



CO HCBS Non-Residential Stakeholder Workgroup Summary

Meeting #2 – December 10, 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
Amy Scangarella, HCPF
Christina Neill Bowen, The Lewin Group
(facilitator)
Kristina Rerucha-Azeem, The Lewin Group
(note-taker)
Michelle King, King Adult Day Enrichment
Program (KADEP)
Tamera French, Goodwill Industries
Stephen Shauchnessy, Mosiac
Deana Conaty, Brain Care
Joan Wilson, Mountain Community
Pathways (Adult Day Program)
Cassidy Dellemonache, PASCO
Candie Dalton, Accent on Independence
Barb Crowder, ACMI, SEP
Danny Holzer, Jeffco OLTC, SEP

Celeste Ewert, Envision, CCB
Jan Irvin, Foothills Gateway, CCB
Gerrie Frohne, PADCO
Mary Jo Rymer, Arc of Colorado
Kasey Daniels, Disability Law Colorado
Anito Evanyo, Rocky Mountain HS
Tia Saucedo, LeadingAge Colorado/Seniors
Resource Center
Tammy Drumright, DDRRC
Jenny Nate, Rocky Mountain Health Plans
Julie Bansch-Wickert, Disability Law
Colorado

Stakeholders Absent:

Karen Lillie, Pueblo Diversified Industries
Saori Kimura, Access Long Term Support
Solutions, Colorado Access, SEP

II. Introduction

Christina Neil-Bowen kicked off the meeting with introductions and a reiteration of the purpose of the workgroup. The purpose is to work together to exchange ideas, develop solutions to problem solve and mitigate challenges, and share best practices related to implementation of the HCBS Settings Final Rule for all setting types and case management. Adam reiterated the goal is not to discuss the Final Rule, but rather to identify best practices for those implementing the Final Rule.

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
- Staff interact and communicate respectfully and address the individual 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.” Two group members shared a challenge related to the Final Rule and the group helped brainstorm some solutions.

Challenge Presentation #1 – Michelle King

I work at an Adult Day Care center. The population we work with is 18-65 year old adults with a neurological diagnosis. Often, our consumers have held individual working lives prior to acquire a brain injury. They don't always have capacity to know that they have acquired a brain injury. My challenge is not infringing on a client's right to want to leave the facility, when it is not always safe for them. We have people who want to go outside, and when they make it outside, they are not safe. They don't look both ways before crossing the street, they are disoriented as to where they are or where they are going. They often get lost, walk through cross walks. It is a huge safety concern.

At times consumers want to be here, and other times they don't want to be here. My question is, how do you ensure rights are respected when they have been dropped off for the day by the facility or the family member. How do you provide access to outside, when this is not an option?

Clarifying Questions:

- Do you have a one-on-one accompanier or “line of sight” need at your site?
 - For this particular waiver, we do not receive one-on-one payment. For this particular individual, they do go off property and even if one person does go and we are able to catch the individual as he leaves the facility, he does not want to be around us.
- Is there a supported job opportunity that you can help him connect with? Also, what is this person trying to achieve by leaving the program? Have you done a behaviorist assessment to see what he is trying to achieve in leaving?
 - By the time clients reach us, it has been deemed that they cannot go into supported employment for several factors (attention span, disorientation, etc.). For those leaving the program, we can ask them what they are doing, but often they forget what the reason they are leaving is.
- What have you tried?



- We have tried giving him a printed schedule as if he is at work. We have given him the task of signing into the front desk each hour (similar to what he did in his previous work). We provide leisure opportunities. We provide a variety of activities for him to participate in. None of these strategies have worked thus far.

