



Regulatory Reform/ Home and Community Based Services (HCBS) Transition Plan

Steering Committee Meeting Minutes:

July 17, 2014 9:30-12:00 PM

In Attendance: Maryellen Moeser, Tamika Black, Liz Booth, Ronnie Cohn, Janet Felker, Kris Garcia, John Gleason, Ann Hardiman, Michele Juda, Mark Keegan, John Kemmer, Lisa Kennedy, Donald Lash, Alicia Matulewicz, Kelly McGuirk, Riele Morgiewicz, Candace Opalka, Frank Pennucci, Jill Pettinger, Peter Pierri, Vicky Schultz, Anne Swartwout, Maria Torgalski, and Barbara Van Vechten

Absent: Steve Holmes, Clint Perrin, Chester Finn, Phil Catchpole, Charles Archer, Ellen Arocho, Kate Bishop, Helene DeSanto, Dan Flanigan, Cheryl Mugno, Megan O'Connor-Hebert, Lourdes Reyes, Mike Savery, Tanya Seaburg, Nicole Weinstein, Ed Weiss

I. Welcome and Introductions: Tamika Black, DQI and John Kemmer, NYSARC

- Background/Context and Committee Parameters
 - Brief Review of HCBS Settings Final Requirements
 - PowerPoint Presentation
- The purpose of the committee is to provide input on the OPWDD HCBS ADM, provide feedback on the Assessment Tool, and provide input on OPWDD's Transition Plan. There are representatives from all stakeholder groups participating, and they are expected to provide input and feedback within tight timeframes. Content experts from OPWDD are also present.
 - The focus of this committee will be on certified residential settings and person-centered planning requirements. CMS has not yet issued further guidance, such as implications of the regulations on day settings. OPWDD will address day settings once CMS issues this guidance.
 - Alicia is keeping a list of systemic challenges that will need to be addressed further beyond the scope of this committee ("parking lot").
 - Future Meeting dates scheduled are: 8/7/14 9am-12pm; 8/21/14 from 1pm-4pm; and 8/28/14 from 9am-12pm; refer to schedule in PowerPoint regarding what topics are expected to be covered and when.
 - Review of key elements of final rule. Our timeframes for this committee are tight because our waiver is up for renewal by 10/1/14. We submitted our HCBS Settings Transition Plan with the waiver renewal application and after posting for an initial 30 day period. OPWDD continues to accept input/feedback on the preliminary transition plan.
 - DQI is also working with the IT Cluster to develop an infrastructure for the HCBS Assessment Tool. Use of this tool by DQI is scheduled to begin 10/1/14.
 - Discussion on timelines and deliverables through Fall/Winter 2015

II. Person Centered Planning and Process : Anne Swartwout, OPWDD MSC Statewide Coordinator

- Overview of Final Regulations
 - Overview of person-centered planning and process
 - Discussion:
- Most PCP requirements issued by CMS are already required by OPWDD. OPWDD needs to ensure that these requirements are being implemented as required.
 - Further clarification/guidance needs to be issued by OPWDD in specific areas, including: Rights Modifications



and compliance timeframe for HCBS/PCP requirements overall.

- Refer to handout of a **DRAFT** decision-making matrix outlining whether a Behavior Support Plan is needed when rights are restricted/modified vs. documenting the restriction in an ISP or IPOP to reflect existing OPWDD behavior support plan requirements.
- We believe, based on CMS Q&A, PCP requirements are on a different track than HCBS Settings requirements as the CMS Q&A references that CMS expects individual plans to be updated for the requirements as they become due. CMS has stated that additional guidance will be coming out in this area. While we don't want to burden our providers further with new requirements, we do need to move forward to ensure that our system is aware of the final CMS regulations in this area.
- Therefore, we plan to provide some training on the new PCP regulations beginning in mid-late October through the MSC Supervisors' Conference and through DQI provider training. We expect to update DQI's MSC survey protocol to ensure that all of the CMS requirements are reviewed no later than October 1, 2015.

