

Participant Directed Programs Policy Collaborative Meeting (PDPPC)
May 22, 2013
MS Society –Colorado and Wyoming Chapter Offices
900 South Broadway Suite 200 Denver, CO 80210

Executive Summary:

We had an update on all aspects of the work plan and will be able to have all issues that HCPF and PDPPC identified as necessary to fix prior to expansion completed by August as planned. The Brain Injury Waiver is on track to be able to offer CDASS as of January 2014. The group agreed to do IHSS and regular agency services in the community at the same time because there is only a two month differences. There are delays and problems with the SLS waiver that were discussed at length. The entire meeting in June will focus on our options for providing our attendants health insurance given changes and choices created by the Affordable Care Act.

The meeting called to order by Candie at 1:00 p.m. Martha Beavers is substituting for John Barry and Linda Skaflen is substituting for Chanda as our co-chairs for the day.

Present on the phone:

Corrine Lindsey
Heather Jones
Margaret Proctor
Barb Ramsey
Rhyann Lubitz
Maria Rodriguez
Don Riester
Sueann Hughes
Beverly Hirsekorn
Stacia Haynes

Present in the room

Candie Dalton
Linda Skaflen
Linda Andre
Gabrielle Steckman
Sara Horning
John Darling
Rosemary Colby
Jessica Lozano
Martha Beavers
Todd Slechta
Jose Torres
Sam Murillo
Tyler Deines
Debbie Miller

April Boehm
Julie Reiskin
Dawn Russell

Excused:

Alan Wiley
Chanda Hinton
John Barry
Ann Dyer

Opening Matters:

- Linda reviewed voting members for this month: The new voting structure was sent out. There was a question about if people still need to call a co-chair or leader if they had excused absence—answer is YES because if you have 3 excused absences you can come to the fourth meeting and keep voting rights. If you have 3 unexcused absences you lose your voting rights. Anyone can regain their voting rights by attending three consecutive meetings.
- Julie Reiskin stated that **new people are welcome!** If the group starts going too fast or using acronyms new people should speak up and ask that we stop. Some topics have been under debate for months, and if we cannot explain the entire issue at the meeting, anyone who is in leadership would be happy to meet with people before or after any meeting to catch them up.
- Martha announced that the Community First Choice council is holding a focus group for attendants of CDASS clients. The focus group is June 4th from 10-11:30 am. Transportation is paid plus \$20 gift card. Please share with your attendants and anyone interested should let Martha or Candie know.
Martha.beavers@state.co.us or candie.dalton@state.co.us

April Minutes:

One correction is Roberta Aceves was listed as Roberta Garcia. There were no other changes to the minutes *and Jose moved and Linda Andre seconded approval of minutes with this one correction. Motion carried unanimously.*

Work Plan Review –Led by Candie Dalton:

Work plans were emailed out ahead of the meeting and were passed out at the meeting. Candie emphasized that these are working documents and if errors or omissions are noted people should contact Candie directly. This is the plan that focuses on the prioritized list: This was the initial list of issues that HCPF said must be addressed before expansion. All will be done by August.

1) HCPF is still working through the **crisis** issue. There may need to be a short and long term plan.-

2) **Protective Oversight (PO).** Draft guidance was passed out and discussed. There is agreement on the policy issues and discussion focused on how this is to be presented.

a) Instructions will be clear that ventilator care will be under respiratory with clarification that one may need someone to be there because if a vent becomes unplugged or breaks immediate assistance is needed.

b) Discussion about using examples to explain likelihood of risk: Example was difference between someone with a seizure disorder who has a few seizures a year and may have one while unattended, versus someone with a history of multiple severe seizures daily. The later might merit protective oversight while the former would not as Medicaid cannot pay for "just in case" level of care. What happened during the seizures would also be a factor, for example if the seizures caused wandering or loss of consciousness that would require more care than absence seizures.

c) Additional guidance will be needed around people with serious mental illness. This could be done by looking at annual ebbs and flows. Example given of someone who has episodes every few months that might last a few days but during those days they need constant supervision. Documentation should be a discussion about the history and likelihood and should not require specific dates and times of episodes and should not require that the client called 911

d) *There MUST be a way to allocate the hours without any sort of penalty if the hours are not used.* Take example in #3. If client had a good year and only had 3 episodes instead of 6 the client should not be punished by losing necessary support because the client did well. Moreover, we need to encourage people to use only what they need and celebrate when someone can use fewer services without making people feel as if they will lose out if they return funds at the end of their year.