Group Brainstorming:

- Look at what is happening on the days that he is happy to be at the center. What is going on differently those days? What is working to engage him on those days? Are there more or less things that he likes on those days that are working that you can continue daily more regularly? If that doesn't work, look at really building in some outdoor time into this particular time for him (and others).
- I think it sounds like the problem is having a center-based program. If we are talking about person-centered design going forward, I guess I don't get why we are stuck in the past with center-based programs. If an individual needs services during a particular time, then you need to have some sort of service plan for that person. However, that plan does not have to be center-based. Also, look at the one-on-one support for the individual; help them find someone to help keep them safe. You also mentioned the issue for the people not wanting to be at the facility. I would go back to the question of being person-centered and develop a service plan that is that person's choice. If they don't want to be at the facility, they don't have to be. Some days if they want to be in the facility, they can. If they do not want to be, they don't have to be.
- I am wondering if you have people with acquired brain injuries. Since memory is an issue, is there any sort of alarm system (something on a watch or other type of technology) where he understands that at this time he is supposed to engage in this and at that time engage in that? That might help orient him. Is therapy a better option for him – like water therapy, coloring therapy, etc.? Is he getting some of those needs met by outside sources? This might be of particular importance if his condition is newly acquired.
- Without repeating what Gerie said, I have to echo what she said. Maybe he doesn't want to be there on certain days. Rather than force him to be there, isn't it better to provide a plan on his needs and interests?
- Is there a way to engage him in the solution finding process himself? Is there a way to engage him to monitor someone else or engage someone else? Can he be an ally in solving his own problems?

Michelle's Reactions:

- There isn't a pattern on days where he wants to stay in the facility versus days he doesn't want to be there. Most of the individuals do this both at the center and at home. This is more of a desire to go rather than a lack of desire to be at the center.
- We have tried walks outside. I'm not sure if that has worked. It does not seem to have.
- I'm not sure if the service plan changes would make a difference since he has similar behaviors in other locations. Revisiting his service plan might not work.



- Alarm system hasn't worked in the past. For all of our consumers, when they want to get out, they just have to go. It is just a need to leave immediately and you can't really get them redirected.
- Tried to have him as a companion to someone else, but he wasn't interested.
- For the population I work with, there will be people who want to leave from time to time. At what point can their rights be interrupted for their safety? They have the right to leave, but they don't have the standard thought process to stop at the street and look both ways – or to use cross walk- they just go. My question is at what point do you stop them?

Your obligation is to keep someone safe. You are absolutely obligated to initiate an emergency control system in an IDD system. You can do this up to three times before you have to do a safety plan that is reviewed every 6 months by the Human Rights Committee (HRC). The plan includes everything involved in keeping the person safe and providing justification of why you had to take certain actions. Even though you have a safety plan, you still need to continue to provide education. The goal is to always provide rights and attempt to teach individuals community safety skills. I'm not sure how it works in other systems, but this is how it works in the IDD system. There is a committee always reviewing the safety plans to make sure that individuals' rights are honored and not unduly restricted.

I am wondering with the Final Rule, if there will be challenges from CMS to any of the current rights limitations that have been reviewed. The HRC boards have the three instances and the safety plans, etc. Everything seems so structured and well documented. The process is working. I am wondering if things are changing in terms of expectations from CMS where some of those things - rights limitations in safety plans – might be challenged.

In the Final Rule there are places where you can develop and document modifications. You have to document why modifications are made in the service plan. For instance, if someone is cognitively unable to walk outside and be safe, this needs to be documented in the plan and would be allowable, for that individual.

Well if that is the issue, can't some providers across CO take advantage of that? If it is only a matter of writing stuff up and documenting it, I think that is a false hope on the part of agencies who would like to get around the intent of the Final Rule.

That is a concern, but the whole person centered planning piece is that if you document a need for safety, you have to document how you are helping that person be safer. The push is to help clients become more and more independent. Even if you document an issue for documentation, you then have to document how the person is being educated to help them become safe on their own.

I'm wondering about the issue of people not wanting to go to a facility based program. What do you want to do when a person doesn't want to go to the facility? We haven't done much brainstorming on that.

One of the things we talked about on Tuesday was the planning process and that pops into my mind when you say that, Gerie. What are others thinking about that?



