

Final Rule Stakeholder Call

Topic: Provider Progress on Final Rule

6 / 7 / 17

Noon call (53 participants on the line)

State Staff: Cindy Wichman (KDADS HCBS Director)

Program changes/modifications to employment?

1. We are continuing to do things that expand our mission with an emphasis on helping individuals live the life they want to live. That has always been the focus of our services. For the non-residential side, we have a job link which has 3-4 settings or services and they can choose between them already. There has been a lot of emphasis in the final rule about choice rather than physical support for access to the greater community. One service we offer is a work center, which is an option for individuals if they choose to do that. We encourage participants to look at integrated employment at every persons community support programs. 50% who do access or focus at work the center also have part time integrated employment in greater community. We want to emphasize the value of choice for that individual. We should do satisfaction survey about their choice. It's an ongoing process. I think for us, it's continuing to offer the choices and to be able to focus on the PCSP. On the residential side, we have an emphasis on living in small setting communities and access to do things. Some have busier lives than we do. We need to work to facilitate transportation – either the communities or our own – so they can access things. Individuals can do things as long as they can do it safely without supports, or if they need support with the individuals. If it needs staff, it is difficult with the capacity and being able to pay competitive wages and it is hard to be competitive. On the residential side we are working on lease agreements for persons on the final settings rule.

We do not prohibit them from getting prevocational support, or from getting sheltered based jobs. We must support them getting access to greater community. An individual in a work center can move and can come and go. They have full access to the community, but sometimes we have to facilitate their movement to doctor appointments as they are not able to do so like someone not accessing HCBS and we have done so over last 50 years. It's what we have to do because we are supporting people. We have to make sure they're safe and their health is looked out for. There are things they're not able to go and do, but in the regulation it does not prohibit facility based support and full access and opportunities for competitive settings. We provide it. We are always assisting and supporting competitive employment. 50% of those that access services in work centers have a competitive pay in these settings. It is very few hours a week, but we do a lot of other things in the community according to their PCSP.

2. WIOA has made changes to day services and employment. Everyone is aware of the changes and into that because of the July 22 or 26 date and are dependent on Voc Rehab.
3. I want to commend and support Cottonwood. Lakemary provides a menu of options that are very similar to Cottonwood. Can someone at some point tell us that we won't be able to provide our site based locations? We can't move forward and plan if we don't know the answer to those

questions. CMS says as long as they have choice. Are we to serve our people on a regular basis, choose site based employment and still be able to bill as a day service?

- a. I share the same sentiment and want to have a more definitive path set before us. I will be working with – now that we have up to 2022 – working with stakeholders to redesign what that would look like. In such a short timeframe, the learning collaboratives are what we envision how we will work through those conversations and will provide a firmer foundation on how services will be structured and reimbursed.

Modifications to Day Service Settings?

Any service impacted by final rule?

How far do organizations feel you are in terms of your final rule planning?

4. I thought we'd have the learning collaborative piece before anyone did any kinds of changes. I thought it was the next step.
5. I started that since we started 30 years ago. We've been pushing to make people as independent as possible. We've pushed as hard as we can always reach. I have the same concerns as [a previous commenter], I am going to have people and parents caught in a crosswind and not sure where to turn with this whole thing.
 - a. This has been evolving over a number of years. Final Rule is opening up a new interpretation of that, but this is work that provider organizations – they have been doing for quite a while.

What, if anything, do providers see as an opportunity to enhance what you've already been accomplishing over the last number of years? Do you see opportunities to build on what's already been done?