Discussion on Rights Modifications, informed consent, capacity, risks/safeguards, and person-centered planning :

Person-Centered Planning and Rights Restrictions (the following reflects discussion points made by various members during the meeting):

- PCP is all about listening to the person. There is always room for improvement. We will need ongoing education and there will be continual revisions.
- Use of CQL by providers takes PCP "up a notch", and speaks to the spirit of CMS' rule to listen to people rather than just restricting their rights. We need to think about how to make someone's life better.
- Is there a way to fold these topics into the planning process where the person with their circle of support gives consent for the restriction as part of that process? Those types of discussions naturally occur in planning meetings.
- In order to make circles of support work, we need to be sensitive to the role DSPs play. There are consequences when DSPs make a mistake, and DSPs understand that.
- There is a misperception about the Justice Center that they are just "guns, badges, and handcuffs". We need to change that perspective. Rooting out egregious abuse is important for the Justice Center but they have just started to think about trends and safety issues, etc. They are trying to become more helpful and assist providers. Perhaps OPWDD should engage them in these conversations about safeguards and risks as well.
- Perhaps we should start looking at restrictions IF the individual considers it to be restrictive instead? Community and relationship building is important. Team meetings have helped with decision-making when people wanted something different than what their family members wanted for them. Relationship building is critical when there are conflicting interests. Look at the risks vs. the benefits, acknowledge fears of the unknown, and create a dialogue on a routine basis.

Safeguards, Behavior Support Plans, and Rights Restrictions:

- An example was used regarding epilepsy and the use of bed rails as one instance where there is a restriction in place for health and safety reasons, not because of a behavioral issue. In those cases, how and where should we be documenting this? Existing behavioral concerns should be addressed in BSPs as outlined in 633.16 regulations.
- We need to document and review restrictions periodically even if they are for health and safety reasons. We should clarify what people NEED vs. what we have always done as a system. We need to ask WHY more, and develop a meaningful process. We also need to use caution with over-documenting the process as well, as that will take away from the intent of the PCP regulations.
- Safeguards have a more positive context, whereas restrictions have a negative connotation. Defining what a restriction is will be very difficult.
- The impact on the person is very important. WHAT makes the restriction a necessity? It's not as simple as whether we think it's just a safety issue. We need to challenge ourselves and push individuals to explore



more options *while* having safeguards.

- Rights modifications go beyond just WHERE they should be documented. There are discrepancies between safeguards and restrictions. What are the most obvious ones that we can organize for now until CMS provides further clarification?
- We have been looking at WHEN we are subject to heightened regulatory process vs. when we are not, but it does devolve to the individual’s reaction . . . maybe that is what should get stepped up to a more heightened regulatory process review. We could map out rights restrictions that automatically rise to that level and others that don’t.

Risk:

- We need to look at the risks/benefits and evaluate the consequences present when determining decision capacity. We need more support to make these decisions. WHAT is the *real* potential harm? It is important to support our DSPs this way. DSPs should be encouraged to ask questions in a supportive environment and should be able to seek guidance when needed. The DSP competencies bring a set of skills to DSPs. Sometimes supporting DSPs means putting something in a plan, but sometimes it’s through day-to-day activities.
- **The Strengths and Risk Inventory Tool** is helpful in creating delicate negotiations, and helping a person move towards more independence. There needs to be a push towards looking more at where the person wants to go in their life.
- Families are getting more comfortable with topics on risk, but we are a risk adverse system. Families are a source of lifelong support. We don’t want to offend family members, but need to point out that the person has a right to decide. This gets tricky when a family member has legal authority to make those decisions for the person. The role of the legal guardian and restrictions in residences with children are clearer, but it is less clear with adults. It is important to document the person’s ability to make that informed decision.
- Balancing risk is complex. What is our duty? What is the balance? This is a very difficult issue. There is a difference in our responsibilities when looking at residential settings vs. non-certified settings.
- All of these HCBS regulations may involve risks, but we should avoid a new slew of documentation requirements.

