



CO HCBS Residential Stakeholder Workgroup Summary Meeting #3 – January 12, 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:

Caitlin Phillips, HCPF
Amy Scangarella, HCPF
Christina Neill Bowen, The Lewin Group
(facilitator)
Kristen Rice, The Lewin Group (note-taker)
Lori Hamilton and Jonathan Wolf, Lennox
Guest Home
Karen Lillie, Pueblo Diversified Industries
Judy Tomcak, Foothills Gateway
Heather Porreca, DRCOG
Hanni Raley, Arc Aurora
Leah McMahon, Access Long Term Support
Solutions, Single Entry Point, SEP
Megan Philips, Weld County AAA, SEP
Steve Valente, Dungarvin, Service Provider
Joan Levy, Strive, CCB
Kristie Braaten, DDRC

Carol Meredith, Arc
Anita Evanyo, Rocky Mountain HS
Pat Cook, Colorado Gerontological Society
Sarita Reddy, Greeley Center for
Independence

Stakeholders Absent:

Adam Tucker, HCPF
Leah Pogoriler, HCPF
Ann Petersen -Smith, University of Colorado
Hospital
Megan Hart, CALA/Heritage Haus
Ginger Stinger, Parent
Blair Wyles, Rooster Ranch
Lori Woods, Jeffco OLTC, SEP
Ann Turner, Cheyenne Village Judy Malin,
Smith Agency

II. Introduction

Christina Neill-Bowen opened the meeting with introductions and a reiteration of the purpose of the workgroup. The goal of the workgroup is to complete a compendium of best practices surrounding the implementation of the Final Rule. Christina began with a role call and asked each stakeholder to share what they think of when they hear "informed choice." Christina went over progress to-date related to participant rights, and stakeholders were given the opportunity to react to a list of best practices collected at the previous meeting. Christina reminded the

group about the brief exploration of informed choice during the in-person meeting and summarized the working agreements for the stakeholder workgroup.

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 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 – Hanni Raley

This is a case from our membership. It is an individual—a fellow in his early 40s. He lived with family for some time and has transitioned into an independent apartment setting with agency support. He expressed to his planning team that he was feeling lonely. When we checked with him after his planning meeting, he had been placed in an emergency respite situation. He had signed over his financial designee status and he was signed up for a group day program, which he had previously said that he did not want. When he talked to his advocate after the changes from the planning meeting, he was frustrated about why everything had changed. His advocate talked to his team. The team said they provided him with all of the choices and he chose those services. This did not mesh with what he told his advocate. How best can a team supporting an individual address separate definitions of what informed choice means? How can we best insure the individual is comfortable once the choices are implemented?

Clarifying Questions:

- Is this individual his own guardian?
 - Yes.
- Can you explain your formal relationship with him?
 - He has received advocacy services for three years while living in independent apartment settings. He contacted us for some day volunteer services. We also provide advocacy. We're his sounding board when he is confused or upset with processes or services. We help him handle any hurdles.

- It seems odd that there was such a huge change in one meeting. Did you ever wonder what was going on in his life? It just seems odd.
 - We agree.
- Could you say again, what the changes were?
 - Prior to the team meeting, he lived in an independent apartment with 13 hours a week of support and he managed most of his finances. After the meeting, he was in an emergency respite host home, signed over payee authorization to the service provider, and was in a group day program.

Group Brainstorming:

- I would suggest that prior to the meeting, spend some time with the person and find out what is important to him to continue with his services, such as managing money, and find out who might be able to help him with that. Have a list of preferences so that when the discussion turns to “well this is how we do it, we’ll be your payee,” he’ll have a response ready.
- That is so confusing how things changed. I don’t know if your agency has an agreement or contract that outlines what his wishes are and how he wants to live, so that when there is a big change overnight, he can be reminded about what he originally wanted to do. It sounds like he is unhappy in his current situation. I see several columns of informed choice. To me, it starts with either the case manager, the family, or the individual. They need to have a file to remind them what is important to the individual. In our case, if we have a family that brings a resident to us—they are happy to be here. Another column is what the provider can bring to the table on informed choice.
- It seems to me that the provider has to have some definition of emergency, especially when a person is placed in emergency respite. It seems to me that placement in emergency respite would be due to a serious emergency like abuse, danger, neglect. Each provider needs to think about defining what constitutes an emergency.
- Wasn’t the team informed when he moved? If it was an emergency respite move, there has to be some communication. To find out after the fact is problematic.
- Asking the individual if they want a meeting or a one-on-one could help. Meetings can be quite intimidating. The individual might prefer to meet one-on-one rather than meet with the larger team.

Presenter Response:

We were just as confused and dumbfounded. It is the role of an advocate and the system to allow the individual to engage in these conversations. The meeting was with an authority figure, direct care workers, and the case manager. It started with discussions around being lonely and then turned into a larger discussion with the host home ending up as the result. The adult day program was another solution to being lonely, but because he is so high functioning, he resists those due to his high skill level and the low skill level of the others there. The team used an

emergency respite opportunity after he talked with the nurse and said that when he was lonely he was sad and depressed. The team used that as emergency criteria, even though he showed no suicidal ideation. The payee thing was “this will be easier and less stress.” The team thought they were making it better for some of his core concerns, but many of the changes seemed to be around staff convenience and offered with circular logic. He didn’t understand that he was making choices that would be more restrictive. When we worked with him, he immediately refused the day program because he didn’t fit into the structure. We had to go back and reestablish his financials. He was unable to re-secure an affordable apartment, so he has bounced between inappropriate host home settings...some of them wildly inappropriate. He definitely had a preference list of important to and for, but in the team setting he felt pressured to make decisions that were pleasing to the team. The way the team offered those options made them sound like they would be progress steps for him. It is because of a knee jerk response about what would be easiest for the service provider.

- I like the idea of sitting down with an individual and putting together their preference list including questions like do you want to be a part of your teams care planning? or would you prefer individual meetings and have that brought back to the team?
- We use those lists and try to prepare with the person ahead of time so that they can be heard. The teams are really good about getting everyone’s input and agreement. It can be easy to forget in the heat of the moment, but it is key to making something work best.
- They could have been more careful to avoid knee jerk reactions, especially around health and safety. It sounds like a total overreaction to loneliness. There are many more options to alleviate loneliness than going into a host home. This is proving to not be the easiest road now since it blew up in their faces. They need to put on their person-centered hat and not think about what is easiest for them. There should also have been an advocate there at the meeting.
 - We certainly attend when we are asked. This particular meeting didn’t work with the advocate’s schedule. The individual thought they could handle an informal meeting on loneliness. Now he is afraid to go to meetings without us, which is not good. Now that he is in these restrictive settings, we’ve seen some behaviors that we wouldn’t have seen otherwise. Now we are working to make sure that he doesn’t get even more restrictions. These preference lists can be a double edge sword. If the person wants to try something new, the team can say “that’s not what you really want.” Without an advocate, they might limit his growth and exposure to new things.
- The broader issue that I often see in Pueblo is that I don’t think there is a common understanding of informed choice. I don’t think the providers and case management agencies are working off the same page. It is causing a lot of problems. They have good intentions, but they do not understand it. We need a common understanding at all levels.



- It is confusing what informed choice means for each different provider. It would be good to have a place to go back to. We need something down in writing.
- This example really speaks to what I think of with informed choice. The most well-meaning case managers and providers can end up making someone feel like they don't really have a choice while trying to get their services set up. It is really important to start out with the individual with something more broadly. "What sort of services are you looking for?" Leave it open so they can state their important to's and important for's.
- Start the discussion around the individual's preferences. Collect that information up front. Often we get caught up with what we need to do to make things happen, we forget to stop and ask the person what is best for them and show them their options. We need to slow down and explain.
- If an individual said that he wanted an apartment, being his own financial manager, etc. –if the team knew those, it would be important for them to review those and be familiar with them. Review them with him. Ask if he is sure that he wants to change that. Remind them of what the changes that would make happen.

