

**HCBS Final Rule  
Draft Transition Plan  
Public Input**

**Public Comment Sessions:** June 16-23, 2014

**Purpose:**

- To meet requirements for public comment period on the HCBS transition plan.
- To listen to comments from the public, record the comments, and submit a summary with the transition plan to CMS.

**Format for each session:**

Wichita State University Center for Community Support and Research (CCSR) staff—open the meeting, logistics (bathroom, cell phone). Introduce state staff.

KDADS staff (20-30 minutes)—present background information and draft transition plan. Ask providers to fill out survey (due June 30). Hand out further information.

CCSR—ask the following questions. Allow time to review documents just handed out. If needed to get conversation going, provide opportunities for small group discussion at tables.

1. What questions or understanding or clarification do you have?
2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
4. What other types of settings should the state consider?
5. What other questions should the state be thinking about?

CCSR—close with reminder to providers to fill out survey (due June 30)

**Public Comments:** Below

KDADS staff: Aquila Jordan

❖ Transition plan posted on the website

- Change is being made based on the final rule: March 17<sup>th</sup>
- Evaluate HCBS settings to see if they are in compliance
- We will be assessing all provider settings to determine whether those settings meet the requirement for those who receive HCBS to live in a least restrictive setting
- Individuals must have a written agreement or lease that gives them the same rights as landlord tenant laws
- Will be evaluating if control and access to resources control of their access to visitors, make changes to their environment, change roommate, access to food, access to the community, lockable doors, competitive integrated employment, places where they live or play accessible to them as much as possible
- [www.kdads.ks.gov](http://www.kdads.ks.gov) to look at those to understand what areas facilities should evaluate
- HCBS program participants must be assured of privacy and control and unrestricted access to visitor
- Who is affected? Consumers receiving HCBS services in any of the HCBS programs community service providers will be affected
- State must comply within 120 days.
- CMS will review plan to come into compliance<sup>3</sup> and look at timelines and benchmarks
- Expect that it will be completed within 5 years, with programs having different transition dates
- Incorporated initial feedback from CMS
  - No clear guidance on what their guidance was
- Outline includes how the transition plan will affect all settings
  - Starting in Jan and over the next year, KDADS will evaluate settings on their level of compliance so we can develop a plan with timelines and benchmarks
- Challenges for current providers
  - CMS stated that it may accept argument that settings within or near an institutional setting but generally will not allow res and day settings to be located in the same building as an institutional setting
  - Nursing homes with wings of HCBS settings, CMS may say those are not in compliance for HCBS

- CMS has not issued guidance on day and employment settings at this time
  - The state sees this as an opportunity to explore creative alternate settings to allow for
  - Will look at if we should consider combining waiver programs
  - Documents posted online
    - Entire Transition Plan
    - Statewide plan for assessing compliance
    - Transition plan for each individual program
    - Summary of the rule
  - CMS asking the each setting be put in 1 of 3 buckets
    - In compliance
    - Non-compliant
    - Facilities that may be able to come into compliance
  - We know that we have some employment settings that are mostly handicapped individuals and we will look at whether that is in compliance
  - NASDDDS: National Association for State Director for Developmental Disability Services
    - Constantly working with CMS to define day and employment settings so as to not limit our access to provide those services
  - Rights and freedoms that people have can be limited but only if there is a specific assessed need that demonstrated the need to limit it, they are assessed consistently and must be approved by the individual, parent, Guardian or DPOA.
- ❖ In other regional areas CMS issued statements that may have impact on out settings
  - For a setting that is fenced in or individuals in an environment that is locked in will need heightened scrutiny. They will look at if this includes HCBS settings
  - A lot on the CMS side that has not been finalized
- ❖ Asking CMS for first six months to assess and the next six months to notify providers who are not in compliance and make plan to move them into compliance
- ❖ Individuals in assisted living or res health care that we look into their situations and grandfather their situation for the next five years.
- ❖ Public comment sessions are running the end of this week.

- Conference calls that are already e Wednesday July 2 from 12-1:00.
- ❖ Questions:
  - What is the family support model?
    - Can come in the form of budget authority and families can use that to help meet their needs.
    - There is also a model similar to shared living but with a monthly rate. We want to explore all of the options as we are exploring how we will come into compliance.
- ❖ Additional information
  - We added an information setting in the Kansas City area at the holiday in at 4:30
  - HCBS provider forum call scheduled in the morning on Tuesday.
  - 2 sessions set up for Wednesday June 18<sup>th</sup> and Thursday as well.
  - KanCare Member call with the ombudsman will be on Wednesday from 12:00 to 1:30
- ❖ Department of Labor rule:
  - Most likely to make change: we will have to go to a 40 hour work week for all PAS regardless of who is providing that service.
  - Nuances that are difficult to determine from a policy standpoint so we will look at different settings and provider types
  - We expect guidance within the next 2-3 weeks
  - The rule regarding day and res PAS guardian cannot provide
  - Those already providing can continue to do that but because of the labor rule that will be limited to 40 hours a week
  - Under the new model if the guarding is choosing self-direction the guardian would not be able to be the paid provider
- ❖ HCBS provider forum tomorrow from 10:00-11:00 with the same information given today
  - Will be for all HCBS providers for all Programs
- ❖ CMS goal is that we do this transition in as little time as possible
- ❖ Transition plan is relatively basic because CMS has not provided specific guidance so we will continue to work on the plan and add onto it
  - There are several documents that are the transition plan
- ❖ PD and FE renewal due in September, so as well as the transition plan public sessions in July, we will also set up sessions to discuss the renewals.
- ❖ We will be gathering questions and collecting answers to provide to CMS when we submit our final transition plan.

