

CO HCBS Non-Residential Stakeholder Workgroup Summary

Meeting #3 – January 14, 2016

The intent of these workgroups is to problem solve and gather ideas surrounding implementation of the HCBS Settings Final Rule. This group is moderated by The Lewin Group at the request of The Department. The intent of these notes is to capture the exact nature of the comments of the workgroup participants and is not representative of policy decisions or the Department's stance on implementation.

I. Workgroup Participants

Stakeholders Present:

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Caitlin Phillips, HCPF
Amy Scangarella, HCPF
Christina Neill Bowen, The Lewin Group
(facilitator)
Kristen Rice, The Lewin Group (note-taker)
Michelle King, King Adult Day Program
(KADEP)
Tamara French, Goodwill Industries
Deana Conaty, Rocky Mountain Brain Care
Candie Dalton, Accent on Independence
Barb Wilkins-Crowder, ACMI, SEP
Celeste Ewert, Envision, CCB
Jan Irvin, Foothills Gateway, CCB
Gerrie Frohne, PADCO
Mary Jo Rymer, Arc of Colorado
Tia Saucedo, LeadingAge Colorado/Seniors
Resource Center

Karen Lillie, Pueblo Diversified Industries
Robin Forbes, Pueblo Diversified Industries
Leah McMahon, Access Long Term Support
Solutions

Stakeholders Absent:

Adam Tucker, HCPF
Stephen Shauchnessy, Mosaic
Joan Wilson, Mountain Community
Pathways (Adult Day Program)
Cassidy Dellemonache, PASCO
Julie Banschwickert, Disability Law Colorado
Tammy Drumright, DDRRC
Jenny Nate, Rocky Mountain Health Plans
Kasey Daniels, Disability Law Colorado
Anita Evanyo, Rocky Mountain HS
Danny Holzer, Jeffco OLTC, SEP

II. Introduction

Christina Neill-Bowen opened the meeting with introductions and a reiteration of the purpose of the workgroup, which is to work together to exchange ideas, develop solutions to problem solve and mitigate challenges, and share best practices related to the implementation of the HCBS Settings Final Rule for all setting types and case management. Participants were asked to introduce themselves and say a few words about what "Informed Choice" means to them. Christina went over the working agreement with an emphasis on respectful sharing.

The Meeting's Focus was on Informed Choice. The Final Rule requires:

- The individual must be able to choose the setting from other options, including non-disability specific settings
 - The setting reflects individual needs and preferences
 - Policies ensure informed choice of the individual
 - Service options include the opportunity for individuals to choose to combine more than one service setting in any given day/week for full community integration

III. The Consultancy Process

The work group engaged in a group brainstorming process called a "consultancy." Three group members shared a challenge related to the Final Rule and the group helped brainstorm some solutions.

Challenge Presentation #1 – Barb Wilkins-Crowder

As a reminder, we work with non-IDD folks in community settings. We had a young disabled adult with mental and physical disabilities. She has a history of explosive behaviors. She is unable to maintain or foster relationships. She is disruptive at businesses and will yell to get attention. She wants services, but no one will serve her. We have given her a list of Medicaid providers and encouraged her to explain her situation and advocate for herself. She won't do this and then she goes on to contact non-Medicaid providers. I would name this dilemma as how do we effectively support the delivery of service within the reality of her behaviors? How do we respond to the reality that she will be unhappy without some change to all of this? There are definite tension points around informed choice and person centeredness. Each client must receive a service at least every 30 days. It can be as little as 2 hours of homemaking. She is informed of this waiver requirement. She chooses the only non-interaction service, the med box. She is manipulating the system. We can't force providers to provide care to her. Another tension is that we've had to let her know that verbal abuse and threats of self-harm will result in police calls. This is terribly traumatizing to her, but we have to set some limits.

Clarifying Questions:

- You mentioned that she is getting the med box monitored, but nothings else. Does she want anything else and if so, what?
 - It changes from time to time, but non-medical transportation comes up and homemaking.
- Does she actually need the med box monitoring? Is there a therapeutic value?
 - We've tried to challenge that, but it has failed. She has challenged with appeals.
- Is she connected with mental health services? Does she or the case manager have support there?
 - We don't have access to talk it though. She has had providers, but has had a terrible time remaining in the relationship. She destroys the relationship and she pulls out.