Capacity and Informed Consent:

- The capacity of the individual to make decisions is critical. This is a delicate and difficult issue for providers. We need to look at how to address capacity at a practical level.
- One agency has been using a document from a Mental Health Journal regarding how to determine informed consent for someone with a developmental disability (shared with group).
- People are presumed to have capacity unless there is a legal determination or assessment that indicates otherwise. There are also definitions in 633.16 around capacity as it pertains to providing informed consent for restrictive interventions. Guardianship does affect people’s rights. We need to educate people on limitations, and keep those restrictions at the lowest level.

Training, Tools, and Education for Providers:

- The field needs education on seeing things such as special cups, bed rails, and protective coated spoons as restrictions. Even if they are for health and safety reasons, they are still restrictions. Education to the field will be a bigger “lift” than we think it will be.
- There is a sense of fear with health and safety,-an “all or nothing” kind of attitude. It’s a real challenge and education on options and alternatives to mitigate risk are critical.
- We need to employ “defensible decision-making”. The subgroup may benefit from sharing resources used in the Person-Centered Quality: Health and Safety in Non-Certified Settings Committee that met last year pertaining to risk and person-centered planning.

General Discussion and Summary:

- The CMS regulations clearly and specifically outline documentation requirements, so there are documentation



requirements that will be unavoidable.

- These regulations are all about the individual's perspective, and how they feel. If the person does not give consent to something (such as using a bedrail), then the restriction shouldn't be there. Positive approaches should always be tried first e.g., mats on the floor may be an alternative to bedrails if the person agrees. Individuals have the right to refuse, and we need to honor that right. The nature and intent of the CMS regulations gets at respecting feelings and being sensitive to what is being imposed on the person. We have a tendency to be overprotective in our system, also because of litigious concerns, but the immediate priority is the individual.
- Person-Centered Plans will need to be updated as they become due. Training on HCBS Setting regulations will be set for mid-October as they relate to PCP concepts. OPWDD will revise its MSC survey protocols no later than October 1, 2015. Committee members should think about the final PCP requirements and whether further tools/guidance is needed. Eventually, we will look at regulations down the road. The Strengths and Risk Inventory Tool is helpful for showing that the dialogue is actually occurring on an individual level.
- There will be a subgroup established by Anne Swartwout on PCP with just a few members. The subgroup can focus on guidance and tools to help the field. The subgroup will look at two things: 1. Person-planning and needed areas to address 2. Rights modifications-guidance on what that means, and when/where/ how to document restrictions. There will be a tight timeline for the subgroup, with a quick turnaround time. We will need written recommendations by the end of August as our deliverable from this subgroup.

Wrap UP and Next Steps : Maryellen Moeser and John Kemmer

- Anne Swartwout will develop a PCP subgroup charter /goals and will send out invites to those interested in participating on that subgroup
- A redraft of the HCBS Settings ADM will be circulated soon prior to our next meeting for review by the committee
- Initial feedback on person-centered planning/rights modifications from today's discussion will be due by the 8/7/14 meeting for consideration by subgroup
- The HCBS Settings Assessment Tool will be shared for committee input as soon as we finish the initial draft
- The video camera policy will be shared for review by the committee prior to the next meeting on 8/7/14. Cheryl Mugno is the lead OPWDD representative for the development of this policy

Background on video camera policy: DQI has had more and more issues related to the use of video cameras in residential settings (and all the rights and privacy issues that relate). A workgroup was previously formed, but CMS has not provided a robust dialogue yet on this issue for HCBS settings. We need to help guide practice in the field in non-ICF settings (guidelines already exist from CMS for ICFs). Initial guidance for HCBS settings was drafted in July of 2013 by Cheryl Mugno and Counsel's Office. We are including a reference to the video camera policy in the ADM and we want to get input from the workgroup and stakeholders.

Meeting Materials Provided:

- PowerPoint
- HCBS Regulations and CMS Guidance Documents including Exploratory Questions
- November 2013 Draft ADM