48 people on the line

1. What questions of understanding or clarification do you have?

(None)

2. Related to the rule you just heard about, what is already working in Kansas?

(None)

3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?

4. What other types of settings should the state consider? What alternatives or opportunities could we explore?

(None)

5. What other questions should the state think about?

(None)

Wichita, June 16, noon-1:30pm

KDADS presenter: Kimberly Pierson

CCSR facilitators: Amy Delamaide & Steve Williams

31 attendees

1. What questions of understanding or clarification do you have?

- Is the state expecting further guidance on person-centered planning and conflict-free case management? **Answer:** Yes.
- Do other settings where people go have to come under the HCBS final rule guidelines? Like the YMCA, or a cruise ship. Do those settings have to come into compliance? **Answer:** these are activity locations, not residential locations, so we do not expect these to be required to meet the HCBS final rule.
- In a group home, does the “able to lock their own door” part apply to the whole house, or each individual? **Answer:** The intent is for individuals to be able to access private space if they want it.
- It might not be safe for every individual to be able to lock themselves behind a closed door. Will provision be made for those exceptions?

**Answer:** We think CMS may be open to hearing about those circumstances in which being able to lock themselves behind a door is not safe.

- Does access to laundry, kitchen, etc, apply to the whole house or to each unit? **Answer:** The intent is for individuals to be able to access items of living at the time they want to access them. The intent of the rule is less about what is available in each setting and more about the principle of choice and access.
- Where it says that individuals should be able to access communication through text message and email, is it expected that providers would provide those tools, or that the individuals would? **Answer:** It would be up to the individual to choose those forms of communication.

2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?

- Individuals who use services from DD providers are already offered choice. It's part of how we operate our services.
- Most agencies already try to provide least restrictive environments and provide people opportunities.
- We do a very good job with person-centered support planning for the I/DD waiver.
- This might be true more for the I/DD waivers than others. Need a consistent document for others.
- Choice of providers for other waivers is good in urban areas, but not rural areas (limited provider choice).
- Kansas is a leading state for positive behavior supports—KU, Jessica Hellings, dual diagnosis.
- KDHE and KDADS already have a cooperative system for licensing and working together (esp. foster care and day care facilities).
- I/DD waiver providers promote: integration, inclusion, individual independence, and productivity to the highest level the individual is capable of.
- I/DD waiver case management—we currently have a good multi-system, client-led system in place.
- The home setting is important because our daughter is healthier than when she was in a school setting. We go to the zoo, the park, bowling, and other outside activities. Psychiatrist and physical therapists come to our home. They have observed that she is doing better at home than in a school setting. We are concerned that they want to cut our daughter's hours. They don't want to pay overtime. We don't want other's caring for her. We suggest putting us on salary so there is no overtime.
- In assisted living, we observe residents develop a sense of community, get involved in activities, and come out of their shell.
- There are a lot of options for families in the Wichita area. Individuals get into the community more with agencies who are concerned to do that.

- There is no comparison between institutions and home/community settings. People can stay in their homes, go to school, graduate, reach their highest potential. They can move out, get support in their own apartments, develop natural supports. This wasn't possible in institutions.
  - All providers (in the Wichita area) have made programs that are responsive to what individuals have asked for. Our range of service choices are in response to families.
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
- People waiting on waiting lists cannot access the good services that we're providing. These rules don't speak to the waiting list issue, but we need to reduce the waiting list so that choice and least restrictive environment can be provided.
  - The limitations on hours of care provided is a concern. There needs to be a better way to bill—levels of care, or flat payment. The documentation you have to fill out takes time. You don't get paid for about 30% of the care provided.
  - If a person chooses to stay at home all day, how does that work with the rules requiring someone to be out of the home at least 5 hours? If a person chooses not to attend programs, and that's their wish, how is that going to impact the residential provider?
  - How are the sheltered workshop day programs (I/DD program) going to look under these rules? Changes? Options in rural areas?
  - What about when you have a nursing home that has changed a wing to assisted living? In some cases, like for diabetics, medical aids staffing the assisted living unit can't provide insulin, but in attached facilities, a nurse is available to provide insulin.
  - There may be a problem when people can participate in "scheduled and unscheduled activities." This will challenge our staffing. You can't just take five people to five different places every day.
  - Talking about choice—having guests over. What about when individuals want to have people over at 2am? How do we regulate visitor time and still comply with the rules?
  - Regarding case management—individuals want case management provided by the agency that is also providing their direct care. How do we continue to make that happen?
  - Open visitation—all waivers—some people make poor choices about who they want to hang out with (drug dealers, people who exploit them, etc). This may endanger other residents' safety. How should facilities respond to this and still be in compliance?
  - If providing access to food at all times is an expectation, will the state increase compensation to providers for the cost of food? Raw food is not covered, just the time it takes to prepare the food.