I think the issue of people not wanting to do something (or wanting to do something) is the heart of the discussion. The issue shouldn't be how you make something that people don't want to do more attractive, the issue is instead how do you work with someone to meet their needs. If someone doesn't want to go to a facility, the answer is really creating a new plan. It must be flexible enough to change as the person's needs or conditions change.

If someone is in a setting they don't want to be, it sounds like the decision is more what the family and or guardian wants.

I think the bigger challenge for me, is that for some days, at different points in the day they do want to be here. There is just a part of the day that causes them, for whatever is going on with them internally, they have an uncontrollable need to leave here. It isn't an overall lack of wanting to be here, it is a transient, temporary thing. It is not a constant.

What is the individual doing at the facility during the day?

He has the option to sign up for activities that he wants to do. He always chooses the activities. He says he is satisfied. There is just a switch that goes off that says, I need to be somewhere else. It varies including "I need to go to work", "I need to go see my family" "I need to go"... it is uncontrollable. They can't control themselves. It is physical.

Could you present him with something "work like?"

We tried to give him rounds daily and then he would sign in like he used to. This approach worked some days and other days it did not. It is important to note that this want to not engage and to leave does not happen every day. That being said, it happens enough that we want to have a locked facilities to keep everyone safe.

Challenge Presentation #2 – Gerie Frohne

In the ID/DD world, and in some other Medicaid arenas, when someone leaves school they end up utilizing a day program. Day programs are areas where individuals receiving ID/DD services gather together and are served by agencies in various ways. Individuals can go in the community (a van) which is often called van therapy. They will stop at food court as a group at a table or two with only paid staff with them. Sometimes they will go do an activity as well, as a group. Sometimes they have these programs at facilities. This is both site based and community based. Either way, they are congregate communities. My challenge is, I would like to see all of these end and instead all activities would be individually planned in a service plan. Because families need this service coverage for this time that the parents are working or something like that, that there is a need for this time to be served to be covered by Medicaid. However, this time should be filled doing something the individual wants to do.

Also, due to the long lengths of time that these people interact with staff, there develops friendships between paid staff and the individual. The challenge is to break up this system and move towards a more individualized system based on individual preferences. What do you do with people who choose to go to congregate day program? I personally think this should not be a paid option through Medicaid.



Group Brainstorming:

- I understand Gerie's thinking. I respect it. I would like to ask, that as we continue down this road to avoid characterizations like "van therapy." I think it is really insulting to those of us who are trying to get at what activities people want to be involved in and we try to schedule those regularly, with limited resources. We don't have funding that would allow us to have one-to-one service for everyone. I don't see how the system could do that. If we could get there, that would be great. I think moving forward, it would be helpful to not bash the current system. I would not like to see that someone says that a service should not be a choice.
- I think part of the challenge – two things.
 - The rates paid for services available through the waivers are not sufficient to provide the individualized support that we might wish for everyone. They are based on group activity instead. I think they are on the spectrum of totally individualizing and isolating activities and some congregate activities to let people leave.
 - I also believe if we really work harder at providing supportive employment for people, some of those activities could be replaced with people doing jobs instead of settings. I think the Final Rule provides opportunities to build systems that work for people's lives and that don't force individuals into particular projects. There are many people who might think they are fine, but don't know any other options. I think we can be creative and come up with broader array of things. Some people might want to do things in a group. There is no reason to think that others want to be isolated. We should look at the rule as a way to let us be more imaginative about what we do. We also need to make sure that lawmakers know that in order to do what is required, we will need a change in funding sources.
- Often, I agree with looking at jobs and enclaves when people get out of high school. If an individual has an opportunity to build a social network or having a job, to some degree they will choose the job. I think it is harder to go backwards. I think first, we should look at job opportunities. I have found it is difficult to have them stop going out with their friends vs. going back to a job. When they are going out with their friends, they are building a social network. They are doing that, rather than having the only person who is building relationship is the one that is paid to be with them.
- Colorado is an employment first state technically, though, that hasn't been implemented fully. Some of us are working on legislation on this. Most students who leave high school are guided to find a job, get some training, etc. We don't do the same thing with other populations. If we really were serious about employment and supports for employment, as a first option to occupy people's time (and mind) we could go a long way.
- It brings me back to the question, "what is meaningful to the individual?" While I understand the populations are completely different, this rule applies to both ID/DD individuals coming from high school. It could also involve those who have an acquired neural disability. For those individuals, it is good for those to have a place where they can make friends who are in similar positions, is not necessarily an ultimate evil. It helps them. Their old friends and old supports often fall to the side.



