

# **Participant-Directed Programs Policy Collaborative (PDPPC)**

**December 16, 2015**

## **For approval at the January 2016 PDPPC Meeting**

**Executive Summary:** We discussed the implementation of the Fair Labor Standards Act (FLSA) and our decision to move to Fiscal Employer Agent (FEA) only, eliminating the Agency with Choice (AwC) model. We discussed the issue when one person is directing services for more than one client and they share attendants they will be considered a joint employer and the attendant cannot do more than 40 hours between them. This is true even if each client has their own employer identification number. We discussed if HCPF should put protections in place to prevent overtime from being accrued—for example by prohibiting more than one Authorized Representative (AR) per client. We did not make any specific recommendations. We discussed the IHSS data report briefly. People were reminded that they can choose any FMS agency until March 15<sup>th</sup> and that all paperwork to move from AwC to FEA must be done by March 15. We heard an eloquent presentation from Debbie Miller about how hard family caregivers work, a reminder that we should not make assumptions about the lives of others.

**Introductions and attendance:** Everyone introduced themselves with the following being present:

### **Present by phone:**

Jeff Epp, Margaret Proctor, Kelli Tobin, Kelly Morrison, Liz Wuest, Stephanie Holsinger, Heather Jones, Dyann Walt, Julie Morlan, Renee Farmer, Kathy Estes, Julie Reiskin, Julie Miller, Cathey Forbes, Kevin Smith, Curt Wolff, Lucas O'Connell, Cheryl Vennerstrom, Craig Morrison, Diane Alvaressi, Tim Moran, Kelly Brown, Christy Michael, Sandy Kasprzack, Gabrielle Steckman, Tiffani Rathbun, Mark Simon, Brent Salner, Connor McCloud, Maria Rodriguez, Caitlin Brady, Ann Dyer, Julie Farrar, Leslie Taylor, Christina Johnson.

### Present in the room:

Keith Copen, Jennifer Martinez, Linda Skaflen, Kirk Miller, Grace Herbison, Bonnie Rouse, Rhyann Lubitz, David Bolin, Roberta Aceves, Katie McGuire, Alisha Singleton, Jason Smith, Kari Vinopal, Linda Medina, Kathi Sargent, Debbie Miller, Rebecca Sturdevant, Gerrie Frohne

Excused Sueann Hughes

Linda Skaflen reviewed the attendance record and voting rights

### October and November Minutes:

October 28 draft minutes: Linda Medina was going to send notes to Rhyann to add and she was unable to do that, she will send and Rhyann will see if there are omissions. There were no other changes. After discussion it was decided **that Linda will send her notes to Rhyann who will determine if the minutes need to be amended. If so they will be sent out and in any event we will vote next month.**

November minutes: ***Kirk Miller moves and Stephanie seconds approval of the minutes. There were no corrections. The motion carried unanimously.***

John reminded the group that Julie Reiskin is not going to be present in January. **Linda Medina will do the minutes in January.**

### Housekeeping Items:

#### Scheduling November and December 2016:

November: John said that we have always done our meetings on the 3<sup>rd</sup> Wednesday in November to avoid meeting the day before Thanksgiving. John asked if we can agree now that is what we will do so he can assure confirmation of the room. In 2016 the date will be 11/16/16. The group agreed.

December: In December the 4<sup>th</sup> Wednesday is between Christmas and New Year or 12/28. The third Wednesday is the 21<sup>st</sup>, which is a few days before Christmas. John asked which date we wanted for our December meeting.

Several people said the 28<sup>th</sup> was good and no one objected. Since this would be our regular meeting time we will keep the meeting on the 28<sup>th</sup>.

John stated he has verified with stakeholders by email and at PDPPC meetings that the meeting calendar for 2016 does not include any meetings that fall on known religious holidays.

***Linda S. moved and Kirk M. seconded that we change the November meeting from the 4<sup>th</sup> to the 3<sup>d</sup> Wednesday in 2016. All of the other meetings in 2016 will be the fourth Wednesday. Motion carried unanimously.***

**Nut Free Zone:** Rhyann reminded the group to not bring nuts to the meeting. This is a reasonable accommodation for someone that has severe air born allergies to all nuts. This includes food with nuts like festive breads with walnuts on them or peanut butter cookies. Maria also mentioned some people are allergic to perfumes or strong smells.