- Re: locked doors. What is going to be the practical response for those who are not safe behind a locked door? Similar to the access to food question, which might not be safe for everyone.
  - Regarding individual choice, whose choice are we talking about? The individual? Or guardians? Some guardians have little interaction with the individual.
4. What other types of settings should the state consider? What alternatives or opportunities could we explore?
    - PD waiver—some people on the PD waiver are in and out of homeless shelters, weekly motels, etc. Services cannot be adequately provided in these settings.
    - For those who are of retirement age (or those experiencing dementia/senility), some are tired of working and going out. We need to come up with ways to support the individuals in settings that are appropriate for people with those issues.
  5. What other questions should the state think about?
    - If the state adequately funded residential services, there would be better retention of staff and more involvement in the community.
    - If assisted living and other places can't come into compliance, what will that transition plan look like? What will happen? Where will those people go live? Many of them are in assisted living because they are not capable of full independent living.
    - What about if the service is not offered at an agency building, does that come out from under having to comply with the HCBS rule? We do not want the state to have to license these additional places.

Wichita, June 16, 5:30-7:00pm

KDADS presenter: Kimberly Pierson  
CCSR facilitators Amy Delamaide & Steve Wilson

7 attendees

1. What questions of understanding or clarification do you have?
  - It seems confusing that we only have half of the final rule, but CMS is requiring the transition plan. What will happen once we find out about day and employment settings? **Answer:** we cannot get the waiver renewals we need to accepted status unless we submit the transition plan.
  - Comment: when we get clarification on what “conflict-free case management” means, the I/DD population will want to provide further input. **Response:** yes, KDADS will want your input on that as well.
  - When does the 120 days start ticking? **Answer:** CMS has allowed us some extra time. The clock hasn't started yet because we submitted our waiver



renewals, then withdrew them to allow us to draft the transition plan and get public input.

- How will the transition plan affect people trying to get onto the waiver services now? **Response:** the federal rules imposed on the state do not impact our eligibility rules. Those stay the same during the transition to compliance with this rule.
  - Will Home Plus be assessed? **Response:** Yes, every setting receiving HCBS funding will be assessed.
  - At this time, do FMS providers need to complete the survey that is out? **Response:** No, not at this time.
  - Does the state have to be on-site at every setting during the 120 days? **Response:** No. We're using a survey to get an initial sense of what settings are in compliance. We're not sure what the next step will be. We'll ask for guidance from CMS and get input from providers that are not in compliance. On-site visits may come later.
  - What has to be done in the first 120 days? **Response:** we have to submit our plan. Then we will have a year to add more details to the plan. Then we hope to have up to five years to carry out the steps contained in the plan.
  - Regarding FMS changes, the state will offer public input opportunities. Will that input be included in the HCBS final rule transition plan? Can we meet the timeline? **Response:** If possible, yes.
  - Regarding the survey process, how are responses to the survey being reviewed? Are the results that are in already being reviewed and red flags identified? **Response:** This is a discovery tool, then we'll look at next steps.
2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?
- There is a broad range of choice already made available.
  - The people I work with like the idea of having some of the control—they can hire their caregiver. If they want to move in with a friend or a relative instead of moving into a facility—they want to keep that choice.
  - Giving choices
  - The rule talks about person-centered planning. We've used that for many years already. Kansas' level of person-centered planning is advanced.
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
- Will patients have to change facilities? Will they have to change to another setting?
  - It's not really clear what's changing. We don't have a clear answer of what they're doing yet.