3) **Allocation development:** The testing for the new process started May 01 so there is not enough data to know anything yet. There have been some questions from case managers. We asked the two case management agencies at PDPPC for feedback. Initially case managers do not like it but that may just be because it is new and requires a different mindset. They struggle without a clear foundation and lack of a form with calculation protocol but this is so new that the learning curve has not yet happened. Candie shared that there was a CDASS planning guide to help clients and case managers figure out how to put together an allocation absent the task sheet. Candie incorporated the feedback she received initially and is sure that there will be more feedback. There will be more concrete information on utility of the new process and any tweaks

4) **Physician Statement.** *-Candie needs to go back and figure out where we are -- there was a lot of back and forth and it may be ready for completion but she needs to double check all of the comments and her notes. She will update us via email*

5) **Expansion to the Brain Injury Waiver.** *We are completely on track to have CDASS available in the BI waiver by January 2014!!!* Most of the work plan is data and systems related. The question was raised if we could move it faster and Candie said

she did not think so. We asked about emergency rule under the health and welfare issue if we could get enough people in bad situations and Candie said she would explore. We also discussed the need to allow people to start the process of allocation development, training, and even selecting attendants and getting their paperwork “good to go” so clients can start on January 01. *Candie will do a step by step guide for clients regarding this.*

The step by step guide was embraced by the group as something needed for any potential CDASS applicant.

This also led to discussion of problems with transitioning into CDASS for clients coming from institutions and clients going on the buy in. *Dawn said that when agencies provide services in these situations they can be reimbursed retroactively and said that this should apply to CDASS, Group members agreed.*

Julie said that for transition clients the only way to make it work is to do an individual request for reasonable modification of policy under ADA to allow all of this work to happen while the client is still in the nursing home. *She suggested that it would be less work for transition coordinators and HCPF if they created a system and process for this.*

It was also made clear that for buy in clients who need their attendants at the job we need a much faster way of entry to CDASS

Candie clarified that when she said “the department only wanted to do one waiver amendment at a time” that this referred to each waiver, not the whole system. So the amendment to the BI waiver will not cause slow down of expansion for other populations.

IHSS Update

- Sunset review is almost complete and the part involving external stakeholders is complete. It comes out in October so it is likely going through internal clearance at DORA over the summer.
- HCPF is creating a web-based training for care managers and agencies on IHSS and face to face regional training for case managers on all issues. Candie said that anyone from PDPPC including but not limited to clients and advocates could observe these sessions.
- Candie is trying to create an email list of IHSS agencies so she can have more effective direct communication.
- Question: If IHSS is a delivery model why are there specific service providers—why can’t anyone be a provider? Answer is that in exchange for flexibility and freedom from certain components of the nurse practice act these agencies provide extra services, primarily the Independent Living services which are
 - Peer counseling
 - Individual and systems advocacy
 - Independent Living Skills Training
 - Information and referral

IHSS agencies can do this directly or contract with a certified Independent Living Center. The problem is that the entity that can determine who is a qualified provider for all of these HCBS programs is the health department. People at PDPPC lamented that CDPHE did not understand or respect the Independent Living Philosophy. Candie is trying to work with the health department on appropriate standards for certification.

