August 28 2013 meeting of the Participant Directed Programs Policy Collaborative (PDPPC)

Executive Summary: There was a positive discussion about IHSS that included outreach, dealing with CDPHE, and making it clear that IHSS is more like CDASS with help than an agency with a little more freedom. CDASS goes into the BI waiver on January 1 and waiver amendments and rules are to be submitted in September. The new allocation determination process testing showed that we are not ready to proceed. The short term solution will be training for case management and a small group will be formed. There was a discussion about training of case managers in general and the effectiveness or lack thereof with HCPF developing training without end user involvement. There was discussion about a Department of Labor issue on a federal level and legislative issues regarding eviction of live in caregivers. The group agreed that attendants can vote if they meet all other criteria.

Co-chair Mary Colecchi opened the meeting at 1:05 p.m. Linda Skaflen was co-chairing in the absence of John Barry.

Present in the Room:

- Candie Dalton
- Roberta Aceves
- Linda Andre
- Kelly Tobin
- Kelly Hogan

- Gabrielle Steckman
- Tracy Branagan
- Linda Skaflen
- Douglas Howie
- Jose Torres-Vega
- Bonnie Silva
- Rhyann Lubitz
- April Boehm
- Dawn Russell
- Sean Bryan
- Louise Apodaca
- David Bolin
- Corrine Lindsey
- Barb Ramsey
- Josh Winkler
- Debbie Miller
- Elena Leonard
- Julie Farrar

On the Phone

- Ryan Zeiger
- Sarah Roberts
- Kelly Morrison
- Kathy Forbes
- Don Riester
- Martha Beavers
- Group from foothills gateway
- Mark Simon
- Kimberly Smith
- Stacia Haynes
- Julie Reiskin

Excused Sueann Hughes

Housekeeping:

1) Mary reminded everyone of the PDPPC agreements and reviewed them. Candie emailed documents to new group from Foothills so that they could see them.

2) Candie said that the documents were longer because there was a request for 14 point font double spaced.

- There was a recommendation that we put one on the website in larger print double space but also send documents regular so people do not have to waste so much paper if they print out the documents.
- Mary proposed only printing a couple copies in large print, and the rest copies in the format they originated in for meetings. Posting both versions on the PDPPDC website. Up for brief discussion during next month's
- Mary reminded people that we can provide accommodations but that they should be requested a week ahead

Minutes:

Linda Skaflen moved Jose seconded approval of minutes as presented and the motion passed unanimously.

Barbara Ramsey wanted to respond to the minutes-regarding the discussion about the motion to push a date for CDASS in SLS. Barbara said that "The CDASS option was removed from the SLS waiver because CMS would not approve the expenditure reductions needed to address the $40 million dollar over expenditure without removing the CDASS language from the waiver that reflected the model that was under correction by CMS." She also wanted to respond: wanted to be clear that her position is that we are not going to pursue CDASS in SLS waiver but that we are not doing it yet due to funding issues that will be explained in detail.

Voting Question:

Shall non family members who are paid as attendants get a vote at PDPPC? This arose because originally we only gave votes to clients/families, and agencies and said that attendants who were family members could get a vote. Julie Farrar and

Linda Andre both said that we have not given voice to the real workers, people who do this for living should have a vote, but they have to meet same criteria around attendance and participation. Like others they can also come and participate even if they cannot vote. We also said that if provider agencies can join, then workers should have that same ability.

Dawn clarified she is adapt member and IHSS client, and that is more of her identity than working for a provider.

We also affirmed that the purpose of PDPPC is to have many different points of view. Linda Andre said she supports attendants' right to vote but said that many are working at time of committee so they may need a different structure to be able to get access to vote. Louise raised the point that attendants have high turnover, what if they get fired or no longer working? Do they have a vote? There was a discussion and Linda S reminded us why there are rules of 3 meetings in a row to be able to vote. People agreed that this showed commitment so should qualify an attendant even if they are not working at the moment. The concern of an attendant talking negatively about a client/supervisor was mitigated as if someone did that at PDPPC they would likely never work again.