- It's unclear how it impacts individuals living in the family home. Most of this applies to provider-controlled settings. In-home support services—we're not sure how we fit in this.
  - The rule talks about the provider-controlled setting as if the provider is the barrier to individual choice. In some cases, it seems like the system of how we provide services in Kansas is the barrier to choice.
  - Another barrier to choice can be living in a rural area where there are fewer providers or services to choose from.
  - It will be tricky to comply without further guidance. For example, a resident in a group home setting where some things are off-limits for all because of the safety needs of one person, how does that affect others?
  - What about visitors to some residents affecting the safety of others? Also access to food and ability to lock their doors.
  - Once we more fully understand the expectations of the HCBS final rule, will they be reasonable and achievable? We allow visitors if they are within certain guidelines, but we can't say "yes, any visitor is allowed at any time."
  - In the normal course of life, with neighbors or roommates, we set expectations that limit each other to allow for good living together.
  - Is an individual competent to make those decisions?
  - For families with in-home support, we face challenges and timelines that are going to be included in these waiver submissions at the same time. We've heard about other kinds of settings. Parents that are in that situation need something to read describing what alternative settings could look like so they can react to that.
  - Regarding employment, the expectation seems to be access to integrated, competitive employment. There needs to be a standard of reasonableness—is that something this individual can achieve? Is that something they want to achieve? Will the state of Kansas support them achieving that?
  - As a parent of a severely-involved individual, I see little opportunity for vocational rehab to do much to help my son. Why do we put that on the HCBS provider to ensure that, when/if vocational rehab can't/won't?
  - In a private home, mom and dad can decide that it's not appropriate for an individual to achieve a job. But once they are in a facility, this rule would require it.
  - What happens when you've got somebody who could go to day services or be employed, but their choice is to stay home?
  - At what level does "right to risk" apply? If individuals are choosing unsafe options, the system doesn't pay for that.
4. What other types of settings should the state consider? What alternatives or opportunities could we explore?
- There could be good opportunities to fold waivers into each other or go to a universal model. This would reduce separate waiver rules and

requirements. It would be nice to cover birth through end of life and not just have to be on the TA waiver to get care as a baby.

- If the family or the individual doesn't want to go into a facility, and wants to live with a friend (a setting that isn't necessarily licensed), how can we help make that possible? Allowing writing a private contract.
- Waivers currently do not allow someone to do the IADLs (instrumental activities of daily living) and still receive the hours to take care of someone. Could we change the capable person rules to allow that?
- It's hard to separate out the IADLs from the ADLs.
- Allowing for the foster care reimbursement or family support models would be good. 2015 is going to be tough with all the changes coming. These models might be easier.

5. What other questions should the state think about?

- From summary of HCBS rule, page 3: "Residential supports may be provided in an individual's own home, in a group home setting, in a disability specific apartment complex, in a rural farm or campus for other individuals with disabilities." This feels like a big range, and I'm worried that if a rural farm setting is okay, that residents may not have sufficient access to the things that allow choice, such as activities and a local convenience store. Concern that this may be isolating.
- On the other hand, if that's what an individual chooses and prefers, maybe it's okay.
- Rural settings may make complying with some other parts of the rule difficult, such as employment.
- Does the parent or guardian have the right to "sign away" rights to employment or access to activities because of a preference to live in a place where those choices might not be available?
- Rural farm or campus setting might be okay if there are regular checks on how things are run there and individual choices are affirmed.
- How does the state monitor for safety, welfare, ensuring that residents are making independent choices? Oversight is important. Sufficient state funding for staff to fulfill oversight role is important.
- **How is the information going to get out to the actual client? How will individuals on waivers find out about what choices they have or which facilities are compliant?** As providers, we're having trouble understanding this, how will we help people eligible for waiver services understand the rule?
- When you're talking to CMS, will you ask for a waiver from CMS for third-party liability billing (insurance) for services that are never covered in the private insurance industry? It is an administrative nightmare.
- Please advertise these meetings better.
- Will program managers please improve/increase their email distribution lists (especially beyond I/DD, other waivers)?

KDADS Presenter: Aquila Jordan  
CCSR facilitator: Amy Delamaide

24 attendees

1. What questions of understanding or clarification do you have?
  - Who will be doing the assessments? **Response:** Quality management staff and field staff, survey and certification staff, and MCOs.
  - Regarding day services, if we've been creative with the "5-hour outside of the house rule," what will the impact of the HCBS rule be? **Response:** We need to have a conversation about that. Anything that increases compliance with the rule is a good start.
  
2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?
  - On the I/DD waiver, choice is already something that we do a very good job with.
  - We do a good job with rights restrictions.
  - We do a good job with person-centered planning.
  - Our current I/DD waiver affords us a fair amount of flexibility, except for the 5-hour rule and the rates don't support the services.
  - I like the idea of the annual planning sessions. Ideas come up in the meetings that our family or my brother might not have thought of.
  - As an MCO provider, it's been positive working with all of the other providers. They have been good about coordinating visits and sharing information.
  
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
  - We're seeing a move toward more individualized services for people. This is good on the surface, but when it comes to implementing it, this will take more funds. How will the philosophy and the implementation come together?
  - We're worried that if a provider finds they are not compliant, and they choose not to provide certain services or they shut down, where will the people go?
  - There's a relatively small pool of providers. If they shut down, we're concerned we won't meet the needs of individuals.
  - Especially in rural areas.
  - Regarding guardians. We provide PAS hours and day services for my son. We're worried those will go away.