Authorized Representative Training Issue:

Last month we discussed the topic of training for Authorized Representatives (AR). The issue was if “successful” AR’s need additional training when they take on new clients. The issue was raised when a successful AR was told she must go through training before taking on a new client. Advocates raised this as a concern and said it was not necessary and burdensome on people who are volunteers just trying to help peers obtain needed services. Candie met with PPL about the concern. Candie said that the current policy is as follows:

Existing ARs who take on a new client have the choice to waive the training. Currently PPL will require a training if there are clear problems such as over-spending by more than 10% of the budget, extremely high employee turnover etc. Sometimes the case managers ask or require that the AR be retrained. This can be connected to them taking a new client and in general.

The grey area is when an AR appears to be doing OK but there may be a problem, for example the AR is overspending but under 10% or very high employee turnover.

Discussion:

- Jose said that the client and the AR would know best the situation and PPL should listen to them, for example there may be a good reason for high employee turnover that is not because of poor management.
- There was a lot of discussion about this issue—PPL was also cautioned to take employee complaints with a grain of salt especially when the employee was terminated.
- There was concern about the word successful –agreement to use different word but no alternative identified.
- There is a new component of the training focusing only on authorized representatives.

Conclusion: *ARs that are keeping the client at or under budget and the client is not presenting for preventable emergency care will not be required to do retraining. If there are other (grey area) concerns, the client and AR should be listened to and given great weight.* The group is OK with this policy if consistently implemented. This was a consensus and no vote was taken.

AR still must know the client for two years prior to becoming the AR. Julie mentioned that CCDC has provided temporary AR services for clients who are getting on the program so the client does not have to wait for training.

The group did ask PPL to report on the following:

- How many AR' in the system?
- How many clients in the system?
- How many AR have multiple clients?
- How many AR are family members to the client?

Health Insurance for Attendants:

We will spend the ENTIRE meeting in June discussing this issue. Several months ago HCPF was asked by this group to research this matter to see if the Affordable Care Act (Obamacare) would require PPL to provide insurance for our workers.

The bottom line is that the current model that Colorado has (called agency with choice) is covered under the Affordable Care Act. There is substantial cost to this. There are options including using the exchanges. There will be significant information to digest and serious decisions to make about how to take care of the attendants. We will need to look at what the exchange is offered and all of the different models available.

Part of this discussion involves the FMS rate and what services it buys. Perhaps some of the services being paid for now can be exchanged for health insurance. Because of the enormity of this topic NOTHING ELSE will be discussed in June. Any updates will be sent out in writing.

Follow up on support for family attendant when client dies: This issue came up last month. Members felt that family members who do care as a job should have a little time for grief because having to go get another job. . Gabrielle said that she checked and in situations where clients have died, the family member employees have been able to get unemployment insurance without a problem. Therefore this issue is closed.

IHSS IN THE COMMUNITY:

Candie provided a handout with a work plan looking at various scenarios and what time factor is involved for each. There is only a two-month difference between getting home care/personal care in the community for everyone and getting it for IHSS only.

- There was a significant discussion about this with the consensus being that we would rather get services for everyone in the community if the difference was only two months.
- Advocates felt that Sarah Roberts misled in January when she said at a different meeting that IHSS did not need to be part of the benefit collaborative process because HCPF can “just do it”. Advocates explained that this issue was tied up in betrayal over the whole process of the home health benefit standard. Julie Reiskin provided a brief overview of what occurred. Last fall Advocates let the home health benefit standard rule go through based on numerous promises of protections for agency clients and a

promise that home health in the community for everyone would be forthcoming. Julie said that this was very tied into advocates concerns because advocates pressured their communities to make an agreement based on protections that were promised and not forthcoming. Dawn and Jose explained that this led to decline of trust.