#### **PDPPC Recommendation:**

Rhyann received the recommendation regarding the dual signature issue and forwarded it to the Department Legal and Program Integrity sections in the department. This was the recommendation passed in April that requested that HCPF get us a specific legal or regulatory citation stating that two signatures is a state or federal law or regulation (as opposed to what HCPF legal thinks is best practice). Rhyann is not going to be able to get a response by the 20<sup>th</sup> of the month because she is waiting on other entities. She hopes to have a response by next meeting. Curt explained the recommendation and that this was a follow up to ask if there was a specific regulation that required the two signatures. This was passed in April. Providing the formal recommendation fell through the cracks during our PDPPC leadership transition.

#### **FLSA Discussion:**

There were handouts sent out ahead of time and available on the website. These handouts were relevant to the discussion.

1) Frequently asked questions document was mailed to all CDASS clients this week so clients should get it soon. It is also on Consumer Direct (CD) website. Linda S. asked how many people using AwC are really uncomfortable with the switch and has everyone on AwC been reached? The answer from Consumer Direct is that there have been some questions about the FEA model but most people are not uncomfortable. They cannot say for sure that all 2700 AwC clients are 100% on board with the change. CD has been doing informational sessions and will continue to do these sessions. Each FMS has been doing outreach. Kari from CD said that CD has been doing info phone sessions and sending email blasts to everyone for whom they have email addresses over the past two weeks. The sessions are at various times. They have reached 100-200 people through these sessions to date. The staff at CD goes through a script which is based off of the HCPF letter and FAQ. They are collecting common questions and will be enhancing the FAQ. One of most common questions is "do my attendants have to fill out new paperwork?" (BTW the answer is yes if the client is in AwC). CD is also explaining open enrollment and exempt relationships re family members in these sessions and through their materials. Some people calling into the information sessions have had specific questions about their personal cases. CD has asked them to call back so personalized information can be provided to those people individually and privately. CD continues to reassure everyone that the FMS continues to do all tax filing under FEA. They explain what it means to get an FEIN number in the FEA model. There is also a handout about FEA that was put together by national resource center for participant directed services (National Center). There will be another info sheet coming later that will be more extensive and will reference certain parts of the contract with the FMS vendors. This cannot be finalized until the contract amendments are finalized so the numbers and lettering about what is covered and where it is in the contract is correct. This will not be the last document about FEA.

## Questions:

Leslie Taylor asked about the contract. She said she has been having a series of conversations on escalating level with the United States Dept. of Labor and they have been talking to the US Attorney's office. She said that this has to do with the 97 page document. The federal register was clear that you have to have an employer and employee agreement. This superseded a 1940s law regarding elder care. There were employment agreements between agencies and caregivers—now the agreements are between us and our caregivers and us and the FMS agencies. Leslie is concerned about PPL Colorado employment packet because it says "thank you for providing services to a client of the consumer directed program". Leslie said that a client that is receiving entitlements should be looked at differently than a wealthy person who is hiring a nanny. She said our workers cannot be considered independent contractors. Leslie said that we have never in lifetime of this program individually executed an employment agreement. She said that this agreement says what the employee is supposed to do. She said "I did not write this contract so I am not obligated to do anything with it".

Rhyann said that the info is coming from the National Center and they are the national experts on all of the various rules related to hiring personal care providers under consumer direction models. Rhyann said that they are highly credible. She also pointed out that the FEA model is up and running in other states with full CMS approval. In fact FEA is the model most frequently used in other consumer direction states. Rhyann agreed it should be clear in the employee packets who is and who is not the employer and employee. Linda S. said that given that many states doing this (FEA) have been doing so for years, that if there was an issue it would have been caught well before Colorado started down this road.

Leslie said that everyone said they were relying on the national center for participant direction and she does not think there is documentation that trickles down to the agencies. Leslie felt this is some sort of loophole

because Leslie feels there is a law that prevents clients from being employers. Leslie asked if the National Center talked to the US Department of Labor. Several people responded that they thought the National Center had indeed contacted the Department of Labor but had no specific information at this meeting

Rhyann pointed out that the medical services board, attorney general office and department of labor have approved FEA for Colorado/multiple states. Leslie said that there are people at Dept. of Labor that are talking to Leslie who say no one talking to them. Leslie says all this does is turn back the clock to 2014. She said there are conflicts with workers compensation and health insurance that are provided by the same agency that this nullifies the employer relationships. She says if we are doing recruitment, hiring, training, supervision and submission of taxes we should get the allocation directly. We could then execute our own employment agreement. Since HCPF and Leslie are getting different information Rhyann said she would call the person at Labor who Leslie spoke with to clarify and make sure the information was accurate. The person Rhyann will call is Aleta Thomas at 303- 318-8151.

