



CO HCBS Residential Stakeholder Workgroup Summary Meeting #2 – December 8, 2015

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:

Adam Tucker, HCPF
Caitlin Phillips, HCPF
Leah Pogoriler, HCPF
Amy Scangarella, HCPF
Christina Neill Bowen, The Lewin Group
(facilitator)
Kristina Rerucha-Azeem, The Lewin Group
(note-taker)
Megan Hart, CALA/Heritage Haus
Lori Hamilton, Lennox Guest Home
Robin Forbes (Karen Lillie), Pueblo
Diversified Industries
Sarita Reddy, Greely Center for
Independence
Judy Tomcak, Foothills Gateway
Heather Porreca, DRCOG

Hanni Raley, Arc Aurora
Ginger Stinger, Parent
Leah McMahon, Access Long Term Support
Solutions, Single Entry Point (SEP)
Lori Woods, Jeffco OLTC, SEP
Megan Philips, Weld County AAA, SEP
Steve Valente, Dungarvin, Service Provider
Joan Levy, Strive, CCB
Blair Wyles, Rooster Ranch
Ann Turner, Cheyenne Village
Kristie Braaten, DDRC
Carol Meredith, Arc

Stakeholders Absent:

Ann Petersen -Smith, Univ. of Colorado Hospital
Pat Cook, Colorado Gerontological Society

II. Introduction

Christina Neil-Bowen kicked off the meeting with introductions and a reiteration of the purpose of the workgroup. Adam reiterated the goal is not to discuss the Final Rule, but rather to identify best practices for those implementing the Final Rule. The goal of the workgroup is to complete a compendium of best practices.

The Meeting's Focus was on Individual Rights. The Final Rule requires:

- The individual must have rights to privacy, dignity, respect and freedom from coercion and restraint
- All information about the individual is kept private

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- Staff interact and communicate respectfully and in a manner in which the individual wants to be addressed
- Informed consent is granted prior to the use of restraints and/or restrictive interventions
- The setting offers a secure place for the individual to store personal belongings

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 – Blair Wyles

Rooster Ranch is in Franktown. It offers affordable housing to individuals and works to build a community where neighbors want to offer each other natural supports. Rooster Ranch is not a service provider. The aim of the ranch is to connect to providers similar to a general contractor to bring service providers into the community. Blair and his family are working on developing this community.

Blair shared a challenge related to individual rights from his own son’s experience. His son is 20 years old. He needs a lot of supports. He doesn’t communicate verbally. He is in a wheelchair. He needs 24-hour one on one support. Blair’s challenge is to show that he and his family are honoring his son’s rights, when his cognitive ability is compromised. A lot of the things around PCP are challenging. Trying to bring the supports of his son together has been difficult. They have OTs, PTs, SLPs, and educators– all sorts of people in his life. The challenge is to bring them all together when they have competing priorities to help create the person centered plan. In addition, they are rural so there are some scenarios that look like they are isolated. They need to work through those concerns to protect the rights of the individuals.

Clarifying Questions:

- So, you are developing an opportunity for affordable housing – and services are supplemental to that? The challenge is then, bringing all the services that your son needs to you? For residential providers this is an ongoing challenge.
 - The challenge isn’t bringing providers into the community. The challenge is more, how do we get service providers to participate in a person-centered plan on a non-business hour? We are just one of many individuals who might deal with this. There is no option for the service providers to be paid for person centered planning.
- Another compounding issue might be how to best build a PCP with a person who is unable to represent what is important to and for the individual.



- Yes. Recognizing that the PCP is how we assure rights are met – when cognitive abilities are compromised, this takes a community, including service providers.
- I understand where you are coming from. It is hard to tease out what preferences are – are they consistent preferences and those types of things? As we are developing these rules and regulations, we need to think as a community “what does this look like?” “How do we judge who is saying what to whom?”

Group Brainstorming:

- How do you tease out the rights of someone who doesn't communicate verbally?
- How do you bring together a team of many different providers?
- How do you ensure rights?