LINDA ANDRE MOVES EMPLOYEES HAVE A VOTE IF THEY MEET ALL REQUIREMENTS JOSE 2ND AND APPROVED BY UNANIMOUS VOTE.

Candie Report:

1) **Response to SLS recommendation**: We will have response by next meeting to recommendation on SLS and CES expansion, recommendation follows essence of minutes in terms of what we want.

2) CLAG and Communication: Jose-asked if we should have someone from DHS because of waiver simplification, Mary clarified that that and CLAG is future and PDPPC is right now. Discussion on this issue included mention that there is a lot going on in various committees, all of it is fluid and we should keep informed. Julie clarified that if any other committee or entity had proposal that affected CDASS and IHSS that they should come to us before moving forward and the answer is that YES that would be expected by HCPF.

Sarah said there are members of CLAG who are members of PDPPC who sit on CLAG. Mary said "this is a two way street if CLAG wants to hear from PDPPC they can contact her, and she will make sure it gets on the agenda. Just as Josh came to her put CFC on the PDPPC's agenda in October." Jose raised a concern about asking him to represent CLAG or PDPPC to each other as no individual has authority to represent a group/committee.

Josh said CLAG is set sunset 2014 and CFC is yet another group working on waivers—looking at many years out on those issues but there is work to be done right now on issues. CLAG is macro not details or specific policies while we are dealing with specific policy changes. Someone asked how we are communicating broadly and Candie said all recommendations and responses are posted on the website together.

There was discussion that it is important that communication is clear because when people think about CDASS they think about how it is today –how the whole system is today. They may not understand that most aspects in CDASS were set up for a specific reason. For example there is a reason training is mandatory and a self paced version is allowed. Not everyone will need to know specific details

about how our allocations are done, but may need to know the details of why certain rules or procedures are in place. Linda S asked that we be told what the final work of the CLAG consumer direction committee was and to understand why that committee was disbanded.

3) ALLOCATION SURVEY

Candie reported that 12 surveys came in. There were separate surveys for clients and case managers and there may have been some duplicates. Of those that came in 5 caused an increase, 6 caused a decrease, 1 stayed the same. Changes in allocation spanned from $50-$600 difference. All of the reviews were CSRs none were new clients. Because of this we need to step back and cannot move forward with this new way of allocation determination at this time. Candie asked the case managers and clients to give feedback on service planning guide. It was positive, but the problem is that they were looking for tool to list every single need that could come up. Candie said that she heard that there are things about current process that are not working so wanted to look at a short term approach for making things better while we step back and rethink a long term strategy. She suggests providing guidance to case managers. She also felt a need to expand service guide and provide more feedback especially for people who have never used these services. She also said she could guidance on tasks and norms. She wanted reactions and input:

Mary mentioned they could start using the new process on the Brain Injury waiver since that would be a new population and would be small so they could start and get useful data. Candie said no that until the new process and tools were validated she could not use them widely.

Julie wanted to dive down to find out what happened –where the current allocations "right" or did the new process get the right answers re allocation? She said that we should do training, have reasonable guidelines, get rid of urban legends that tell case managers if one does not spend to the penny they should get cut, clarify again that "norms: are simply guidelines not rigid rules, etc.

There was discussion that there should be a small group to help Candie create training for case managers that includes strong guidance. Candie wants this to be rolled out before January 1, 2014 so the training can be done for case managers enrolling BI clients. Candie wants some help, small group to hammer out details. Linda Andre asked how much training had been done as we have been hearing for years that HCPF is going to do this training with case management. Candie said none since she had been there. Linda said that she and Julie had done a lot of work preparing case manager training in the past and that was wasted.