- Candie said a massive survey was put out and not back yet. Candie is going to do a separate survey for IHSS because there were only 2 pages relevant to IHSS inside the massive service.
- We had extensive discussion about an IHSS pilot and the conclusion was that there was not any real benefit to doing a pilot when we know the direction we want to go.
- We also agreed that even if personal care or IHSS agencies are currently doing services in the community no one will admit that.
- We also discussed the need to figure out how to address travel time. There is currently no available data on this nor is there a way to obtain it other than manually,. Candie said she will need to work closely with CDPHE to make sure that the agencies do not get cited if they are working in good faith on a new process. Agencies will need reasonable leeway on implementation. It was decided that this project should be the focus of a small group. *Based on the discussion Candie will recommend to her managers to proceed based on her timeline and work plan with the goal of all clients eligible for services in the community by March 2014. Candie will flesh out the work plan and report back and may form a small group if there are distinct policy issues that require discussion beyond what this committee can manage.*

CDASS EXPANSION INTO THE SUPPORTED LIVING SERVICES (SLS) WAIVER.

Barbara Ramsey from DDD was asked to explain what is happening with the expansion into the SLS program. The problem is that because the DD waivers are run differently it was originally thought that it would be simpler to just do personal care and homemaker to start and leave home health care out. However the amount spent on those services in the DD system is must lower because more of the HCBS services are spent on other things such as community participation, supported employment, etc. Based on the low utilization and the way we cover the FMS rate there is not enough to pay the fiscal agent so DDD wanted to ask the legislature for money. Linda Skaflen and Julie Reiskin and others feel strongly that this is a bad idea because it makes CDASS look more costly when that is not accurate.

They are currently renewing the SLS waiver and would not start on CDASS amendments until after that. There are many components and options. If they went back and included home health –which is complicated because it involves moving money between lines of two different agencies at this point,--that might not even be enough to help.

Bottom line is Barbara said there is no way for them to make this happen by July 2014. There needs to be public comment prior to waiver renewal.

Question: Why can we not have a separate contract with an FMS (PPL or other) for a lower rate since the level of service is likely to be different? It is likely that most SLS clients using CDASS will have family member ARs. There will not be a need for support brokers. There may be other things to lower the cost of FMS

Question: CDASS was in the SLS waiver in 2009 and the only reason it was taken out per John Barry was due to CMS requiring us to come up with a different way to pay the FMS? Now that this is fixed why cannot it just go back in?

Answer: Tyler says that because we changed the way we pay the FMS the whole process changed and we are starting from scratch.

Barbara said that in light of listening to the previous discussion of us being upset when commitments were broken that she would not want to commit to doing something without a complete understanding of all of the dynamics involved. She said that this is accompanied by frustration and disappointment of not doing what we want to do. Barbara said that we have poor outcomes when we push to get something done without implementing it with a full strategic approach. This includes really understanding all of the impacts of our actions across systems and in all areas of clients' lives. She said it was irresponsible to just push ahead and implement anything without this complete understanding and ability to address all impacts across the board.

Discussion:

- CDASS in SLS cannot be part of waiver simplification process because that is way too far out into the future and not definite.
- We cannot just put something in a waiver and not implement it, which happened before.
- We can build it into a waiver with a time frame for implementation even if it cannot be implemented at the beginning of the waiver term.
- Gabrielle said that PPL does this work in 24 states and PPL has many products. Gabrielle said that PPL is there to be a partner and would work with HCPF to figure out a way to make this work and would be happy to do a different contract for the SLS population.
- Several members said that if we are really starting from scratch then we should just do complete consumer direction, including all SLS services.
- *Conclusion: Candie will talk to Sarah and Bonnie to assure that everyone at HCPF is on the same page. She will then get in touch with us to setup smaller group to address further in June.*

Public Forum:

It was announced that as of July 01 rates will increase by 8.26%. Clients will get a letter from the state using the language from the CDASS noticing settlement agreement within a week followed by a letter from case managers about your new specific rate. The letters will also include information about the unit pricing (cent per unit) as explained by Randie Wilson several months ago. If there are concerns or the rates seem off people should contact their case managers first, then Candie if necessary.

Julie reminded people of the messaging this group agreed to which is to make sure that clients understand that the intent of this increase is to give our workers the raise, not to increase our hours. Our workers have gone years without raises.

The meeting adjourned a few minutes past 4:00 p.m.

Respectfully submitted

Julie Reiskin