Group Brainstorming:

- My idea may not be super helpful, but I speak as a parent of an adult son with a severe and persistent mental illness and is on a waiver. He doesn't like people in his home, so the med box is the only service he is on. We periodically try new things to see what will work. I encourage you not to stop working on it. The med box can be very helpful. It has saved my son's life and kept him out of the hospital.
- I'm wondering about mental health resources again. Does this individual have a psychiatrist or someone to do an evaluation and make some suggestions that would be constructive for this person? We all know that behind behaviors, something is going on. I'm wondering how much that has been looked into.
- This may not be available in your area, but in Denver it may be possible to connect her with a peer if that program is available. As far as a place for crisis calls or more emergent situations, maybe direct them to call Rocky Mountain Crisis Partners. Some of the folks we work with have utilized that to get support around specific crises.
- Based on personal experience when you're dealing with complex mental health issues, it is more complicated than just a behavior. Have they looked at a consumer-directed option? I know that this can be scary. I don't know if this person might have any family. The client could hire whoever they want even if they aren't a Medicaid provider.
- Does she have family or any other community supports, or a guardian?

Presenter's Reactions:

- There is no guardian, she has full capacity. She has some out of state family that will act as advocates from time to time. But that relationship has been contentious as well. We have a release for a while and then it gets pulled.
- It might be very difficult to implement that, but of all the suggestions, peer support might be worthwhile. We have seen stability when she has self-chosen. She was involved in a church, and considered Consumer Directed Attendant Support Services (CDASS), but it has not gone well. She does have access to mental health services, but again that doesn't go well. She has been in and out of residential treatment. I applaud the ideas about empowerment. When we have backed out and stopped responding to each crisis, she has stabilized more. She has a right to ask for these services, but we don't have a good effective way to make that successful.
- I didn't bring this challenging one to be obstinate. We talk about empowerment, but sometimes it feels impossible. The more we can talk about best practices around these issues, the better.
 - This is a good example of informed choice. Because of her disability, she is making a choice that we might not agree with. She is choosing not to engage in mental health services and blow through providers. Person centeredness doesn't meant that we're going to fix everything either. This is a good example.



Sometimes you take a backseat and they just have to live with those natural consequences.

- How do we document that sufficiently to keep CMS happy? I appreciate the context.

Challenge Presentation #2 – Celeste Ewert

This is a struggle that we have in our day programs that are around choice. I'm a program services director. The first 18 years I only did residential. We had to reduce and lay off a lot of people when we consolidated programs (residential and non-residential). Residential was my expertise, when we consolidated there was a lot going on in the day program that needed to change. We did a lot of restructuring. We had staff become specialists in certain areas. We have done a lot so things are changing and some good things are happening, but there are a lot of factors that limit choices. We support people with DD. In our day program it is adults. There are many factors. There are two types – community connections and specialized habilitation. It is either integrated or segregated. It isn't clear-cut whether it is facility or non-facility. We have to decide how many units they want to do. You're expected to predict that with the person for the entire year. We support over 100 people. We do not hold our own with the rates. We rely on grants—United Way and others. We provide some one-on-one, but we do need to do groups as well. The problem we end up with (we try lots of things) is that this is what was scheduled today and one person doesn't want to do it. Units are tying our hands and limiting choice for people. The fact is we can't provide one-on-one for everyone. The first challenge is that not everyone in the group wants to do the same thing. The second thing is that even in our own lives we don't have unlimited choice, but I feel that day programs are held to a higher standard and we're scrutinized more harshly.

Clarifying Questions:

- Could you describe what you mean by integrated day programs?
 - If we have some going on, the integrated pieces are activities that occur with typical community members. We bring in the county clerk's office to teach about voting and open it to the community. Integration is not necessarily determined by location.
- What Celeste described between community connections and day habilitation would probably be fixed with the waiver redesign. Waiver redesign ought to fix this problem.
 - I hoped that there would be day habilitation and it doesn't matter where it happens.
- In a nut shell, what I hear the dilemma is that sometimes you can afford to let people do one-to-one, but sometimes you have to tell people that groups are the only options.
 - Yes, that is correct. The waiver units do not allow for it.