- I would just like to reiterate what has been said with Michelle. Our adult program for seniors offers a great place for seniors to come to the days and we provide education to the caregivers, we are helping keep them in the least restrictive position possible. Until we look at funding sources that are adequate to cover the costs to provide these services, it is a huge cost. I could reiterate a lot of what was already said. I do think that day programs are a great way for people, especially older adults and younger adults with ID/DD, to provide an opportunity for people to get out of their homes and get active in the community. When looking at barriers and how to overcome, we really need to look at overcoming barriers and see how to best support them.
- It would be interesting to see those looking at leaving high school and going into employment. I can honestly say it has been a very long time since we have had any referrals of individuals coming from high school into the day program. It would be interesting to see where folks are going.
- We do have a senior adult day program, serving individuals who are post-employment and in early Alzheimer's. We are providing respite to caregivers. These individuals are not in the employment portion of their lives. It is important to remember these differences. Most of our participants are funded by EBD. We don't have restrictions. We are last step before going into a facility. We try to give a lot of choices in our centers. The reality is that they have Alzheimer and that is a disease where people won't get better.
- We do have an aging population in the individuals we serve. We find those who get older choose to "retire" and no longer want to go to the day program. Their choice has been to stay home, like anyone else would. That works for us. That works for them. It is okay.

Gerie's Reactions:

- The issue of isolation is often brought up when you no longer have day programs on the menu. I think if we are doing PCP, there will be some individuals that potentially related will choose to do things alone. Isolation sounds like a negative word. For some people, it is how they want to spend their time. They may need a support person, of their choosing, to assist them. To the individual it would not be isolation; it would be a person-centered choice.
- It really scared me to hear people talking about folks wanting to be around "people like them" with similar challenges and disabilities. It seems to me that the intent of the Final Rule is to give people the same opportunities with folks who don't have these issues, this might go under informed choice, but for people to decide that the only place they are comfortable, happy, accepted, etc., is spending time with "people like them" and prefer that, it is frightening.

Open Discussion

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



- I think it is about assessing individuals and identifying what is important to and for them to see the best ways to support people while keeping them safe and happy. The movement towards PCP and the tools to help identify those kinds of things is a great first step. If we can implement those, which can really help balance the risk and choice situation.
- One word that comes to mind is “choice.” I think we will want to build something around that. I hope one thing we don’t do is take away choices.
- There is a theme about money. I’m not certain, if I were CO and was able to ask CMS a question, the question would be “Are we supposed to plan for March, 2019 completely separate from the issue of money?” It seems like for a lot of things a lot of us would see as valuable, it will require different funding level.
- An idea of the best practices is to really attempt to identify ways to implement this rule with the funding we are currently working under. There won’t be much of a change in that due to budget shortfalls.
- Early assessment and intervention options. What does the person really want before they become accustomed to something? Continually assessing as the life pattern changes and as their personality changes, make sure you know what is important to them – not as what has historically been important.
- Have a sounding board for providers so they can call on one another to talk about potential rights restrictions vs. provider liability. Does not have to be the HRC but something that serves a similar function.
- With supported employment, you have additional funds due to individuals being paid by an employer. Anything in the employment arena saves us money. If we put employment first, it does leverage dollars to help others.

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 14, 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)