- This increases the relative importance of the person-centered support plan (PCP). When we increase the individualization of services, the PCP becomes more important. If someone is working in a competitive employment setting, they have an obligation (tacit employment agreement) to show up. It can't just be their choice not to go to work, if that's an expectation of this rule.
  - People should have the opportunity for choice, but they should also have responsibilities to attend or show up.
  - Along the lines of competitive employment, will we increase vocational rehab services? That seems inadequate now to meet the need.
  - Is there any increase in funding based on this rule? If the HCBS rule requires "more," but the funding doesn't increase, how will this work?
4. What other types of settings should the state consider? What alternatives or opportunities could we explore?
- My son recently moved from a group home of 8 people to a shared living house of three people. The three of them share responsibilities for cooking, bill paying, doing their own laundry, etc. He was happy in the group home. But he has really blossomed in this shared living environment. My ultimate fear, if we get more people along that path, it will be difficult for a provider in a small community to continue to provide those services. It will be very expensive for them.
  - Regarding supported employment, we want to see more creativity in funding streams, for example combining vocational rehabilitation and HCBS funding. Braided funding would lead to better outcomes for folks.
  - Cautionary note: we've heard, during this transition, concern from families that their sons or daughters may be encouraged to move back home. We're not sure this will lead to independence.
  - At Mosaic, we have "host homes" all over the state. If they are monitored closely and people comply with regulations and training, our quality satisfaction rates have increased. Staff turnover is lower. Sibling, uncles, parents can be host home providers in other states. My brother living with our 90-year-old mother would like to live with one of his siblings when our mother passes.
  - If any of these models (shared living, family support, supported employment) are working in other areas, I'd like to know where they are working. Where are these models working well? I'd like to research them further.
  - We recently re-did (off-cycle) my son's person-centered plan (PCP) as he moved. We updated the skills he would need to have from day one, and rehearsed and practiced those so he was ready. I'm a real fan of the PCP.
  - There will be a house resolution introduced to encourage people receiving services on the I/DD waiver to be considered taxpayers instead of a tax drain, through tax credits, incentives, other things that would bring work into our workshops. This would support our folks being earners rather than receivers of tax money.

5. What other questions should the state think about?
  - Regarding sign language and foreign language interpreter services, how can we make that more individualized? Along the lines of competitive employment, there might be limited resources for someone who needs these services to communicate with a potential employer or service providers in the homes.

#### Conference Call, June 17, 7-8pm

KDADS presenter: Aquila Jordan  
CCSR facilitator: Amy Delamaide

Ten (10) people on line, including facilitator and state staff.

No comments offered.

#### Consumer conference call, June 18, 12:00-1:00pm

KDADS staff: Greg Wintle and Kimberly Clare  
KDADS Facilitator: Kerrie Bacon, KanCare Ombudsman

36 people on the line

#### Comments?

#### Lawrence, June 18, noon-1:30pm

KDADS presenter: Kimberly Pierson  
CCSR facilitator: Amy Delamaide & Kevin Bomhoff

24 attendees

1. What questions of understanding or clarification do you have?
  - Question: Can persons in assisted living bring people help in from the outside. **Answer:** KDADS will need to add this to list of questions that need clarification.
  - Question: When does the 120 day period start? **Answer:** When Kansas submits any waiver renewal or amendments. CMS is giving Kansas the opportunity to propose our plan to come into compliance. The “clock” has not started yet and we don’t know exactly when it will start. Kansas will request to come into compliance with the final rule within 5 years.
  - Question: Why are nonresidential settings being assessed when there is no guidance at this time? **Answer:** We are assessing if the service under HCBS) is in compliance with the final rule. We will do surveys separate

from the assessment. This is for discovery. CMS has not provided guidance on nonresidential settings.

- Question: Would you recommend providers look at the current rules and apply this to areas where there has not been guidance provided? **Answer:** We really don't know what the guidance will look like. We are in a discovery stage to see how the rules we do have will apply and what we would need to do to come into compliance.
- Question: Why this rule? Why now? Was there an event? **Answer:** That would need to be asked of CMS.
- Survey button would be helpful on the website. It is hard to find.
- Question: What is the process if the HCBS provider does not complete survey by the deadline? **Answer:** KDADS will need to provide an answer for this.
- Question: What is the difference between this meeting and conference calls? **Answer:** Conference calls are shorter format with same opportunity for input. This is for those who cannot make meetings.

2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?

