



CO HCBS Settings Non-Residential Stakeholder Workgroup Meeting #4 February 11, 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. Notes from workgroups to date can be found at:

www.colorado.gov/hcpf/home-and-community-based-services-settings-final-rule

I. Workgroup Participants

Christina Neill Bowen, The Lewin Group
(facilitator)

Christina Wu, The Lewin Group (note-taker)
Adam Tucker, HCPF
Mandy Smith, HCPF

Celeste Ewert, Envision, CCB
Jan Irvin, Foothills Gateway, CCB
Gerrie Frohne, PADCO
Karen Lillie, Pueblo Diversified Industries

Stakeholders Present:

Tammy Drumright, DDRRC
Tamara French, Discover Goodwill
Industries
Deana Conaty, Rocky Mountain Brain Care
Mary Jo Rymer, Arc of Colorado
Candie Dalton, Accent on Independence
Cindy Reynolds, Mountain Community
Pathways (Adult Day Program)
Leah McMahon, Colorado Access, SEP
Barb Wilkins-Crowder, ACMI, SEP

Stakeholders Absent:

Cassidy Dellemonache, PASCO
Julie Bansch-Wickert, Disability Law
Colorado
Jenny Nate, Rocky Mountain Health Plans
Danny Holzer, Jeffco OLTC, SEP
Michelle King, King Adult Day Program
(KADEP)
Tia Saucedo, LeadingAge Colorado/Seniors
Resource Center
Stephen Shauchnessy, Mosiac

II. Introduction

Christina Neill-Bowen welcomed the non-residential stakeholder group attendees and reiterated the purpose of the workgroup, to complete a compendium of best practices related to the Final Rule. Adam Tucker and Mandy Smith introduced themselves as representatives from HCPF on the call. Christina then followed with a roll call of attendees and asked each stakeholder to share what they think of when they hear "community integration". Christina summarized and presented the following key words from the stakeholder sharing: full access, individual enjoyment, active citizenship, challenge to find natural supports, scaffolding (structure to support), belonging, and "just like us." Today's group will discuss the progress to date, pending topics to be included in the compendium, and focus on community integration. Adam sent to all

participants the link for the HCPF website regarding CO implementation of the Final Rule www.colorado.gov/hcpf/home-and-community-based-services-settings-final-rule

III. The Consultancy Process

The group engaged in a group brainstorming process called a “consultancy.” One group member shared a challenge related to the Final Rule and the group helped brainstorm some solutions.

Challenge Presentation – Deana Conaty

I work for Brain Care, which is part of Rocky Mountain Services, serving an adult population with acquired brain injuries. We offer both residential and non-residential and community-based services. This scenario has to do with a man who has since moved away, but I thought I would share his story since it provides a good overview of the challenges we face. This man is in his 40s, and he suffers from a traumatic brain injury as a pedestrian who was struck by a vehicle. He presents with frontal lobe deficits and severe expressive aphasia. He can sometimes get 1-2 words out with a lot of struggling. He struggles with social appropriateness and it is often difficult to redirect him when he is fixated on an issue. He exhibits inappropriate social behavior and outbursts that come without warning. He doesn't have a sudden reaction, but rather sits on something for a long time and after a few hours it would come out. Once, a staff member redirected him on his behavior, and a few hours later he came out and struck her. He lacks insight on his disability. It would be obvious due to his social behavior, but he did not appear to have a disability when he was walking around Walmart since it was not physical. When we took him out on day trips, he would follow women he thought were attractive, try to talk to children, and touch people's babies. He once followed a woman to the parking lot because he wanted to see her baby. This behavior frightened people out in the community. The staff would try to redirect him, but it was difficult to break him away from the task at hand, which was to talk to people in the community. We faced a ratio issue, since our ratio is 8 to 1, and it was difficult to support one person who would need more supervision when the staff was responsible for the whole group.

Clarifying Questions:

- When you say the ratio is 8:1, would he only be able to go out in a group of 8 with one staff member?
 - The maximum number of participants per one staff person is 8, but we could also have 2 staff members with a group of 10 participants.
- What medications was he on?
 - I'm not sure offhand, but he presented a frontal lobe injury, significant aphasia, and lacked insight into his disability, so it was really the trifecta of brain injury. These were not behaviors that would be improved through medication management. It was the result of organic brain injury and trauma.
- What factors do you use to decide ratio?