Mark Simon said the guidance from the National Center is pretty good. He said that it represents our specific situation about the IRS requirements in their guidance manual. Mark wanted to know if HCPF can ask them to provide the specific IRS regulations that they used for the manual. Mark said we should send the issues Leslie raises to the National Center and get the guidance in writing so we know we are on the same page. He said this is better than a conversation that someone may later deny. He said that we need the backup documentation that the National Center relies upon so we can see it. This would accompany their guidance. Mark said the question is "does either the IRS or United States Department of Labor have a problem with the FEA model?" Then we should outline specific concerns and ask them to answer each one. Rhyann asked for Leslie to email the questions and concerns and she will forward to the National Center. Leslie said she would email Rhyann a list of specific concerns.

Rhyann said while she will ask these questions we need to move forward now. After this group voted to move to the FEA only model, the Medical Services Board has voted to eliminate the AwC last week as an emergency rule. Because of this the rule is deemed passed and in effect now. Rhyann said that the priority now would be to make sure clients understand the FEA model and wanted to make sure it was clear who was holding FEIN number and how it works. In rule either the client or the AR must hold the FEIN. There are some specific situations we must address.

- a) If a client manages their own care and then also acts as an AR for other clients, then any shared attendant hours totaling more than 40 hours a week or 12 hours per day between them will require overtime payment.
- b) If there is an AR that manages care for several clients and they share attendants the same situation applies.

Rhyann—we must move forward with this, it has been accepted by Medical Services Board and we need to make sure we are informing people so they pay proper amounts and protect allocations from costs that are outside of anyone's control. She also wanted to know if we should limit the role of an AR to one client or prohibit sharing attendants. Another VERY important piece of information is that the National Center said that overtime liability is the same regardless of who holds the FEIN. They will look at liability based on who is controlling the worker. The Department of Labor cares more about who is directing the care. This is more important than who holds the FEIN. If there are two clients, and each holds their own FEIN and they share an attendant, and one client is really controlling the worker (AR) for both clients, overtime and travel time will still apply. Same if there is an AR acting for two clients, even if the client has their own FEIN. If the AR is managing the schedule and hours they have overtime and travel time liability. Rhyann said other states do it a bunch of different ways. Some have the client hold the FEIN all the time. We need to decide what to do.

Curt: He talked to people in PA and learned that some states require client to carry their own FEIN number. We should make sure clients can have FEIN number if they want to because some AR may not be willing to have the responsibility of an FEIN number in their own name. The National Center says DOL is not likely to look at who holds the EIN

Someone asked how workers compensation works in other states? This also varies, in WI they do not require workers comp.

It was mentioned that we also do not have limits about how many people someone can be an AR for at a time. Rhyann wanted to know if people thought we should impose some sort of limit.

Linda S. asked if there was confusion—she asked if it was within the definition of an AR to make them responsible under the Dept. of Labor as employer. Bonnie said Dept. of Labor does not go by who holds the FEIN but who is carrying out the employer responsibilities.

Mark said that we have variety of ARs. AR that does broad spectrum of work that has to be done. Some do pushing paper, timesheets, etc. and others do everything. If AR is only doing the paperwork and client is really doing the work then who is really responsible? Bonnie clarified that if someone is on program and requires an AR (because their doctor said they were not competent to direct their care) then the AR must do all tasks. If someone is able to direct their care but elects an AR, then the client can then perform some tasks including supervision of the workers and scheduling. Also, if there is an AR in the program, this means that the AR went to training and signed off that he or she understands he or she is responsible for managing all of the care.