6. I concur, we are all willing to do all we can to provide best options possible. The learning collaboratives are the key, and word collaborative. I look forward to working together and gaining clarity on the parameters of where we are going. They are essential and that we are all on same page so we can move it forward.
 - a. Thank you for that. I feel the same way. There is a lot of uncertainty. I believe we can get on that path to the real work that will need to be done
7. I want to emphasize that I hope the state, in the plan, allows for what CMS has allowed for in the settings, that doesn't specifically prohibit a work center, as long as you can show that people have opportunities to seek employment and access to community in the PCSP. We talk about it to them and make them aware, we keep that emphasis in there. I certainly hope that the state doesn't take a restrictive view. There will be families that are very, very, upset and will voice that. Many of them, having their son/daughter/family, for a portion of their day in a work center; they know that is what they (family) desire. The choice of the individual, a menu for them, and have them choose that. I want to make sure the state is not more restrictive than CMS in their settings.
8. One factor not put out there – we pushed out to have people get jobs, without any rewards. We lost day funding. But what about the future of the people we placed? They are not going to do it in 3 days and do it on their own. They are going to need continual staffing for a long time. There is no funding that I found that enables us to do that. That factor somebody else has to take care

of, we certainly can't. I have a few folks that would probably try and succeed but most wouldn't succeed on the voc rehab model.

9. We had an individual who was going to have a life skills training setting (guided activity) into an individualized setting (1-1 support) with the IDD areas. He preferred to get exercise – LSDS area – and was influenced by peers to not do much. They didn't ask for extra funding, notifying the MCO that this change was going to occur. They said they cannot fund it as a day service. Is that self-directed PCS? How can they be educated on individualized schedules and being challenged by MCOs on the individualized funding?
 - a. We are developing design teams on the learning collaboratives. The MCO partners will be part of that mix. So, it's a preliminary response to what sounds like an involved situation. The point that resounded is that the MCO partners are involved in the work that is being done moving forward.
10. MCOs need to be involved, and need to be seriously involved. I'm not convinced they are as involved as the community service providers are involved in listening to the people who provide the supports and not just looking at the bottom line.

Has anyone started work on the landlord tenant act agreements?

11. We've started incorporating that into our agreement.

Service delivery models – What's in place, and when full compliance is achieved – what concerns or areas for conflict with intent of final rule? Meets the requirements but not unnecessarily restrictive? What areas do providers see as areas of potential conflict?

12. My concern isn't about programs/services, it's about the execution given the staffing crisis nationwide. A sufficient number of qualified staff to carry out the final rule.
13. Most of us have been around 25-35 years. It's an aging demographic. We serve a large number of high needs dementia and Alzheimer's clients. The vocational option is not something they're going to choose or participate in. It is a reality that can't be ignored. Most are having to look at special settings/environments that we can creatively put together that are therapeutic and predictable for them. I want to reiterate, there is a staffing crisis and we are hopeful that as we collaborate with the realities of Kansas... I've seen Kansas at the cutting edge of progressive person centered systems in the country that we have done all we can do to design customized systems for families based on the feedback of the families & persons we serve, and to meet the needs. That we are always evolving and are committed and obligated to meet their needs to serve them through the end of their lives. We are optimistic about the efforts of other providers and will bring the capable staff I can to the table.
14. I wholeheartedly agree.
15. I am grateful #####, #####, and ##### are speaking out – Everyone speaking out as if this is a black & white issue, leaving out shades of gray. The people we serve have IDD. Not all are capable of making a choice. Not all are capable of doing what is expected of this. This is being diluted and not coming out for people with IDD. I read a lot of stuff into what it is being said that disregards it. That no one has a disability and can do what their choice is. Individualized choice is getting lost considering the population we do support.
16. If Individuals were able to do anything and everything others do in the greater community they wouldn't need our services. They have to see that if they are eligible, there's a reason why they

are getting services and support through the HCBS system. We do a wonderful job facilitating their choices given the financial parameters and crisis with staffing. If they are able to do it all on their own, they wouldn't be accessing services. The irony is remarkable.

Values should be promoted and how they fit in with the final rule. Particularly what values should be paramount to our thinking and with the final rule?