Challenge Presentation #2 – Karen Lillie

The challenge that we're faced with is that we want to get people out in the community with jobs, but in a rural community, the options are limited. In urban areas, there are more options of business and activities. We're provincial. We've been pretty creative and successful getting jobs for some people, but that won't work for everyone. Are we going to have options out there (jobs, recreation, social) that are accessible on a reasonable basis? This is a rural challenge.

Clarifying Questions:

- No clarifying questions.

Group Brainstorming:

- It seems that choices are limited period in rural areas for everyone in terms of jobs, recreations, access to medical care. We're working within a context of a lot fewer choices and resources. Part of the reason why people choose to live in rural areas is because there isn't as much of a concentration of resources, people—the busyness of life. I'm not sure how systemically this can be addressed. Maybe more flexibility in how providers can craft those solutions?
- What we've heard from the ombudsmen from rural areas is that everyone in small towns knows each other. This keeps folks from verbalizing preference if they're fearful of going against someone that they've had a relationship with. It can be an intimidating situation if you are trying to empower yourself to make your decisions.
- It does resonate. It's that trade-off between having a small community where everybody knows you and having a small community *where everybody knows you*. It is inherent to

that type of community. Coming up with methodologies that will work across the board is not going to work. A lot of times you can't craft the solutions you want because the system won't allow it. In rural areas, is it the system that gets in the way or just a lack of choice? Can you share some of the creative ideas?

- Sometimes those similar things are still a problem in a big city if a certain reputation follows an individual or family because of a history. Regardless of geography we have to look at that. I appreciate that providers have rights too, but that is what self-direction can do.

Presenter Response:

- We have a really great advocate. We had one lady who has a vet tech license, but couldn't go out and sell herself very well. Her parents came to us to ask that we help her with social connections. She got that and we were able to place her with a vet. In this case, connections came in handy. Sometimes if you have close family ties they can help—sometimes they hurt. My point would be, let's not eliminate options, but be more thoughtful about getting folks to understand what may or may not work well in some cases. Some people are probably not going to be really suitable community members...behaviors and such. Let's keep other options available and not rely on the traditional one unless we have to in those cases. We've got a big and strong guy working at a farm supply store, but there just aren't that many of those kinds of jobs. We got a guy a job as a janitor at a local recreation center. His self-confidence grew and now he is engaged.

Challenge Presentation #3 – Carol Meredith

This revolves around access to food. Some people have restrictive diets. Under our system, doctors rule. So when auditors go in to audit quality of services, if there are doctor's orders you can get dinged for not doing that. Also we have a lot of people on psychotropic medicines that can give serious munchies, well beyond marijuana. How do you give people access to informed choices around access to food when the system is like this?

Clarifying questions

- We have the same issue, but we don't get dinged as long as we can show that we have offered the diet, but the person has chosen not to follow it. Are you saying that this is the case? It's not just about offering choices.
 - We have never actually seen anyone get dinged, but I hear a lot of providers stressing over those issues. Maybe it is more a fear of getting dinged. Maybe we should share your way of doing it with our providers. [Christina to insert in compendium – liability vs risk]
- Are individuals able to understand the decisions they are making around food?



- Some yes, and some no. Psychotropic medicines are really challenging. It is hard to tell if people have control or the medicine rules and makes them want lots and lots of food. I might have to do some research in psychiatry. Also, people with intellectual or cognitive issues---does the research hold up for them around choice versus obsession.

