

Participant Directed Programs Policy Collaborative (PDPPC) Meeting Minutes  
December 19, 2012, 1:00-4:00 P.M.  
MS Society Offices, 900 South Broadway Suite 200, Denver, CO

**Executive Summary:**

This was a positive meeting: We discussed protective oversight, and will wait until February for a vote to allow time for CMS to provide input as to what they will and will not allow. We also had a robust discussion about crisis management and reacted to a briefing from staff. We provided input and staff will revise and bring back in January for a vote. We addressed the “stable health” question and made suggestions to revising the physician form. We heard from staff on recommendations we had previously provided and received a preliminary work plan for inclusion of CDASS into the Supported Living Services (SLS) waiver in the DD system.

**Present in the Room:**

Bonnie Silva  
Gabrielle Steckman  
Linda Skaflen  
John Barry  
Tyler Deines  
Linda Andre  
Julie Reiskin  
Gabby Melicia  
Linda Sienkiewicz  
Dawn Russell

**Present on the Phone:**

Rhyann Lubitz  
Heather Jones  
April Boehm  
Corrine Lindsey  
Leyla Lindsey  
Robin Bolduc  
Kelly Morrison  
Candie Dalton  
Debbie Miller  
Sara Horning  
Don Riestler  
Roberta Aceves  
Mark Simon  
Rosemary Colby  
Anne Dyer

**Excused**

Josh Winkler  
Chanda Hinton

Jose Torres  
Jennifer Martinez  
Sam Murillo  
Todd Lobato Wright  
Sueann Hughes

John Barry called the meeting to order at 1:02 p.m. Chanda had asked Linda S to fill in for her as Chanda had a medical appointment that she could not change. Linda S read the agreements and clarified who had voting rights for this meeting (this was also provided in a handout).

### **Minutes:**

*Linda A. moved and Linda S seconded that the November minutes be approved.* There are no corrections. Motion carried unanimously.

### **Protective Oversight: (PO)**

Candie Dalton was asked to review:

We started to work on this topic two months ago. In November, recommendations were presented and we were to vote this month. Candie was able to meet with CMS to get more guidance regarding their definition and interpretation of what “custodial observation” means as this is not allowed. Candie also raised other questions such as the ventilator issue to CMS. The regional CMS personnel felt the need to get guidance from Baltimore because some of our questions are larger in scope than what they felt able to address. Our options are to go forward and vote or wait to see if she can get additional information from CMS. The purpose of waiting is to avoid the hassle of making a recommendation and then having to change it based on CMS feedback. Candie did impart to CMS that this cannot wait for months. Candie was asked if she needed us on the phone with CMS. She said she felt able to explain our issues and concerns but if we wanted to be on the phone she was fine with that—however involving people on a call could slow this down. Advocate/client members of the small group felt Candie was able to express our perspective and did not feel that we needed to be on the call with CMS.

We had discussions on the following issues:

- 1) Ventilator example: PO is currently only a benefit in personal care (unskilled) and all ventilator care is skilled. Therefore, vent care may need to be covered under respiratory care. It is obvious and undisputed that someone on a vent who cannot physically manage the vent cannot be left alone.
- 2) How do we address the requirement for a need for “hands on” care when many people need verbal redirection? The example of wandering was raised—if someone is wandering they should be verbally redirected not physically in most situations.
- 3) If PO is ONLY available for times when hands on tasks are needed why do we need this at all, why not ONLY use each task? For example if PO is needed because someone might need to go to the bathroom why not just approve the task of toileting? Response was that it could be for something such as someone who has seizure disorder and frequently has seizures cannot shower alone –the person does not need someone to help in shower but if there is a seizure may need hands on assistance.

- 4) PO has to be for events or interventions that are likely to occur and cannot be for “what if” situations. For example, if someone has not had a seizure in three years then having someone daily for showers may not be reasonable, where if someone has seizures several times a year and usually while in a shower then it would be reasonable to cover PO for showers.

*CONSENSUS WAS THAT WE WILL VOTE IN FEBRUARY.* This will give CMS time to give HCPF guidance and, if necessary, will allow Candie to reconvene the small group.