We are not sure that DOL will give specific case by case responses or responses at all. We need to make decisions based on what we know now. If people share attendants and an AR how do we ensure travel and overtime costs are not incurred or are incurred within the control of each

client/AR. That is what Rhyann needs guidance on now. Specific suggestions included

- 1) Leslie --We can decide who will hold FEIN numbers but there will have to be a hearing through department of Labor if someone does not get overtime they feel they deserve. Leslie said that overtime monies could come from redlining some areas that are not necessary. (Rhyann clarified that we cannot work off of budgets from other areas of Medicaid even if we think they are available or not worth the money. We cannot spend any more money than we have so all suggestions should not involve spending more money in CDASS).
- 2) Julie F. said we should be having meetings with the right experts. We need more training for authorized reps and this will be more important as we move CDASS into I/DD waivers. She also suggested that FMS agencies should not combine paychecks for attendants. If an attendant works for more than one client they should get one check per client. This way the worker knows what they are being paid for. If it is one big check they often don't know what they are getting from whom. Someone said that taking FMS out of the role of being the joint employer should resolve this as the FMS is really the payroll agent for each client. Under FEA the FMS would process the check for each client so it would not make sense for the FMS to give the attendants that work for more than one client only one check.
- 3) Julie R. suggested come up with a process to allow AR to be paid attendant only for family members with specific safeguards in place. Grace thought CMS might not allow it (she later sent the specific guidance and while we would need to be careful it is not specifically prohibited)
- 4) Identify all ARs who were just ARs due to lack of training for clients (mostly in rural areas from before we had specific training vendor) and get those clients trained.  
Someone said we should look at all options and do pros and cons.

Someone asked how many people we are talking about. Here are the numbers:

A) 31 clients are AR for someone else. Of these 31 only 6 share attendants.

B) 106 ARs manage more than one client. 61 of these have shared attendants between the clients they manage.

These numbers are from PPL but there are very few from Access\$ and Morningstar.

Bottom line is this affects about 70 people out of the more than 3300 clients but this is still a concern for those individuals.

5) Are some people who have AR more appropriate for IHSS?

Response was probably yes but IHSS is not available for everyone.

They have to find agency willing to take them. Because of lack of budget authority some attendants would not be willing to switch over if there was a cut in pay. Also, agencies can decide yes or no in terms of taking a client and there is not IHSS statewide.

Question: What are pros and cons of limiting AR to one client?

There was a question—can overtime come out of client allocation?

Answer is YES if it is under control of your allocation –so a client can choose to pay an attendant more than 40 hours and pay the overtime. However an AR cannot decide to direct an attendant to work more than 40 hours for 2 clients combined because the AR cannot decide that one client has to cover the overtime.

Keith: We need to remember that ARs are volunteers and we should not be putting more responsibilities and liabilities on them. Doing so will create a problem. If we limit AR to one client this is a problem, he said in training they are seeing more cases of two aging parents that both need LTSS. In these cases often one adult child is AR for both. He said with increase in elders needing care he expects to see even more of this and families are already stretched so finding a

second AR for the 2<sup>nd</sup> parent could be a huge burden and barrier to care.

Someone reminded the group that there are exemptions from overtime and travel time for live in caregivers.

Leslie said the FMS should handle this because they are paid. She again said that we should channel money from ineffective programs to pay for ARs and to pay the FMS more to handle this. She said that there should be an AR pool out of the FMS and the FMS could get this done and could provide for breakdown of which caregiver did what for which person. Rhyann said that we need to keep in mind that we take on responsibility to manage our care when we join CDASS and Julie said she thinks we do not want the FMS to manage our care.

- 6) We could have consumer direct provide training to this group of ARs that have more than one client geared specifically towards managing overtime and travel time.

Rhyann asked "How do we protect people from being liable from overtime" Some states do not and just say "not our problem" and if someone is assessed overtime and they go through their allocation too bad OR the client can be held liable for it if there is not enough money. This is why she wants to make sure people really understand the rules.

- 7) Someone asked if there a way to use the backup attendant if someone's caregiver is close to 40 hours a week? Answer—this can be suggested but not required. Backup may not be available when the client needs help. Backup might not be the right person to do specific tasks, etc.
- 8) Can attendant say they do not want to be paid overtime? Answer NO! There are some exceptions like for live in caregivers but you have to meet specific criteria.
- 9) Put in yearly plan how overtime is allocated and used.

- 10) Reinstatement FAS (fund for additional services) and allow this to be used for overtime and travel.

All are encouraged to Email or call Rhyann if there are any further thoughts: We can try to put rules in place to protect people from being able to incur overtime liability or we could operate like Kansas and just have a hands off approach—if we do this a client could incur liability if they work someone more than the 40 hours or if there is AR who does not manage a shared attendant situation.