I don't think of things as just a meeting or a PCP plan. It can't be a plan and it can't be a meeting. The best way to ensure the person's preferences, wishes, choices are well articulated, and is an on-going dialogue. Instead, think about a person who doesn't communicate in traditional ways. You need someone who will facilitate that communication for him/her – hopefully more than one person – will help him/her make his preferences clear.

You can also separate some of the service issues. You might have to ask, “What kind of services do you need?” With the challenge of bringing in service providers, you can have a life planning type of meeting completely driven by the person and the people who know him/her best. Have people in those meetings that the individual wants there, and note that this might not include providers. This meeting can happen before the service provider meeting that leads into the PCP plan. We need to change how we think about the person.

We really need to develop a billing option for PCP.

I really appreciate Sarita's comment about the process of PCP planning and trying to make good decisions regarding what we hear individuals are telling us. I see PCP more as a process than an event. If we look at it as taking the time to make astute observations, we can come up with a richer plan in how we respond to what they want – we can respond to what they tell us they want.

I would echo previous comments as well. It is a process. It is a never ending process that must be continually developed. You have to get the people who know the person better than anyone, get them to think through the PC lens and be extremely observant. They need to write down what they observe. The likes and preferences of an individual will be demonstrated if you watch for them. While a process, it can also be an event process or a meeting. If you implement some form of PCP – it forces you to think about what the individual is really after. I think there are resources out there where you can go out and facilitate those pieces so you can get this accomplished. Our facility can do this for individuals, as necessary.

To tie in all the elements and the idea and concept of needing that billing mechanism, I suggest having guided questions to build in concepts so they are a daily thought process that grows with the individual or the plan. What I have seen in the past is the bare minimum documentation. It is similar to what we talked last time about the culture of PCP. We –have to

look at day to day pieces and we can't allow documentation to stand in place of a true PCP process.

I am "assuming" your son has some form of communication. As parents, we know what are children are happy with or unhappy with. Can a form of communication be used to help him draw out what is important to him? I know exactly what is important to and for my son. I know he how loves grape tomatoes; he would eat these endlessly. It isn't best for him, but at the same time, it is his choice. We need to know what is important to him and take the time to do so. We can use how the individual does communicate to identify what is important to and for him. Having this community understand how he communicates when he no longer has his parents there is important.

Blair's Reactions:

- I think the question really is, "Are you violating the Final Rule if we have a plan for the individual to eat at 8 noon and 3 versus can that person eat whenever they want?" I think the distinguishing features of the question and the reality is where I get lost.
- We know the most about our kids, I agree, but it is difficult for us to understand our son. It has taken 20 years to even start to understand things. I have to be honest and say I don't know what he truly wants in life. I presume things. I know he loves being on a horse, but I can't honestly tell you if he would prefer to be on a ranch or in the city. I don't know.
- What it really boils down to is that it takes a team to create his plan. We need to have others involved.

Challenge Presentation #2 – Heather Porreca

I am a long-term care Ombudsman. We are advocates for those living in ACFs. Our role is to make sure individual rights are assured. For my example, I took a typical example related to guardianship.

A resident in her 80's has recently been deemed incompetent by a judge due to Alzheimer's. The daughter is now the guardian who decides placement and health decisions for her mother. The resident is placed in a secure assisted living facility and needs the placement due to security and safety concerns. Where the issue comes in is that the daughter being a guardian no longer wants her mom to have contact with the mother's son. Her son is no longer able to contact the mother or see the mother due to the daughter's own concerns/issues with her brother. The challenge is that the mother would like to see her son. The ACF typically does what the daughter says and does what they have to follow due to the legal implications.

Clarifying Questions:

- Is there any documentation from anyone else besides the daughter that the relationship between the mother and the son is toxic or awful?
- Great question. That is usually the first question, typically there is nothing.
- Is it more of a vindictive thing on the part of the daughter vs. other reason?



- There is often a sibling rivalry or resentments that is being brought forward with aging parents. If there are other issues where someone is being taken care of, there is often something written into the guardianship.
- Are you involved in the process of guardianship with the courts?
- We try not to be brought into the court if possible. We like to protect confidentiality at all cost.
- Are the guardianship papers clear in terms of the roles and reach of guardianship?
- No. Often the administrator goes with what the guardian says because it is not clear and there are not specific guidelines to demonstrate what their roles are. Often the guardians go further than what their role should be.