### ***Crisis Management:***

A briefing document regarding this topic was sent out via email and is attached here: Candie was asked to review the draft document and did so. The discussion included the following:

- 1) Should we use the term **emergent** and not crisis: *Consensus was that we should use term emergent.* Some will not know what it means so we will make sure to define and explain. This will help to change the “culture” in the disability community that rewards and expects us to always live in crisis. It will still be able to address unplanned emergency needs. This will be opportunity to move the cultural change discussion forward regarding promoting the expectations that we can have reasonable lives, and do not always have to live on the edge and in crisis.
- 2) There has been lots of misinformation about what the process is for changing an allocation. There is supposedly an expedited process available but that had never been defined or shared clearly with case managers or clients.
- 3) *Need to separate emergent needs with respite; the former may be needed when the unpaid family caregiver has an emergent need (they are sick, they have a death in the family and must travel on short notice, etc.). Respite is planned breaks from care giving.*
- 4) The document defined emergent needs –*it should also address when the situation changes (not always health condition) such as unpaid, “natural support”, care provider is suddenly unavailable.*
- 5) The document outlined current process for allocation changes and proposed three new versions:
  - a. Temporary non-emergent needs (e.g. planned surgery for client or unpaid care giver).
  - b. Long term non-emergent (e.g. permanent change in condition or circumstance). This could be ending of unpaid support or secondary or worsening of disability that requires either more time for current tasks or more tasks that need to be done.
  - c. Temporary emergency situations (client wakes up and has flu)

It was temporary emergency situations that involved most discussion:

Discussion included:

- Cannot put “what if” in allocation
- If allocation not micromanaged to minute there should be some extra to manage these issues as clients are trained to save for emergencies.
- Discussion about not being punitive if someone saves and is responsible and balancing that with CMS requirement, the PAR should meet need as much as possible.

- Question about what happens in an agency model if someone is sick suddenly and needs more care than had been authorized: Answer is that agencies cannot do extra under PCP but do have PRN visits in skilled home health. Question was what does agency do if they come in on a Saturday and the client is sick? -Will the agency stay and provide care if hours are not authorized? Answer: Some will and some will not: When the agency stays and “eats” the cost, the care provider is still paid. It was brought up that CDASS clients cannot have attendants who are not family to work without pay. We cannot require non-legally responsible relatives to do free care, but they can do it if they so choose.
- Document suggested that if there was a new increase needed, a SEP should discuss adjusting wages. *Several people said that they had an ethical issue with this in terms of asking workers to take a pay cut because the job was now more difficult or required more hours.* HCPF staff (Bonnie and Candie) agreed and said that this was there only for discussion. If there is a wage that is out of line, the SEP has to address this if needs cannot be met within the allocation.
- Julie and a few others felt that there should never be a situation where we say it is OK to use services and ask the case manager on the next business day. This is because if the SEP does not agree that it was needed there is a big mess and there is no way to really determine what is needed. NOT SURE IF THIS WAS RECOMMENDATION OF COMMITTEE OR NOT?? NEED TO ADDRESS.
- *Need to be clear that clients are allowed to move around their service plans and do not have to go to case manager for everything;; for example, if there are funds in savings and the client uses them when sick or for another emergency, the client does not have to get permission from the CM. If the use of the funds exceeds 10% the client should email case manager so the client is not “dinged” for overuse.*
- Dawn wanted to know what happens if there are extra funds at the end of the year in IHSS.
- Another issue with temporary emergency situation is how many times in a year can a client do this?
- Candie said that while we need to create a process to address and mitigate any potential abuse, waste or fraud we should have balance to assure that the program is not impossible to use. Members felt we should have some criteria, without going overboard, to determine if someone is misunderstanding or abusing any emergency criteria.
- Gabriella offered to help support a better expedited process and Candie said they had a list to bring to PPL. The issue of having to wait until the 1<sup>st</sup> or 16<sup>th</sup> seems to be a big deal and Candie will work with PPL to see if this can be changed.

*DECISION: Candie will make revisions to the document based on the discussion today and we will be able to vote on a revised document at the January meeting.*

### **DEFINING STABLE HEALTH:**

Candie shared that this was started several months ago by one of the old subgroups. Candie provided a briefing document and draft revised statement of physician determination of consumer capability.

Julie and Bonnie gave historical perspective of the Physician's Statement. Because the nurse practice act is waived for CDASS, the Department must still assure "health and safety" to CMS. This was a way for a doctor to state that a client is able to know when he or she needs to call a doctor and manage developing a budget. This piece is more about the need for an authorized representative. The other piece is that to self direct one needs some amount of stable health. If there is no way to predict needs and there are dramatic changes all of the time (or a constant life of crisis that does not resolve), then CDASS cannot work because there is no way to create an allocation.

Bonnie said that she wanted the form to be meaningful. There were comments that most forms that the doctor signs are not meaningful because the doctors do not really read them but just sign them. Part of this is that doctors do not have much time with patients and are overwhelmed with paperwork and are simply trying to help patients get needed care.

Recommendations to change the form included:

- 1) Remove status
- 2) Remove hospitalization risk
- 3) Take out credential and replace with license number.