- The concept of self-direction and self-determination has been at the heart of our work for decades.
- Person's choices and Person Centered Planning (especially for IDD waiver).
- Kansas has been strong in how the IDD waiver has been structured. Wide spectrum of options allows for choice, flexibility, and choice of options.
- Kansas had this philosophy all along. Need works in enforcement.
- Kansas has laws and these have a long history of consistently across targeted populations.
- When those on IDD waiver need restrictions we have a history of a good system of making sure it is needed and for the health and safety of the individual and informed consents in place.

3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?

- Not every provider is following the philosophy of our state. Most are but we need to work on enforcement.
- How will CMS interpret the work centers? We hope they look at the outcomes and quality and not just the settings.
- Choices that consumers make are limited by funding and availability of providers to meet those requests. What will this look like in rural areas? Will this create an undue hardship (paperwork)? What will be a validity or reliability process with the survey? Do a random selection of providers and check with consumers or protection/advocacy agency with direct experience.

- Rates have not been increased in years at the same time CMS is pushing managed care – are these competing activities?
  - Who is assessing? Are consumers (peer to peer) going to be involved in assessment?
  - Those who are not able to conform may be dealing with building, land, or property that are difficult to address. Need to look at quality of services over the building land or property.
  - Additional consumer training will be needed as to how to express or negotiate these rights. These are skills of independent living that consumers and support circle will need.
4. What other types of settings should the state consider? What alternatives or opportunities could we explore? (In addition to those listed in the KDADS PP presentation.)
- We may not be versed enough to answer this. We need to look at what is offered in other states.
  - KDADS does not have enough licensing staff now. How will monitor quality of new settings?
  - Settings are not the question. Funding is the issue. Congregate settings are driven by economics. Non waiver families are forced by economics to live together.
  - Individualized budget authority. A challenge for auditing and analysis. This is a system ideal for self-directed and person centered service delivery.
  - Looking at alternatives for persons with challenging behaviors. This is a cross disability issue. What proof is needed to document that a system is not working. The physical setting is often adjusted to address challenging behaviors. Some of these challenges are short-term. Staff need training for addressing challenging behaviors.
  - Creative co-mingling of VR funds with other funding streams for more opportunities for competitive/integrated employment.
5. What other questions should the state think about?
- Key question – are we funding our system in a way that allows these rules to be effective?
  - State seems to be taking a reasonable approach focused on outcomes and quality and not just the physical settings.
  - Worry that KDADS does not have the capacity (in staff) to pull this off given other demands (KanCare, etc).
  - Increase in transparency in this process and others.
  - Do all waivers have a full 5 years to get in compliance? Some appear to have only 12 months. Kansas will request 5 years for all waiver transitions

Lawrence, June 18, 5:30-7pm

KDADS presenter: Aquila Jordan



9 attendees

1. What questions of understanding or clarification do you have?
  - Question: Is an assisted living that only provides services to private pay going to be surveyed. **Answer:** Yes, all settings are surveyed. Just answer “no” to the questions regarding HCBS. It is important to know if the provider has the elements for HCBS regardless of whether or not they serve HCBS.
  - Question: In overnight situations, can we still provide bed-checks. **Answer:** CMS wants to see a specific assessed need that is regularly reviewed. Rules can be made for emergency assessed need. This would be built into general policies and then noted in the file. Response to falls, would require an assessed need based on a specific limitation. All people cannot be checked on as in a hospital. It must be a specific plan. CMS does not want to pay for institutional care with HCBS funds.
  - Question: How is final rule going to bump up against Article 63 regarding behavioral issues? **Answer:** Each plan must be individualized. One person having a need does not justify all people receiving a specific treatment in response.
  - Question: Will there be a human rights commission to review issues. **Answer:** The final rule will not change the need for the commission.
  
2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?
  - Kansas is ahead in the areas of individual rights and person centered planning.
  - There are already small settings.
  - Kansas is ahead in having waivers that are community based.
  - Kansas already has community based settings. Small towns result in all settings being based in and near the community.
  - We have routine processes in place. Some good risk assessment processes in place for DD. Kansas compares well to other states. This is not as well developed for PD community.
  
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
  - Some settings do not have a preventative approach. Lack of training in this area. Especially regarding medical care.
  - Day service is moving in the right direction but will have the most difficult job complying.