Group Brainstorming:

- We often see family members attempting to do this with members of the opposite sex or romantic relationships. They often say they cannot have a relationship. Even if they are legal guardians, we, at the Arc, often come in and say “yes they can.” Unless they are specifically assigned to dictate relationships, that isn’t their right. We need to put them back in their place.
- I think as a provider it is more not wanting to go to court. It sucks up too much money, time, resources, etc. It is a challenge we are facing. We have looked carefully at the guardianship paperwork. There is nothing in the paperwork to show what the scope of guardian is. You shouldn’t have an individual’s rights trampled due to guardianship. This should be addressed on a systemic level.
- To me it would be the service provider’s responsibility. If there was a notice given, to have a written order from a judge in the guardianship paper, it would fall on the part of the service provider to be a part of the process. I would think it is their responsibility or the Ombudsman to be a part of that legal process if it goes there.
- Is there an opportunity to sit with the people involved to talk about history and talk about what portions can be let go and what can be addressed? With problems in mind, what kind of visitations can take place to help bridge the gap with the visitations?
- In the ID/DD world we have teams. In that world you can call on the case manager. You can use that case manager to help them understand the guardian’s role and be more open to stuff. Especially in cases like this when there is something going on between the daughter and the son and you still need to honor what the client would want and try to support the guardian to coming to that same solution. In the ID/DD world, we would use the ID/DD team to create that.



Heather's Reactions:

- We typically try to do all of this. We always try to talk with the resident and see if we can get directions from them and then get all players at the table and talk about the rights of the resident and what the guardianship paper says. I agree there should be a specific line from the judge if the son would not be able to visit.
- I think getting the case manager involved would be great. They typically don't get SEPs involved in guardianship issues.

Challenge Presentation #3 – Carol Meredith

My concern is more about host homes. For those of you are in other systems, in the ID/DD system, we have a thing called host homes as a residential setting where people can receive services. Most people think of it as foster care. An individual or couple wants to engage with a person 24/7 under a contract. The host provides a vast majority of the services through a contract. We typically pull someone from a host service when they violate an individual's rights. A general concern about host homes is that many of us live in families. When you live in a group situation, you have to abide by certain kinds of rules that we all abide by. When you embed yourself into someone else's family, they have routines and culture, etc. With the unwritten rules on the way they work, how do we ensure that through a PCP process in a host home situation that the host home person has to change some of their engrained ways of living. This could be around access to food, bedtime, how many times you go out at night, etc.

Clarifying questions

- One thing I wanted to add to this problem is the lease of a host home due to the nature in which they are structured.
- Is part of the question of how do we balance the use this model with the level of support for the individual rights and the merging of the person's needs with host home family culture?
- Yes. I think this is particularly difficult in a host home type of model, not only for the legal reasons where you can't kick the person out because it isn't working out but you have a lease, etc. We have worked for so many years to get away from the medical model and do a community living normalization for way of life. Living in the right host home can be that way for so many people. Living in the wrong host home can be difficult for many. There are some agencies that will not do any other type of model and do subcontracts for residential. This just isn't easy. It is a quandary.
- Are host homes up for heightened scrutiny? Have they been identified by CMS like ranches have?
- Host homes have not been pulled-up for heightened scrutiny. The host home model is definitely not in that sphere, but again, this conversation leads to some of the concerns surrounding the host home model with the scrutiny that should come about for this level of concern. This really is a hot issue within the host home community. There are some challenges. The host homes, just like any residential setting must have a lease or



written agreement. Within that there are written protections for both the host home and the client. We are looking at that within the host homes. We are also figuring out how to ensure that host homes do not become a foster family kind of thing for adults, because adults have their own desires or rights. They may want to go out on a Saturday night and the hosts go home at 8pm. So all of this is in question.