*Recommendations were to test the revised form with a small group of doctors asking them if they understand the form and if there is anything that can be done to make it more meaningful and user friendly. The group also recommended that when the waiver is renewed, we change form to allow signatures from a PA or Nurse since many clients see them instead of doctors now.*

There was a discussion about whether a physician had the capacity to determine whether someone can be a manager of employees because the skill set involves more than cognitive ability. Gabriella and others said anyone who makes a decision about who can and cannot manage their own care must be credentialed as we do not want this to be subjective or based on prejudices. Linda A. said that some client's who do not have an AR members, are having family members are doing it, others are not managing and no one is doing it and most of the employee turnover is with a small number of clients. Discussion was that managing people is very difficult. One can only regulate aptitude to a point. People who cannot or will not manage appropriately will have natural consequences (unable to find or keep people). If there are true service delivery choices then clients who cannot or do not want to manage people should be advised of IHSS. Dawn said that this is a big picture issue and that it is also an issue in IHSS. Heather said that they had a situation where a specific caregiver had abused clients and other CDASS clients wanted to hire those same people. If there are not criminal charges (and there usually aren't when it is abuse against people with disabilities), they will pass the background check. Heather said that in those cases she thinks the case manager should be able to nix CDASS.

*Consensus: Physician statement cannot possibly get to this issue. Even the criminal background check does not address everything and clients and advocates have expressed preferences to determine who they hire and train.*

**NEXT STEPS:**

- 1) *Make changes in form*

- 2) *Test with doctors before it is brought back; to make changes if any suggested by doctors. Anyone who has a doctor or doctors who will test it, let Candie know. ([candie.dalton@state.co.us](mailto:candie.dalton@state.co.us))*

### **HCPF Response to Formal PDPPC Recommendation:**

The formal recommendation for allocation development was submitted on 12/1. HCPF will have written response by 21<sup>st</sup>. Candie presented this to an internal HCPF CDASS operations group. The discussion was good and there was not a lot of opposition. Candie will present to leadership including Suzanne Brennan sometimes in January. PDPPC will have draft response before that presentation. The preliminary recommendation from the HCPF operations group is that we test this allocation development. *PDPPC told Candie that we are in agreement and that PDPPC should have an instrumental role in the testing.* Questions for testing include:

- ❖ Should clients volunteer or should they be assigned?
- ❖ Should SEPs volunteer or be assigned?
- ❖ How many clients do we need for legitimate test?
- ❖ What is the testing process?

*FOLLOW UP: Candie is to set up a meeting to work out details and John will send the date and time to the whole group. The regular subgroup meeting on the third Monday is a holiday (MLK day) so Candie will just send a different date.*

### **CDASS in the DD System:**

A task analysis was passed out in a large chart and presented by Lori Thompson who came to present this to us. This was a result of drilling down into each task that has to be done; many of these are already done. Sally says that the data book (sent out on the same day as the PDPPC meeting) will be helpful. We had a discussion about doing appropriate input for this population, for example, do one session of client input that combines rules and waiver. The process must be clear about what we do and do not have input on and there has to be a lot of education. They will look at each aspect of CDASS and see what if anything will need to be different in this waiver. They do not have a specific timeline but all sections of the chart are outlined in a 3, 6 and 9 month simultaneous increments.

Recommendations and issues to address:

- 1) *There may have been legislation in 2007 that allows a choice of FMS specific to the DD system. We all agreed that this would be a serious problem and should be repealed. The department and advocacy community could go together to the JBC and ask to repeal this as we do not have capacity to manage more than one FMS. Lori and Julie R. will try to track this down to see what specifically the law says and then report back on what may need to be done about this. Advocates should take the lead but will need the department to actively support this and it may need to be hooked onto a larger bill.*
- 2) *When we do stakeholder engagement, a stakeholder is someone who uses the service.*
- 3) *The challenge is to manage health maintenance as that is a state plan benefit. DD services are capped and state plan services cannot be capped. They have to figure out how to cost shift HM from state plan to waiver. To expedite they might initially just*

include personal care and homemaker at first while they figure out the health maintenance.

- 4) There was concern about CCB's not liking this and getting in the way and there was a suggestion that *the SEPS who are part of this committee could be good messengers to talk to the CCBs about how good this can be for clients.*

**Public Comment:**

Linda S. expressed her thanks for work by Bonnie and Candie and others to bring this important service delivery option to people served in the DD system.

Bonnie expressed her thanks to the group for putting in many hours to make this work and said she appreciated the amount of work and dedication from everyone, especially from people who are not paid to show up.

Julie R. and Linda A. also expressed appreciation for everyone and said that it finally feels like we are getting work done and that this has become a model committee and very productive and that they appreciated being true partners with HCPF regarding this program.

The meeting adjourned at approximately 4:00 p.m.

**The next meeting will be JANUARY 23, 2013 from 1:00-4:00 p.m. at the MS Society 900 South Broadway Suite 200 Denver, CO.**

Respectfully submitted  
Julie Reiskin, PDPPC Member

Attachments:  
Crisis Briefing Document  
Draft Physician Statement  
DD Work Chart (NEEDS TO BE PROVIDED)