Group Brainstorming:

- It is about an ongoing process. There is never an end to it. We have people with impulse control and medicine issues. It is hard to parse out. Are they making unwise choices or just don't understand? You have to have dialogue with them. Written agreements work for some people, like people with memory problems. The more you get to know people, it becomes less of an issue. You figure out what the best method is. We have to draw the line at "I'm going to make you do this." We keep working with the person and remind them of what the doctor said—this is what will happen if you keep eating this type of food.
- I think a lot about people that aren't being served by a Medicaid waiver and how challenging those decision processes are for any given person. We need to keep a healthy balance on what we are expecting from people. A recommendation is not an order. We have to look at how we are using health and safety in how we are effecting change in a person's life. This often comes up around alcohol and tobacco. They aren't healthy and the best options, but they are an option. Of course, some people are on meds, but they have choices just like any other human.
- When the doctor is writing his order, we need to empower the providers to ask, "Why are you doing this? This will be very difficult to implement, can you write it as a recommendation, not an order, this is not realistic." We need to be advocating in the medical environment.

Presenter Response:

- I think they are all great ideas. I brought it up because it is a tough problem that a lot of people struggle with. All of us struggle with it. How do we encourage healthy lifestyles under a medical insurance funded program? It is tough.

IV. Open Discussion

The group reflected on the discussion up to this point and commented on themes emerging.

- Have you covered what one does in cases where someone has a guardian that does not accept what the person's choices are?
 - We spent a little time on this in December. It is a good one to discuss.
 - As an ombudsman, I would look to the facility provider or administration to be educating that guardian on a resident's right to choose. An example is the



diabetic with a guardian who doesn't want him to have dessert. We can offer healthier choices, but we can't stop them from having the sugar filled pie. The facility has to educate the guardian.

- We run into the dietary issues quite a bit. Our nurse works with the dietician to build in flexibility. Somewhat controlled, but open to options and the occasional splurge. We work with guardians on these issues so it is reasonable, safe, and supported.
- Is this something we could provide for the entire system? What authorities do and don't guardians have? There are a lot of urban myths about how much control they have over an individual. [Christina: We are providing a training in March on this issue based on December's discussion.]

V. Leaving in Action

Christina provided the federal definition of person centered planning and asked that the stakeholders think about this in the informed choice lens: *Person-centered planning is a process directed by the person with LTSS needs. It may include a representative who the person has freely chosen, and/or who is authorized to make personal or health decisions for the person. PCP should also include family members, legal guardians, friends, caregivers, and others the person or his/her representative wishes to include. PCP should involve the individuals receiving services and supports to the maximum extent possible, even if the person has a legal representative. The PCP approach identifies the person's strengths, goals, preferences, needs (medical and HCBS), and desired outcomes. The role of agency workers (e.g., options counselors, support brokers, social workers and others) in the PCP process is to enable and assist people to identify and access a unique mix of paid and unpaid services to meet their needs, and provide support during planning. The person's goals and preferences in areas such as recreation, transportation, friendships, therapies, home, employment, family relationships, and treatments are part of a written plan that is consistent with the person's needs and desires.*

- I agree with all of it, except that it doesn't address risk and responsibility. With guardians, it is about their perception of risk, which is different than ours.
- Related to having authorization to make personal health decisions—over the last years, we've seen misuse or abuse of authorized representatives. I'm concerned that this is ill-defined. We have yet to deal with this in Colorado.
- Best practice is certainly in here and is a fantastic goal. From an advocacy perspective, it is all in the implementation of the plan. No matter how great the plan is, if the person doesn't feel that they are driving their life, then all we've done is check a box.
- I think about an individual who is non-verbal with little to no communication skills – when it says that a person has freely chosen a representative, exactly how does that happen?

Caitlin praised the group, their feedback, and examples. This gave us a lot of food for thought. She mentioned that she will talk to Blair about the non-verbal individual and the guardian issue.

Christina reminded everyone of the next meeting and talked about listening and looking for best practices and bringing them for our next meeting. The next topic will be **community integration**.

Next Meeting: Consultancy focused on “Community Integration”

- Tuesday, March 8, 2016 from 9:30 to 11:00 am.
- [Join WebEx meeting](#) and have the system dial out to you (preferred) **OR** dial in at 1-877-668-4493 (code: 643 829 749)