- Will people become isolated if they don't get the socialization in the workshop settings? However, there will be benefits from interactions with more people that who are disabled.
  - What kind of support will rural communities be given to move in this more integrated direction? Some workshops are like coffee shops.
  - Day services are a product of funding efficiencies. How will we support these more independent settings? Model changes then funding needs to change.
  - What will replace the existing model where an IDD provider has a range of services?
  - Assisted living options are very hard to find. Is this going to make it impossible and push people to nursing home settings?
  - Waiver silos make it difficult to get the car they need and unless the new approach allows waivers to be combined, silos will continue.
  - How will TCM be provided "conflict free" from other services? This will need to be separated. Now it is a requirement or we will lose the waiver. This is not part of the final rule we are currently addressing. That will come later.
  - People do not want to leave their small towns but their settings are close to nursing homes. It will take more funds to offer options. No incentive to develop the settings required by this rule. Assisted living only take people on FE waiver.
  - Not everyone wants people to be able to just drop by.
4. What other types of settings should the state consider? What alternatives or opportunities could we explore?
- Combining waivers will reduce silos.
  - Host homes are a great idea but can we find families (such as the foster care homes). Host homes don't last long in many cases. Similar to foster care there are positives and negatives.
  - DD and FE waivers combined has some exciting possibilities. TBI and PD would be another good thing to combine. Also TA and DD. PD and IDD waiver combined would improve their needs getting met. Mental health would go with any waiver. These combinations hold the most possibilities. Mental health community will need to understand how these populations can be served.
5. What other questions should the state think about?
- Don't just look at the setting. Look at the outcomes. Not just focus on the rule but look at the outcomes
  - Worry that a person served can only have certain staff because they cannot work in more than one setting. Can't coordinate the staff schedules. Encourage a more opened mindedness to staffing. What is best for the person served not rules about settings they can work in?
  - How will CMS address the way emergency rooms treat people with disabilities? How will we educate the community and other providers for

this level of independence? There is a stigma toward them. Providers, hospitals, mental health, etc. How will we fund this education?

- This needs is addressed by the Final Rule Rights and Freedom rules. More community education (again).

Pittsburg, June 19, 12:00-1:30pm

KDADS presenter: Aquila Jordan

CCSR facilitator: Amy Delamaide & Steve Williams

18 attendees

1. What questions of understanding or clarification do you have?
  - If the periodic review is supposed to happen more frequently than once a year, that is going to take additional nursing staff time to do. Is our reimbursement or time allowed for services going to be increased?  
**Response:** we're not asking for a whole new plan of care more frequently than once a year. We're asking for regular review of any limitations in place to ensure they are in place to meet specific assess needs.
  - Will you clarify the assisted living requirements regarding accessibility to food at any time? What about money follows the person (MFP)?  
**Response:** MFP is a separate federal rule. But this HCBS final rule for assisted living will be closer to the MFP rule. We're waiting for more guidance from CMS regarding access to food. CMS doesn't want one person's restriction to become the restriction for everyone.
  - On IDD group homes, is there any discussion about limiting the size? I've heard rumors that there won't be allowed to have more than four living there.  
**Response:** The answer is, "that depends." Quality of life matters more than precise number. Characteristics such as shared staff or institutional-like care will affect the assessment of compliance with the rule.
  - What about settings where residents are extremely isolated because of parent or guardian decisions, especially in unlicensed settings?  
**Response:** There has been a rule released recently about quality measure protocols. That is why the state has moved to using the NCI. We're looking at all unlicensed settings for this reason.
2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?
  - On the IDD especially, we have the DD Reform Act, which puts quality assurances in the law with rules and regulations that come down from there. We're ahead of most states regarding person-centered planning process for the IDD waiver.
  - Member choice in certain areas, such as KC metro and Topeka.

- Based on Kansas regulations, the appeal process for telling someone they need to move out, 30-day written notice, etc., is already in place.
  - With the assisted living setup, the kitchen and availability of food is already in place.
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
- As providers, we offer activities (even though it is not required by the state). We don't always offer more than one choice of activities. Regarding dining options, we don't have kitchen staff on duty all day long. We lose money every Medicaid person we take into our building. Is our reimbursement or time allowed for services going to be increased?
  - Western Kansas is more limited in choices.
  - Residential care (licensed under assisted living) will need to be watched more closely.
  - Backup providers: if a provider is determined not to be in compliance, there may not be others available in this area.
  - More funding will be needed for additional staffing to provide choice of activities.
  - If the intent is to provide quality of life, you can throw an activity calendar up on the wall, but not provide a good quality of life. More than just activities matter.
  - I'm concerned that sheltered workshops or day services are chosen over employment. To come into compliance with this rule we should make sure employment is offered first.
  - Everyone wants integrated employment. But where are the jobs? As providers, we don't create those. So you have to have an alternative to integrated employment.
  - Other jobs will need to be developed.
  - As a care coordinator working with an MCO on the IDD waiver, in southeast Kansas, there are not always employers who are willing to work with this population, and to accommodate their needs.
  - We need clarification on who is "natural supports." Who can be a paid provider and who can't be?
  - It's nice to have a good philosophy in place, but we need training to carry it out. And there needs to be monitoring to make sure it happens.
  - Regarding self-directed care, sometimes the people "Grandma" hires to take care of her is "Granddaughter" who just got out of jail and doesn't do any of the work she's being paid \$9.50 an hour to do. There needs to be some checks and balances.
4. What other types of settings should the state consider? What alternatives or opportunities could we explore?