4**) Training:** There was then a discussion about training in general. Sarah said that the Department is working on training for case managers. ***The Department is working with case managers and state staff without end user involvement at this time.*** The purpose of the training is to teach case managers' better person centered interviewing skills. Linda S suggested that the state could save time by involving end users, because it is likely that without the perspective of the people who are subject of the interviews, the state would miss essential elements and would likely have to redo the whole thing once it did go public. ***It was stated that HCPF wanted to put something together first so there would be something to which people could react. The anger in the room was palpable but not much was said.***

Barbara said that at DDD the entire staff is getting training. This includes people that do not always work with the public such as data analysts so that they can have a complete cultural shift. They are using the using the Michael Smull person centered planning program. Several CCBs are training their staff. This program is a national program with evaluations demonstrating its success, not something made up by staff.

There was more discussion about training. Candie said that HCPF did reach out to Robin Bolduc and received the training worked on by Robin and Denver Fox. Julie mentioned that this was provided to Lorez as well. Tiffani is in charge of training and will be asked to attend our meeting next month and talk in more detail about training for case managers. Candie will send out a doodle poll to everyone on the list so that people who want to participate in the small group working on training can do so.

Rhyann commented that trainings in person are so much better than web based trainings because people are not multi tasking.

5) **Per Day Rate Change Issues:** Debbie Miller said that her PPL portal record shows that Brian is overspent. This is not accurate and the error had to do with the changes made when they input the changes to enter the increases provided by the JBC. Debbie wanted it on record that Brian did not overspend and wanted to be assured that there would not be any negative repercussions against him. Candie said that she is aware of this situation and there are a few people whose budgets appeared to be overspent retroactively and she assured everyone that this is not to be treated as overspending because this is a systems issue related to

the increase. People with these problems should not be receiving letters nor having anything on their records.

Debbie also asked about getting cuts due to the changes. Rhyann said that this is easier to understand if you look at this as a daily rate and Debbie said no one gave her a per day rate. Debbie said she had this problem with all of the people that she supports as an AR also. There was supposed to be a way to give clients this information discussed in a recent meeting. April said that this was not a PPL issue; this overall HCPF system issue created by the way formulas is based in all systems. Therefore, PPL cannot fix it as the fix must come from HCPF.

6) BI Waiver: CDASS will be available in the BI waiver January 01, 2014. People will see a rule change at the next September 13 MSB meeting allowing this to occur. The waiver will be submitted end of September. An email with all of these will be come out this week. The email will ask for public comment.

7) Rule Change: The rules for the pilot program were never repealed and she is repealing them in September. People should know that this is not repeal of CDASS.

8) FMS Meeting: There was the first stakeholder meeting on the FMS last week and there will be another meeting the week of the 16th and another email will go out next week with the date. At the last meeting there was recommendation by Julie Reiskin to do an RFI. There was a draft that Julie commented on and they plan to get that out nationally in the next couple weeks. This will help us frame questions and information for the next meeting. Candie let CMS know and is working with the national center for participant directed services. She said it was a good first meeting and there will be more details in the next meeting. Kathy

Forbes asked that this go out snail mail because there are people who still rely on it. Mary apologized and Candie said that things got hectic and they were not able to get PDPPC info out before this meeting.

IHSS updates:

Several months ago we started putting IHSS on agenda to take PDPPC as a true consumer directed meeting, and talk about both programs. There was a string of emails a few weeks ago to ask that IHSS get as much attention as CDASS. Candie said we have some representation on committee from IHSS but we need to expand representation. We need to see more clients and family members. It has been great having David, Dawn and Ryan. Ryan said that CLASP represents 7 of the 21 agencies. We need more consumers and attendants. PASCO is getting ready to send out newsletter and offered to advertise. Candie says she always lets clients and family members know of this meeting. David Bolin said he would work on this and ask the Independence Center to send clients and employees. Candie said that even if people listen in and provide feedback. David said some were listening but stopped because there was not IHSS involvement, the CLASP agencies will do outreach to let them know this will be a bigger focus. Rhyann suggested we alternate and have IHSS first every other month. Candie is getting more calls about IHSS and David said that agencies are starting to see that consumer direction IS the way of the future. To be a successful IHSS agency you have to believe in people with disabilities and although many agencies are interested there are not a lot of new agencies. Candie asked how to overcome that and David said that part of this is the IHSS training for case managers. Candie said she will do outreach to find out why they drop out since there is a lot of interest but not follow through. David said that Department of Public Health is a