17. I think the important thing is that something they're happy with, satisfying, capable of doing. It's not a cookie cutter system. But primary goals are satisfying and they enjoy what they're doing.
18. Here at Lakemary we have guiding principles. One I think about the most in regards to the final rule and the people we serve is "nothing about me without me". We didn't create it, Tom Pomeranz did over 25 years ago. I question if we are listening to the voice of the people. I applaud the opportunity as a provider to guide good decision making as we move forward. If I were to gather together the 200-300 people in the process, they would be very clear and very passionate, and very articulate about how they want to spend their time for the rest of their lives. I would encourage us all to examine if we are including the lives of the people and voices of the people as we move forward in the decision making.
 - a. That tripped a trigger, when looking at the design team of the learning collaborative that we do not forget to include that consumer representation.
19. For consumer representatives, be sure to get one with good verbal skills and can articulate what their choices are. There are many, many others that would have a voice too, but having a consumer representative does not give you the representation for every person. All voices need to be represented. We need to recognize all consumer input.
 - a. That makes me think of the Friends & Family advisory council with loved ones who are also caring for those persons and who are caring for persons with many needs.
20. Someone was saying something about the planning earlier – about its black and white and all of a sudden everyone has to be put on jobs. I have a consumer, he's been in and out of our day program. Had a job, lost a job, went and got retrained, had a job, lost a job; went through it 4 times. It's not been for our day program being there during the day he would be lost. He lost a job and there was nothing to catch him and help him regain the skills that he needs. They're leaving us with nothing. He's got a job now, but it's leaving him without a bunch of failures and the safety net to catch him.
 - a. Being able to support people throughout the life experience, especially when times are not so great.
21. It seems like the plan put together by the MCOs has become more important to be put together than one put together by the PCP, by the providers, and the case manager. It seems like the focus is on those are secondary to the MCOs and that is very unfortunate.

Evening Call (6 participants on the line)

State staff – Cindy Wichman

1. I work for an ADRC and I'm just here to hear about the changes of what happening, so I know what's happening if they call us or want to know. I am one of the supervisors for the options and assessors and so we want to know what the changes are. I don't know, I have heard too much. I

know I had heard some questions from assisted living that would impact them, but nothing recently since more details have come out. Locks on doors and the sharing of rooms were concerns the facilities had.

- a. Any questions we could help convey better?
 - i. Not at this moment, I'll be sure to send an email after the call. I want to be kept in the loop.
2. I am a parent/guardian for an IDD daughter. It's the only way to know what's going on. Do I need the landlord tenant agreement if my daughter lives within my home?
 - a. I would say if she is living in a family home and she's not paying a room and board then there would not necessitate of a formal agreement.
3. Until I get information back on the revisions, there is not much we can do. I'm happy with what we've got frankly. Day services – we can use more of that, but it's not going to happen. We've gone without a day service program for a year now because of the waiting list. Anything we can do to give people more options.

What would you be looking for in your ideal...?

4. Volunteer activities. She's got behaviors that may not make her good for employment. Activities out in the community. I'm able to get her out in the community well when it's just me and her.
5. We also need to look at pay for these people. I've done a poll for the severe autism mom. Kansas starts out at \$7.50 for PAS workers. We have the lowest paying state in the nation. Most are \$10-17 (Michigan) via their agencies for in-home supportive care help. I just feel like we need to bump it up a bit. We've tried in the past with the legislation. It's imperative. I've been looking for somebody, even on Care.com even at K-State. Nobody wants to work for \$7.50/hr with no benefits at all.
 - a. That came up at noon also. As we look at redesigning to comply, is the idea of what we value most and redistributing the resources as needed to help meet those needs. I don't know that I have the solution to share this evening or whether there is an absolute solution for wages for workers, but want to rethink resources we have within the system and conversation we want to have as we move forward with the learning collaborative working with stakeholders, consumers, and families to respond to the issue.
6. Even at \$17/hr, finding help in home to give them a break. It's not just us; it's nationally. With the pay scale, and the person who is paying, we can't find anyone either. I don't know if it's because, let's face it, they're not cute cuddly ones they want to work with. You'd think somebody, for that money, even part-time, would want to do this work.