- We look at what's regulatory for supervision and conduct risk assessments to determine who will need closer one-to-one supervision, but we are limited by the number of staff employed.
- Is the number of individuals who might be using wheelchairs vs. ambulatory a factor that would influence ratio?
 - Yes, but I am a proponent of asking participants to help with wheelchairs if they are able.
- Does he have a desire to go out? Does he exhibit sadness and disappointment if he does not go?
 - Yes, he is very social, and that's the root of the problem. He is very social so he tries to talk to people in the community but he is very limited by communication deficits and social skills.
- Where did he go and how is he doing now?
 - He was part of our residential services, but was in the day program as part of his rehabilitation. He moved back to his family, and I don't know how he's been doing since he moved back, but they are taking care of him now.

Group Brainstorming:

- Peer support— perhaps try finding someone to be a buddy for him in the program? This would provide some kind of peer mentorship and someone to bond with.
- Volunteers—I know that we struggle with getting volunteers because they have to go through the background check, training, etc. It's such a long process to become a volunteer, people could almost become a staff members. But you could use volunteers to provide one-on-one attention.
- Match funding to needs—In the IDD system, they have a way of assigning funding based on needs. I'm assuming when Medicaid gets through their assessment tool, reconfiguration, redesigning their assessment tool, they're going to find a way to allocate funding based on needs. So if this person has extremely high needs, then they would be able to have funding that more closely matched their needs. That doesn't fix anything for today, it just holds out some hope that they would be able to have some one-to-one support in the community. If someone has a needs level of 6 (1 to 6) then that does cover 1-to-1 support. This seems to be the direction we're moving in.
- It might help to appeal the funding situation, saying that this community integration is part of the program design and going forward with the Final Rule. So if that's the expectation for service provision, then it needs to have appropriate funding (one-to-one in this case).

Presenter Response:

I spent some time working in the UK. Ireland was going through the same exact process for national legislation policy change, and institution of day programs, it's interesting to see that the issues are the same across cultures and systems.

I like the idea of peer mentorship and volunteers, but we have difficulty with getting volunteers through the door. For the particular needs of someone extremely hard to re-direct, a volunteer or peer mentor would need a lot of training. Even staff members that are well-trained have trouble. Generally, the staff who are in this type of work are here because of their caregiver personalities. They want to support people in a kind and gentle way, but sometimes boundary setting for these kinds of situations requires people to have a firm personality, and this is against the grain of personality that attracts people to healthcare.

With regards to matching funding to needs, the UK was doing this, and Ireland thought about following suit: an individual gets allocated a specific amount of money and becomes the consumer who could choose their services. For example, he or she would go to the day program service and ask them to sell the service to them, or take the money elsewhere. This model allows the consumer to make those decisions and to be in control of the services they would purchase. I would love to see that implemented here.

IV. Open Discussion

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

- Does the department (Adam Tucker) want to speak about the landscape and how it's going on in the policy side on the state? [Christina]
 - Funding – We are hearing that the funding is not there, we definitely hear that but we can't guarantee any of that will change. HCPF does not have much power over that and it is more of a legislative thing. We are in the middle of having a couple of years of large spending deficits.
 - Developing natural supports – We are pushing for natural supports, peer support, those sorts of things. If you can help us figure out tools to develop those supports, we are all ears and we want to get info out to others. Coming up with the best ways that providers can develop those tools would be huge.
- There is a culture shift that is required, and this is bigger than any of us. Natural supports won't be there until the cultures shifts. If we are looking to integrate, my fear is that we're looking at access. That is not the same as integration. These individuals are still segregated as a group of brain-injured peers, they're not really integrated. If we have a group of people with IDD's roaming the shopping mall, this becomes the new institutionalization, the new day program. There are people in the shopping mall when they don't have the money to spend. They are still not contributing to or participating in society in a meaningful way.
- Can someone share the example of the knitting group mentioned in the residential group? [Christina]
 - There were two ladies, whom I think had brain injury. They enjoyed knitting, so they independently located a group of women who welcomed them into their group so they could all knit together. They initially were accompanied by residential staff and then transitions to going on their own to the knitting group.