- It looks like now the state is not looking at a “flat-earth” waiver (all waivers together). We deal with IDD. We’ve learned through KanCare that that is a unique system. If we combine, I would have concerns.
- We like the a la carte idea—for example, each person having a set amount of money and each person chooses which services they want.
- We like the idea of having a mental illness waiver.
- Shared living models such as host homes have a lot of possibilities. I would like to see this stay as being licensed under a provider, not a separate licensing process.
- Expanding supported employment to all waivers, not just IDD.

5. What other questions should the state think about?

- Regarding campus facilities, in our community there are two assisted living locations. What do we need to do to put us in good shape for this rule?
- Based on what there state is doing, how can they meet the needs of the 900-1,000 physically disabled people who are waiting for services? They are waiting now to get older to become eligible for the FE waiver.
- Look at personal, individual outcomes of KanCare, especially for IDD. We’ve been working together a long time, but have a ways to go. It seems based on a medical model. It needs to be more focused on personal outcomes, not just the medical side of it.
- I’ve been waiting for a long time for adult protective services (APS) and child protective services (CPS) reports followed up on when we call the hotline. I just get calls from angry family members. Individuals are following through the cracks. This is a big problem in southeast Kansas.
- Regarding APS and CPS, many of us have been disappointed with the reports that have been screened out or unsubstantiated findings. People have gotten to severe circumstances before action has been taken.
- When you call a report in, you can request that someone follow up with you, to let you know if it is screened in or out. You have to request it, they don’t ask you if you want it.

Pittsburg, June 19, 5:30-7:00pm

KDADS presenter: Aquila Jordan

CCSR facilitator: Amy Delamaide & Steve Williams

4 attendees

1. What questions of understanding or clarification do you have?
  - Presentation of information was very clear.

2. Related to the rule you just heard about, what is already working in Kansas? Where are we already complying? What do you like about home and community based settings?
  - In the southeast region of the state (twelve counties), you'll probably find a lot of compliance with the rental agreements. That was emphasized several years ago.
  - Most of the settings (both residential and day) you'll find in this region are healthy and safe.
  - Historically, Kansas has done a very good job for people with developmental disabilities.
  
3. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?
  - Day services will be a big challenge to come into compliance. They're the oldest service in the business, they're pretty entrenched in how they do things.
  - You get what you pay for. In the past, the state hasn't paid for us to move in the direction of supported employment. If you don't want people to be in a workshop, pay less for it.
  - Have everybody ready to move that way.
  - Sometimes, you give someone \$800 a month to take care of you, but the person doesn't do everything they are supposed to do to take of you. What recourse do I have in that circumstance?
  - Getting providers to adhere to the philosophy of person-centered care may be tough. We need a massive amount of training, especially in the western part of Kansas, to make sure providers understand that. And putting supports in place for providers so they can understand this.
  - Sheltered workshops will probably be the hardest to change their way of thinking. For vocational rehabilitation, we don't consider sheltered workshops employment, because it's not integrated and competitive. Sometimes in rural areas, people get put in workshops because the providers don't know what else to do with them.
  - Help providers think bigger. Share innovative ideas from other places.
  
4. What other types of settings should the state consider? What alternatives or opportunities could we explore?
  - From the vocational rehabilitation side, with the supported employment, how can we work together, so that's not taken away from VR but an example of working together?
  - Family support and shared living models both sound good, as long as there are safeguards in place. Checking in—did the person really choose this?
  - Some host homes didn't get the philosophy of choice.
  - Independent living is a good model. They've had success with some people who are really hard support. There is choice and freedom.

- Maybe we can have some conversation with people who provide that type of service and see where that is coming from.
5. What other questions should the state think about?
- I'm on SSI. Is this rule going to mess with that if my living arrangements change? What about my services from KDADS?
  - Technical assistance and support, making sure that people are going where you want them to go, in a very supportive way. Having an attitude of "how can I help you to get where you need to be" is important in quality assurance.
  - If you model person-centered support to the providers, the providers will give that kind of support to the consumers.
  - I hope we keep focused on person-centered support. I hope we don't revert back to a checklist.

**Provider conference call, June 23, 11:00-12:00pm**

KDADS staff: Greg Wintle and Kimberly Clare  
CCSR facilitator: Amy Delamaide

36 people on the line

6. What questions of understanding or clarification do you have?

(None)

7. Related to the rule you just heard about, what is already working in Kansas?

(None)

8. Based on what you heard today, what concerns do you have? What might need to be changed or improved to come into compliance with the rule? What do you think our biggest compliance issues will be?

- Where do we see this final ruling affecting individuals who live in group homes? They've lived there for 15-20 years; this is a family for them. They have a few hours of independent time during the day. Is this something where we're going to have to encourage them to move?
- How vulnerable is too vulnerable to live alone in the community?

9. What other types of settings should the state consider? What alternatives or opportunities could we explore?

(None)

10. What other questions should the state think about?

(None)