huge problem because they are requiring the agency to supervise workers, but the law says that the client is supposed to be the supervisor. David said it is OK to do spot checks to make sure that people get service, but that the client is supposed to be in charge. This was supposed to be CDASS with agency support, not the other way around. For example someone may only need help with firing.

Stacia asked if IHSS was when someone was on CDASS and was able to get short term home health from an agency. Candie said no that it was more like in between agency care with agency control and CDASS. The client can hire, set the schedule, who does the work, but the agency does oversight, backup and sets the wage. IHSS does not require you having a stable health condition because of the extra support from the agency. Stacia said her daughter needs weekly blood draws and cannot sit in her chair right now, she has had a nurse coming from Medicare but that is running out and they say she has to get Medicaid to cover. Stacia says that every agency she spoke to had never heard of CDASS. Candie said that she can talk off line. Someone in CDASS who needs acute home health through an agency can get it short term for this kind of issue. Candie will call Stacia after the meeting to get this handed.

Dawn said that IHSS provides independent living skills training and other IL services (peer counseling, information and referral, advocacy, etc).

Linda Skaflen asked when the DORA stuff would be out. Candie said that IHSS is subject to sunset and DORA does a review, the draft is due in October and the final will be later. There was comment that stakeholders should get copies of the draft. Candie thinks that the report should drive a lot of the work for IHSS as this will create legislative priorities. The things that Vivienne has shared are the same

things that came up in this group. David said one of the problems is Public Health and Environment focusing on safety in a way that is inappropriate to our lives. Candie did meet with CDPHE a few months ago to have this discussion. The problem is that while the statutes waives parts of Nurse Practice Act , the licensure was not as specific as needed. Licensing was not around in those days. They are willing to listen and Dawn said that is why they need to be where we are. Candie said that there is some limited nurse oversight in IHSS and she and Vivienne talked about how to get CDPHE on board with the philosophy. Julie Farrar said that the new acting director of CPDHE was awesome. He is much better and wants to learn and understands that they work for us. This is another pretty good example of where we need to train people from the onset. Anyone who touches a piece of paper that has anything to do with the person who is served should be trained in these principles.

We should pull out the PowerPoint document on differences and similarities between IHSS and CDASS and we should all use this to share this info in everywhere.

IHSS is only in the EBD, SCI, and CHCBS waivers. We need a statute change to make this different. We asked for statute change last time and got nowhere. Originally it was only EBD and CHCBS –SCI got on because it was modeled after EBD. People look at IHSS as more open home health not as consumer direction with support. Josh said that having IHSS talked about here not in home health meetings would help shift the mindset. The lack of CDPHE is a big difference between CDASS and IHSS. It could work for many more people and could be a part of CFC. Consumer direction is the trend and will be what makes CDASS work. It is really important to emphasize that IHSS is CDASS with help. Candie