- Phased in support, paid staff built bridge and then backed out
- When I was a case manager, I would use the website “meetup.com” which lists social events in community. Knitting groups are common on this website. For one client, we were able to find a “Star Trek Vulcan philosophy” group that met once a week that he joined. [Adam]
- When I was an ombudsman, I would see stuff like knitting groups created where the staff would get them together, teach structure, and then bow out.
- Have any others worked to partner with community groups, churches, or synagogues to support community integration?
 - The local art museum has a new marketing/education director. She has worked with her group to come up with a grant proposal for financial endowment for the arts. The grant was around taking art into the community. They are still brainstorming about it, and it won't be implemented until 2017, but they looked at how to incorporate theater, rhythm, and things difficult for our participants to have access to. We have staff that make all the adaptive equipment that people need to do a lot of different things. For example, in a pottery class, if they only had use of one arm, we could make adaptive equipment that would help them to throw the clay with one arm. This is the first time a group has shown an interest in making opportunities available locally, so we are very excited about that.
- It is important to think about how neurotypical people engage in the community. This is usually through a job, working with other people, maybe meeting customers and clients. I would suggest as we move forward in this arena that more attention should be paid to supported employment, and I mean real jobs, not sheltered jobs, because that's how adults engage in the community.
 - We hired someone to do this, and we've had 4 placements and 12 referrals from DVR to do job training and placements. I agree completely.
 - I also agree, employment brings purpose and meaning to people's lives.
 - Having a job also provides them with incomes so they can make decisions on how they spend their money.
 - We just ended all piece-rate employment as of December. Now, all of our individuals are in jobs, and it's a much greater challenge than people realize to find jobs that meet standards, minimum wage, as well as businesses who are willing to hire these individuals.
 - We should shift resources to support these employers. We have to make the case that individuals with disabilities are reliable, and tend to stay in jobs longer. We will be helping people find jobs and stay in those jobs. Sometimes this will have to be customized employment, which isn't easy, but again it's a culture shift that goes beyond anyone on this call. As much as I appreciate these programs, most of us don't spend all day hanging out at the mall or at the museum. Although that would be nice, neurotypical adults engage in society through employment.
 - This also means we have to deal with things like transportation.

- It is difficult. We need to have really good tools to assess interests, likes, so you are focusing on what would be good for this person because they would enjoy being there. We need good matching. There are a couple of bills around employment first and tax incentives in Colorado, but I don't know how far they'll make it. The employers would quickly realize they are good employees who are meeting needs they haven't been able to meet. There are things that would make it easier for us moving forward.
- In summary: ways to engage in the community, meetups, partnerships, supported employment [Christina]

V. Progress to Date: Reviewing Compendium Outline

Christina displayed on the screen a working list of themes for the compendium based on previous discussions, and presented each theme to the group for further discussion and revisions. Christina asked participants to discuss what they were doing related to these themes and to comment on any themes they felt were missing from the list.

1. PCP as a process vs. an event
 - Ongoing philosophy or process vs. one-time check of the box for regulations.
 - PCP makes it sound like it's an event. It's "Person Centeredness" – what we do to support those with ID/DD or how to support them to do for themselves.
 - It's a philosophy, transfer to the people you work with. Colorado Access, care managers, looking into Person centeredness training for their staff
2. Making the most of the care planning meeting – pre-planning with participants ahead of meeting to list out preferences in the form of important to and important for. Asking if the participant would prefer to meet one on one for the meeting.
 - At our agency every employee completed a "one-page profile" for every person that they support. It involves meeting the person one-on-one, asking for contribution, what types of person works best for me, what's important to me, likes/dislikes. Having this all on one sheet of paper that can be transferred to other staff and volunteers is very helpful.
3. Including a definition of informed choice to promote a common understanding among providers.
 - This idea came out of informed choice discussion. Is that something we need to write about, what are you all thinking?
 - Just putting some language around that for providers was the discussion point.
 - I think people felt pretty strongly about coming up with a definition, I wonder if we should follow up on that to provide more information.
 - Don't know if it's possible because it's different for every single person, not sure if there's an actual way to define it?
 - Way to tackle would be to define the process that would need to take place to ensure facilitation of informed choice, people may make choices that we wouldn't

make for them and may jeopardize their health and safety, supporting providers and having the confidence to make choices that we would consider bad choices