Group Brainstorming:

- We are training our host home providers on PCP process. Any change that is going to occur will require buy in from those who are providing host homes. One other thing we are doing is putting language around PCP into host home contracts, specifically about having access to common areas of the home and being able to adorn places in the home. We don't want it to be like renting a room, but having a home. A lot of this is in the contract now.
- Is the process to be a host home an easy process? I would think they would have things weeded out. I don't know the process to become a host home provider. Is it tough or fairly easy?
- I would say it is not an easy process. However, it is not overly cumbersome; there are quite a bit of background checks and trainings. The living environment hasn't been a major concern to date. Where it is complicated is the written lease process. Now if renting out the house to others – what happens? How does the lease occur? How does a house that is being rented to a host really work itself through? Is there a sub-lease?
- One of the things we do is really vet our host home people. We do some trial stays on weeknights and weekends and do pop-ins. Once someone is in, there is a lot of trepidation about moving them. A lot of the trepidation can be deliberate at the beginning and not doing things on the fly. Training on the front end can help with this.

Carol's Reaction:

- We have a lot of residential processes across CO. Everyone does it differently. I am wondering if we would want to do a temporary lease or temporary rental agreement as a "getting to know you" agreement. People with behavioral disorders may see a honey moon period for 2-3 weeks and then it goes a different way for a few weeks. Six weeks out things might look different. Need to find a way to protect an individual's rights and a host home's way to do things.

Open Discussion

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

- I think it will be critical for all of us to focus on our monitoring and the amount of time we spend in the settings and knowing the individuals in our settings really well. I know there are so many people to monitor, but I think it will be the only way to get a feel in the home. We will always be battling the "I'm in it for the money" whether that is the



reality or not, it is a piece of it. I think we need to figure out ways to monitor, ensure that rights are not being violated and the placement is the best for each person.

- Relative to host home model, where the issue is that host home providers must be trained and monitored and overseen. This puts us in a precarious position as provider agencies. The root is really at regulatory level on how these can be established.
- The state needs to look outside the box and form some partnerships. There are agencies that are putting together good PCP plans, need to look at smaller organizations to help extend the services that are provided and available to provider agencies, individuals, etc.
- It seems to me when things work well, it is because people have relationships. When things don't work well it is because there is no one in their lives. A huge piece of work we need to look at is how CO will support bridging organizations between the people we serve and people in the larger community. There is plenty of evidence to show the more people are out and about, the safer they are from abuse and neglect. If you don't have relationships, it becomes really difficult.
- How this can be overseen with private contractors? It is looking outside of the box to provide your eyes and ears. The pharmacy delivery goes into houses daily. Let those people know they can be reporters if they see something that is not okay. Thinking outside of the box can be really beneficial for some.
- For the fire department, we have a responsibility by law to report anything we see. I am sure it could get there for delivery persons.
- We need to do more training. We need to figure out how to give an individual informed choice, rights, etc. You want to have the host home provider have the ability to make sure that host homes are allowing the individuals living with them the freedom to live a self-directed life.
- I suggest providing incentives for host homes to stay involved in an individual's life. In Denver, the Denver Health has done this with pregnant mothers by offering them strollers.
- This is for ALF and HHs. People often think about how much they can make money on hosting an individual. This should provide you an opportunity to weed some of these people out. You would have to be a true caregiver to actually be able to be a host home provider. This Final Rule really makes the process more about human interaction. It is hard to figure out a way to regulate this when you have other things going on. We have to do a combination of process and paperwork. Seeing on a daily basis and seeing the daily routines, this isn't easily on paper or on a rule. We have case managers that are happy to place individuals at our organization which is great. We help case managers know how their client is doing. Having a source of information from case managers or surveyors or other providers coming into the home, it is a really good way to see what is really going on. You can ask, "What are good things you are seeing?" "What are you seeing in the home?" "Do you have any concerns?"



IV. Leaving in Action

Christina closed the meeting and reminded everyone about the next meeting. She talked about listening and looking for best practices and bringing them for our next meeting. The next topic will be **informed choice**.

Next Meeting: Consultancy focused on “Informed Choice”

- Tuesday, January 12, 2016
- 9:30 – 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)