wondered if having someone from CDPHE coming here on occasion might help them understand the consumer directed model. Agencies sometimes have to explain the model to surveyors. Bonnie said that we need to have specific asks in mind before we bring them in. We know it is not working so we should have a specific ask –maybe in small group—before we continue go further down the road with something that does not work. We are a small part of their world. Mary said if we bring them we should push IHSS at beginning of meeting. Josh asked if we need to wait for sunset before addressing issues like the spouse being paid. It has been a year now that we have been pushing about the in home restriction and we were promised that IHSS would be dealt with. There was a survey on home health, nothing has even moved on IHSS even though that would be an easier fix. Why would we need to delay any work. Candie said that that she brought a work plan for IHSS and the tasks several months ago based on what is in statute now. Some things we can work on and other things where there is either no permission in statute or rule or conflicting rules. Candie said that she could come next month prepared with a list of which items we could work on and which we could not. It will be outlined which items required statutory change, rule change, budget item, etc. Josh asked for citations of rule, statutes, etc. when we get this info. We can start going through what we can do now, make recommendations, etc. using the same process we did with CDASS. It is expected that the DORA report will be helpful in terms of recommendations for the legislature. If CDPHE asks for more regulations we will be the right group to respond to this to explain why they are wrong. Candie said that Vivienne appears very committed to IHSS and understands consumer direction. Bonnie said that she has had discussions with CDPHE and they are willing to help us figure out a

licensing process that fits with our program goals. David said it worked OK when they had one surveyor that did all IHSS because she learned the program. She left and it has not been working well since that time. Someone said that CDPHE is really trying to improve. Mary asked if John Barry would send us the link when the sunset report comes out. Candie said yes.

Public Forum:

1) Douglas Howie heard about something recently and was not sure if it fell in this purview. He said someone hired a live in caregiver. The person was fired. The state law allows the person who is a live in caregiver to stay there for three days. The law protects the caregiver more than the client. This is an employment law and housing law. You can fire someone anytime, but you cannot make someone leave. Mark Simon said that he and Julie were working on this legislatively. Labor law says if housing is provided as part of your employment that upon termination of employment you have to be given 3 days to vacate. When you read the statute you can tell it was intended for staff at a nursing home, people in a supervised setting, not in the clients own home, even though the way it is written it would apply to a live in attendant. We are asking legislature to change statute to eliminate three day rule if attendant is living in employers home providing services to employer/client or if there are indications of harm to client. If legislature said we cannot just throw them out that we might have to have the client pay for a hotel for a few days. Josh said as this moves forward we need to have a voice as this is a powerful group. This is a unique group because it is not appointed members; rules and membership were created by this group. Josh is not sure what process would be to have this group testify and would move this to the next level. Linda S. just had a staff person walk someone through an eviction

having nothing to do with paid attendant. No protection for the PWD and there is squatters law that we may want to work with because they may be able to be to use squatters law. Mark said issue that would arise would be if they were a tenant or employee. Julie Farrar asked if this could be dealt with through abusive caregiver reporting because this is fresh in mind of legislature. Julie said this is a double edged sword because once you identify yourself as vulnerable your ability to self direct is questioned. Jose asked if we have people in CDASS as live in attendants. The answer is yes. Bonnie said that she thought recommendations on housing or labor laws would be outside the group but a group could use this as a springboard.

2) Josh reported that there is a department of labor regulation that is pending to undo the companionship exemption that allows people to work more than 40 hours. While people should be paid overtime if Medicaid is not going to reimburse for that it causes a huge problem. The department of labor did not like what they were hearing from disability groups so they stopped inviting them. NCIL and ADAPT wanted to keep exemption. Regulations should be released around Labor Day and there is a lot of information out there. It could affect us if overtime is required for all employees. If you are limited in who is providing services you could run into a situation where allotment is not going to last. This is a federal process. The controversy is that there is no fundamental problem with paying people time and a half, but there is not enough money in an allocation. This is a bigger problem for consumer direction as some people in remote areas may only have one attendant or not enough to promise 40 hours. The latest petition is to just stop it for consumer direction. The website is www.doloffmybody.com the website was meant to be controversial. The point

is that this takes away the right to decide who touches my body. This can also lower overall pay for attendants. People will have to cut hours or lower the base wage.

Julie Farrar said that we should try to keep dialogue going because the two groups (workers and clients) should be together about this issue.

3) Mary was applauded for running a great meeting.

The meeting adjourned at 4:00 p.m.

Respectfully submitted

Julie Reiskin