- Best practices provide those definitions.
4. On-going dialogue about rights
 - This one refers to having ongoing dialogue about your rights, not just when you move in or join a residential or non-residential setting, but a conversation that is ongoing. This theme was more on the residential side. It involves always checking in to see people understand their rights.
 5. Providing an opportunity to have one on one support for participants in group settings to help facilitate choice. Cultivating this one on one support in non-traditional ways as well through use of volunteers and informal support. [Christina: How should we frame this in the compendium? What resources come to mind?]
 - Having resources matching people's needs, I think that's what we're charged with doing, meeting people's needs
 - [Christina: Taking example of knitting circle, what would you need to know to implement that?]
 - Who, what, when, where, how, time frame, maybe the startup process
 - Volunteering: want to make sure that the way of handling this change is not to see volunteers as the solution.
 - I understand we're talking about reduced resources, but digging into the data over the last few years, there has been a significant reversions of funds, and it isn't because the need isn't there. The rates we're currently using are for people to be supported in groups, but not all can be. The money is in the system but it is allocated differently. Some people are okay in groups, some people need a lot of supervision. We need to figure out a better way to distribute the resources we do have. I'm trying to reinforce a point that this work to become more person-centered cannot be all done by volunteers. We need to figure out how paid support can be provided in least intrusive and most individualized way.
 - Referring to the previous story, what were the barriers to him being in a group or individually in typical community activities? The barriers were instances of him seeking out children, babies, following attractive women around. In looking at what was keeping him from being successful, happy, sociable in the community, we should look at the specific barriers and try to tear down those barriers. Obviously it takes a lot to do this, but we would need to help him find a satisfying situation, whether it's work or the community, where you can take those barriers out of the equation somehow, to help him have a satisfying experience without those getting in the way. My point is to look at it like this: if someone needs one-to-one support, what are the barriers we can possibly tear down or get around that lessen the support that we provide them.
 - As a provider, I support one-on-one services for those who need it, but it's hard to make it work with the reimbursement. We cannot provide someone with those resources who comes in as a tier 1 or tier 2 it just doesn't make sense financially.

- Re-allocation of funding
 - Waiver redesign
 - If the person requires individualized support, they shouldn't be at a tier 1 or 2 level.
 - Since we all implemented to state tool, we know the issues in the system with that tool. People who need higher levels of support are not necessarily getting the right levels.
 - Most of us in this group are associated with the IDD world, but there are some that don't deal with SIS (supports intensity scale). Deana's case has to do with brain injury, and he was still not getting right levels, so it's not just in the IDD world. Needs to go beyond.
6. A sounding board for providers – Develop a Human Rights Committee for all populations.
 - There needs to be some sort of awareness of the fact that there is tension and conflict within meeting the final rule. Sometimes informed choice creates conflict with community integration. At the end of the day, he might choose going to a playground to play, but that's going to conflict with the most appropriate community integration for him. We can't have a Human Rights Committee for every single consumer, but need a decision tree for when those layers conflict with each other.
 7. Protecting participant rights and working with guardians
 8. Managing intersection of rights and decision making
 9. Putting increased emphasis on employment.
 10. Awareness that Department is working to advocate for enhanced reimbursement, but working within current structures, what can providers do now.

Due to time constraints, Christina ran through the last few themes together and asked the group for any additional comments.

- Public education – You can get others to fund that, it doesn't need to be through State Medicaid system. There are plenty of organizations who would support a public marketing campaign directed at inclusion. It takes some organizing, but there are a lot of advocacy groups that could help work on that. It's a "community challenge"

VI. Next Steps

Participants of the workgroup raised that they wanted to provide written feedback on the Compendium Draft prior to the next meeting, and to have the opportunity to review others' comments. While the logistics and timeline are to be determined, there seemed to be a general consensus that participants would send their comments on the draft document to the Lewin Group, who would organize the comments in a document and disseminate to all participants in the group. Some participants expressed a desire to see individual comments and who they were from rather than organized into general themes.

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 **review work to date**.

Next Meeting: Review work to date

- Thursday, March 10, 2016 from 9:30 to 11:00 am
- Pre-work is to review the compendium draft slides and submit written comments by March 1, 2016.