Group Brainstorming:

- I have a comment about the rate issues. When the Community Living Advisory Group (CLAG) recommended that waiver redesign begin with the DD adult waiver, the intention was that a single waiver would be available that would allow greater flexibility. One of the first elements that we looked at was whether residential waivers should be separated from non-residential. We believe that it would be best if the issue of residential and non-residential could cross all services. Choosing a waiver based on location would become secondary. Service definitions are another thing. Currently the definitions are fairly prescriptive. We're hoping to broaden them and allow more flexibility. The group issues wouldn't even be part of the definition. The community could range from social events or some time doing nothing at all, but with appropriate supervision. The key is that service definitions need to be flexible enough to allow us to use the dollars that we can. The difficulty is coming up with clear enough definitions that an outsider, like CMS, can know that what is in a person's plan is being delivered. In the DD world, when the rates were set and the state moved to FFS, the rates were determined at the same time that the Colorado economy went in the tank, so the rates were slashed. The rates were inadequate from the start and everyone knew it. The activities that met the definitions could not be sustained with those rates. Without pouring more money into the system, we have to be really vigilant in advocating for adequate rates. We may have to make reductions somewhere else. The person centeredness won't let us just blame the rates.
- This is probably going to sound pretty pie in the sky. The way to save money now and improve the situation would be to get more buy in from more people who are volunteers. It is hard and it takes a lot of initial investment to get more volunteer people. They are out there if you look at all the tremendous amount of charitable stuff that goes on. You probably need a huge investment campaign to generate a really viable volunteer force. That would help a lot in this whole situation around choices and trying different situations. Getting buy in from community people is key.
- The last point is perfectly in keeping with where we want waivers to go. We don't want to limit our thinking to one agency that provides one program. We have to keep our options open. What we have now is a system where people are paid to be involved in our consumer's life. What we should aim for is a system where the people want to be there.
- I agree. If we can find natural supports to help out. I'm assuming that folks chose these programs over any other options that are available—this is where they want to be. I think there is a lot in redesign that will help. It might vary from agency to agency. You make a prediction at the beginning at the year, and if over the course of the year you realize that it isn't panning out, then it should be an easy process to revise that service plan so that the individual gets to make that choice. The paperwork shouldn't be driving the person.

Presenter's Reactions:

I appreciate all of this. We actually have a group with our person centered planning leaders and coaches that are natural supports and looking at our procedures within the agency. It is very difficult to allow someone to volunteer, but we are working on that. If we see that someone is over or under utilizing units, we try to correct that. We have been down three case managers. We've been burned in the past when we tried to change the IP and then couldn't back-bill. We can try to take a leap with that. We check quarterly. I'm hopeful that the redesign will really help.

Challenge Presentation #3 – Tamara French

I work with Goodwill and we run programs for DD and seniors. "Bob" attends our adult day program under the waiver. Bob has gone to three others before us. We are his fourth choice. He has Parkinson's and Lewy body dementia. He has a decline in movement and other physical challenges. Has problems communicating his needs and it is very frustrating for him. He seeks out more vulnerable people when he gets frustrated. He lives with his wife who has a full time job. We serve as respite for her. He states that he doesn't want to be there and tries to leave. His wife has told us that if he can't succeed with us, he will have to go to a nursing home.

Clarifying Questions:

- Are there any days that he likes being there? Are there any patterns or trends for when things go well?
 - We haven't seen any yet. We have served him about four months. Often with dementia, it is really hard to find consistency.
- Has he had experience with any other programs?
 - We are his fourth. His wife has tried to relocate him. She is kind of at her wits end.
- Under his waiver supports, are there any in-home services available?
 - There are, but I'm not sure if they have looked at it. He would need full time care.
- What does a good day look like?
 - Unfortunately, it is when he does not go after someone and doesn't try to leave our facility. He does not participate in any activities. He sits in a recliner and stays to himself. That's probably the best.
- Have you talked to the wife about his behaviors at home?
 - She is really struggling at home too. Bob escaped her home one night and ended up at one of our facilities and was very disoriented. They ended up tasing him because he was becoming violent.

