed something on a certain day it didn't matter, he made it so we would have to schedule it on a day for his convenience. But that's gotten better. He's come over to my house a couple times because I was in the hospital for 6 weeks and ever since I got out, my health has improved quite a bit. But the problems I had with scheduling with the case manager, I complained and they listened to me, it has been much better since then.
- I don't have a CM right now, I think due to budget cuts. I would like to get one back.

### **Doctors, psychologists and therapists**

- More psychologist/psychiatrist availability.
- More psychologists or psychiatrists.
- Maybe more therapists – it just seems like some of them are too booked up. [CMHC name] lost a cook and a therapist and it affected us when they did not come back. They cut our funds and it is hard on us. It is very stressful to lose someone you need.
- Not having to wait two weeks to see a counselor again, too long of a wait in between appointments. Also, Crisis Line is pathetic - they don't know what you are going through at all, yet they pretend like they do. Or they are reading a script or something, they are told to say things and it doesn't fit my situation. It is just a joke.
- More therapists.
- Would like to see psychologist when paranoid, not just an APRN.
- Counselor is leaving first of the year. Hard to choose another one, I'm sad, I just got used to her.
- I think state cut backs have caused turnover of psychiatrists. Have had four different ones in the last 6 months.
- Some counselors got laid off and that has been hard.
- Wish I could get my old counselor back, he left and got a different job.

### **Groups, classes, and activities**

- Cooking classes. They used to have them, but they don't now. They have said that not enough people participate to keep doing them.

- I graduated from a lot of the programs here. I wish there were more I could take. When I get bored I get really anxious so having something to do all the time is very important. If I couldn't come here for groups and classes and activities it would be really hard.
- I wish they still did the groups or classes that they used to have. They had these activity groups, one that used to go to the Y and mental health groups that would explain things, like relaxation techniques and a behavior thing. Classes that would teach you how to do things and about mental illness. They would offer those activity groups.
- I would like to be in an exercise group here. I don't know if they have one or not, but I know I need to lose weight to be more healthy and happy.
- I would like to go to a group, like a support group, that is all women with depression, people like me I can talk to and relate to. Maybe they have that here, I've just never asked or been told about it.
- Organize things like lunch or meals, go to the Y to play sports or go to food pantry to volunteer.
- More groups at the center. We used to have a breakfast group, bring that back.
- Parenting classes.
- Wish they had a regular exercise group and walking group. Bus tokens, but I think these got cut because of Brownback.
- Maybe the timing of the groups - they have a lot of groups that are great, but sometimes you have to wait for one to open up or come up.
- I have the support I need. I have a case manager and a therapist. And I can see a Nurse Practitioner at this mental health center. I think I'll be fine, but if they take more things away from [CMHC name], because they are continuing to take things away, then there's going to be more of a need. If they keep just cutting the system, there are going to be more issues. I do wish there was like a support group for people with certain mental health illnesses, like borderline personality disorder. So people that are going through BPD have a class and stuff that they can get together and learn from a class or get together and say 'I'm having trouble with this. What skills should I be using?' Or 'I'm having a great week and here's the skills I've been using.' To my knowledge, they said they've had this in the past but now with funding cuts they can't do it.
- More support groups.
- Peer-support is available but I'm not sure how to get it. I think you have to get a referral from your counselor to do that, I'm not sure. Seems like it should be easier to get, but I am going to look into it.
- I hope they don't get rid of the group I am in. It works for me, I like these people and our peer specialist.

### **Other support services**

- I have been homeless for a while, I need more help with housing, an extension of what the state does, as I've been trying since 2013. They have state programs but can someone connect me to them? Those on drugs/alcohol they get help, why not me? I lost my home to a fire and am not dependent on substances.
- My therapist is great, but maybe more help with other things, like housing or jobs. The apartment I hope to move into soon is Section 8-- a friend lives there and helped me.
- Supported housing. Also, I am a contracted transportation provider for the CMHC (that's my part-time job) and they recently told me that there's a limit of 1000 hours I can work in a year. Why is that? Can it be changed?
- Help understanding our insurance – or how to get it for my husband – he has MS and no coverage.
- A way of getting a new medication that works, what I am on now doesn't seem to work for me.
- Maybe someone to watch my kid during appointments.
- Job services, how to do resumes or some job training.
- They use to have trips out in the community to do activities and they don't do that anymore.
- They used to have Education specialists to help us know where to go for GED or college, but now they just have Employment specialists.
- There needs to be more waiver services for kids and adults, maybe form a sub-board or committee here at [CMHC] on specific advocacy issues in regard to the state and waivers.
- More support in regard to dealing with sexual abuse.
- A person comes from the CMHC once a week and helps me line out my meds for the week. She also said she could take me to appointments in another town (where my cardiologist is), but I have a service dog that isn't allowed in their vehicles due to allergies of other clients who use the van. I wish I could take her up on this offer to go to appointments.
- In-home health or assistance, I know I qualify for some, but I don't understand it. If they could help me with figuring out how to get the home health that would be great.

### **Scheduling and appointments**

- Quicker appointments, less time waiting to get back in. Although I think this will be solved by the new scheduling system that takes effect here on November 1<sup>st</sup>.

- The new scheduling method they have is very inconvenient for me. I work and I care for my mom so my time is limited. My work schedule changes all the time and sometimes it is rather unconventional hours. They used to allow us to book appointments 3 months out, which worked well, but now you call 2 weeks in advance and sometimes I don't know my work schedule to do that. Before, I could plan ahead with my employer and make sure I had that day off, but with that little notice I can't do that. And on top of that sometimes you call and all the appointments are booked for that 2 weeks so you have to call back again in 2 weeks. This is problematic too because I have to see the doctor to get my prescriptions, even if it is just a refill. And these aren't controlled substances, just regular meds for my illness that I have been taking for years. It used to be that you could get the med called in, but now they make me see a doctor every time. I understand that changes had to be made due to people not coming to scheduled appointments, but maybe there could be exceptions for someone like me who just can't make this work. I have not run out of meds yet but am afraid I will sometime.
- This month they changed how to get appointments with a medication doctor. Now you have to call to confirm each appointment. I have memory problems and health problems. They need to model how to respect people with mental illness. Sometimes they are rude.
- They are changing their scheduling process. They give you a card to remind you to make an appointment, I wish they would go back to the old way.
- I just wish sometimes you didn't have to wait so long to see a nurse. I've been here today over an hour and I'm not sure when they'll see me.

### **Other Comments**

- I think I'm getting what I need as far as mental health.
- Health Homes was really helpful. My therapist does what she can for me, but having that extra support was helpful, but I know [CHMC name] can't do everything.
- Can't think of anything, they are great here.
- [CMHC name] is pretty amazing. 'Get Brownback out'-- he talks about mental health issues but then cuts funding.
- I get what I need. I like that they are asking people if they want to display their artwork in the lobby here. I think I'm going to do that with my painting. They appreciate that we all have various talents.
- Actually, our county is much better than any other county, so it's difficult to pull something out. When you're at the top of the mountain, it is difficult to examine.
- They are excellent.

- They just need more funding to keep doing the good work they do here. I think they've had to lay off some staff due to money issues and that doesn't seem right.
- Everything is great.
- They are great here.
- The caseworker and psychiatrist are enough. There are groups I could join and I used to go, but I don't need those anymore.
- They are great here. I have started coming in more and am so glad I did.
- They have everything I need.
- [CMHC name] has always been great.
- I love [CMHC name]. Don't know where I would be without them.
- They are awesome
- They are great.
- None, they do an awful lot.
- This is a really great place.
- [CMHC name] services are the only thing that works.
- I really appreciate [CMHC name]
- They take good care of people here.
- Not really, they are great. [CMHC name] was the first contact I made after I moved from out of state. When I got here I was literally in my house for weeks and didn't leave, but once I started coming here I loved it. They are the best.
- [I am] Starting groups this Wednesday, we'll see how that goes. I got a new case manager a couple weeks ago and he has helped me learn all they have available.
- They are great here, I'm happy. My grandson actually comes here for therapy too and I'm grateful we both can.
- They are really good.
- They have helped me so much.
- This place is excellent. My counselor is the best. She's my heart.
- [CMHC name] is great. I know they help me all they can with my limited ability to pay.
- I love them, they do so much to help me and help me understand how things work.
- They provide everything I need.
- I had difficulty with one gal at [CMHC name], but that was resolved and now I see [counselor name] per my request and that is going well. I had a big problem with the

last gal, she was very rude and not respectful to me and wrongfully accused me of things and inappropriately approached things, but now things are better. It means a lot to me to have the respect of a qualified doctor here.

- They need a more accessible bathroom, the toilet is really low.
- We tend to isolate, people with mental illness can isolate. They should sent out newsletters, info about services and providers.
- I have taken all income paperwork to them and food stamps paperwork, but I don't think I'm getting a sliding scale for certain services. I know I have to pay out-of-pocket before spenddown is met, but I have several bills from them that seem really high. For example for my recent assessment from the CMHC it is over \$300. I can't pay that.
- I wish my PCP could take me for my mental health, but she explained to me that I have to get that at [CMHC name] and I like them, so it's all right.

## Appendix C

Surveys Completed by Site and Method

CMHC (City)	Counties served	Surveys Completed		
		Telephone	In-person	TOTAL
Valeo Behavioral Health Care (Topeka)	Shawnee	3	36 (4 site visits)	39
ComCare (Wichita)	Sedgwick	5	33 (3 site visits)	38
Four County Mental Health Center (Independence & Coffeyville)	Elk, Wilson, Cowley, Montgomery, Chautauqua	5	30 (3 site visits)	35
Johnson County Mental Health (Shawnee & Olathe)	Johnson	9	24 (5 site visits)	33
Wyandot Center (Kansas City)	Wyandotte	4	26 (5 site visits)	30
Center for Counseling & Consultation (Great Bend)	Pawnee, Stafford, Rice, Barton	5	9 (1 site visits)	14
<b>TOTAL</b>		<b>31</b>	<b>158</b>	<b>189</b>