Group Brainstorming:

- I've worked with a lot of people with Lewy body; it is very challenging with hallucinations. I've had people take a break from adult day and then coming back after the disease has progressed. I would say try using multiple resources. Mix up home care and adult day so that he isn't in any one situation for a long period of time.
- Are there things that soothe him and could prevent the agitation? Give him the music he loves in earbuds, so he is less aware of the people around him and he can stay in his isolated space.
- Have all medical and drug interventions been explored? Has there been any improvement around them?
 - He is not on any meds when he is at our program. His wife has said that he is declining a lot. We're the last stop before long term care.
- I'm not sure if this would be appropriate, but what about a companion that can come in to add variety that is targeted toward a hobby or interests of his?
- If you can get a couple of successful days under your belt (however you might do that) and then build on it in increments. People with Lewy body get overwhelmed with a lot of stimulation. This is a great example about how difficult it is to give a person informed choice. He doesn't want to be there. He is uncomfortable in his own skin to an extreme level with the diagnosis that he's got. This is not what any of us want, but you have to find a way offer the different things that are out there with a limited impact on his daily restrictions. What a change from being contributing members of society and then such a decline. It is hard and frustrating.
- You said that sometimes he just likes to hang out in his recliner. It seems to me that is an informed choice. Somehow we have to get permission from CMS to document that this is an ok and informed choice. We offered other possibilities that have gotten negative results. The ability to do nothing should be one of the choices, like it is for all of us.
 - I agree. Our concern is how the new ruling will affect this with community integration especially for folks in this facility.

Presenter's Reactions:

These are some really great suggestions. Splitting up his days and weeks are worth a try. Finding what he likes—I'm not sure how well we have tried that it. It would be a great exploration. It would be good to get him involved in something to get his mind off of leaving. We usually do volunteers as a group, but it is worth exploring.

Open Discussion

- I would say that exploring opportunities to provide people more one-on-one care in any sort of way—like with volunteers.
- There is a tremendous amount of goodwill amongst providers to provide what the client wants, but we are restrained by barriers that prevent us from fully offering the choice that people desire.
- Given that reality, providers can build in a more robust volunteer program. Though it is hard to get the base volunteers. I like that idea.
- Christina: What does everyone think about putting volunteer requirement resources in the compendium?
 - You can add it, but what has happened is that in long term services and supports, we build a box around things so that we can call it a service. If you overly formalize volunteers, then you get into background checks, skills, and makes it less accessible.
- Finding collaboration, sounding boards, and then be able to document that to show that we are taking person centeredness and informed choice seriously. We talked about the rights review community. We don't have anything like that on the aging side.
- If we have some thoughts on informed choice that we have not really gotten into today or any of our other topics, is there a way to send in a document or something? I was thinking that probably in the IDD world, the majority of people in congregate day programs are much more functional and much less the exceptions that we've been discussing today. I put together some stuff that interested me for that population, but I didn't know what to do with it. Can we send them out to the whole group? Can we have an additional session on the feedback?
 - Christina: Yes, email them to Adam and Caitlin. Next meeting we'll focus on community integration and then during our final meeting we will pull it all together and have you react to the compendium of best practices. Anything you can send us is hugely helpful to the process.
 - It seems like you will need an additional session to get through all of that stuff.
 - Caitlin: We can discuss it internally and see what we can do about a wrap-up call. If we have information to constitute having a whole other call, we can set that up. Whatever you send, I will be sure that I send it out to the rest of the group.
- On the first consultancy, we ran into the issue of no providers coming forward. There was recently a report that talked about a provider with a no-eject, no-reject model. A provider of last resort. This is a new concept, but it will be coming up in discussion in the legislature and I would like people to be aware that that is a concept on the table in Colorado and however that would be worked out—it would be a contract of course and probably additional financial rewards.

V. Leaving in Action

Christina closed the meeting. She reminded everyone of the next meeting and talked about listening and looking for best practices to bring for our next meeting. The next topic will be **community integration**. We hope to show you what we are developing in terms of a product so that you can react. From the discussion, it sounds like maybe we should get this out ahead of the next meeting. Caitlin praised the group and the new ideas that were presented. She liked that alternatives due to Medicaid system constraints was brought up organically. Building a volunteer base to get people one-to-one is a great start. It is looking at service delivery in an integrated way, while working within our budget constraints. We will continue to discuss the documentation and will get that out to you once it is formalized.

Next Meeting: Consultancy focused on “Community Integration”

- Thursday, February 11, 2016 at 9:30 to 11:00 am.