### **Open Enrollment:**

Bonnie asked if we want to have each FMS present to us and tell us about them and tell us why they should be selected since we are now able to select new FMS agencies. Linda A. said that we should get their materials together and send this to the group ahead of time and let people know who will be presenting and ask people to review the material before the meeting.

The time limit is that by March 15 all paperwork needs to be done so the case manager can send paperwork to Xerox. This is to assure that everyone will be FEA by April 01. During this whole time people can change to another FMS if they want to.

### **Tracking sheet**

Rhyann said that Mark Simon had suggested a tracking sheet to keep track of recommendations given to the department and to make sure they do not get dropped. Rhyann agrees. She felt that this should be managed by a member of the group not the department. Historically this has been managed by the co-chairs. It was raised that once it is submitted to department- the chair would not know the status of the recommendation, that it would be the department who has this information. We decided it should be a joint responsibility between the department and Co-Chairs. The Department maintains formal written recommendations from the PDPPC on the PDPPC Department webpage. This lists the recommendations made and the Departments response to the recommendations. Then the co-chair

will maintain a list on behalf of PDPPC also. Even if group makes recommendation and we do get a negative response we should still decide if we want to revisit and set a date. This will be used to hold all of us accountable.

**IHSS Subcommittee:** At the last meeting Department staff came from budget and talked to the group about the origin of the IHSS expansion financial predictions. After the meeting there was opportunity for more questions and there was only one more question received by the Department. Budget did respond and the answer was sent to John just today. That response will be sent out in the next 24 hours. Further questions about the data should be sent to Rhyann.

Grace announced that she was leaving the department. She will be missed. Several people commented on how great it was to work with her. Grace has held the fort down during the time when we did not have CDASS director in between Candie and Rhyann. She has done a great job with IHSS and managing the CFC work as well. Rhyann will be interim staff for IHSS until she can get someone hired.

### **Audit Recommendations and Responses:**

These were provided to the group last month: If there are questions get them to Rhyann.

Gerrie asked what is the implementation and next steps. What happens? Rhyann said that once they implement the recommendations or explain what they learned then the audit is completed. There are 11 specific items they were to look at. Four are completed and the rest in process.

Other questions: Who in the legislative audit committee do we report to?  
Answer: Reports go through leadership to the Legislative Audit Staff who provides information to the committee.

Is there a deadline and when? Next deadline is this month which is contract review. The next deadline after this is in January regarding review of the Attendant Support Management Plan and assessing whether hours need to match with the plan and assessment. HCPF said they would look at this issue but did not agree to any specific change as they cannot agree to something that violates any state or federal laws and needed time to assess. Rhyann has a spreadsheet with all recommendations and work happening on them that leadership can access. Rhyann said it is expected that she will implement the recommendations on the timeline outlined in the HCPF response. She said at some point in 2016 leadership may be able to report to the committee. Rhyann also sent the audit to National Center and asked for their input.

Linda S. There was a report/response from the disability community about inaccuracies of the audit. This report was sent to HCPF and Linda wanted to know if it was also sent to the National Center. Linda said if they just see audit they may be looking at inappropriate recommendations. Rhyann said she has not sent the community response but will do so. Rhyann also requested data from FMS vendors about pay rates and hours. Rhyann also asked the National Center to look at ASMP. She wanted to know if the department was overstepping in any way.

Julie R. shared that she found correspondence from CMS that was clear that hours and times and services do not have to match between what is allocated and what we do---so if someone is allocated 10 hours of homemaker and 10 hours of health maintenance a week but used 15 hours of personal care at a higher rate that this is perfectly fine by CMS. Julie suggested that Rhyann send that letter to CMS (and she had already shared the letter with HCPF).

Leslie asked if there is a way for us to track the audit responses on the website. It is on the PDPPC page and Rhyann will make sure it is updated as there are changes but she can only put on the website what is cleared so it will not always be 100% timely.

## Open Forum

Maria Rodriguez wanted to know what happens to the funds that are not used that used to go to FAS. If the money goes back to the state, where does it go? Is there any documentation? Answer: The money is never spent, so it is not anywhere to be sent back. When a case manager does an authorization it is authorization to bill—like a purchase order. The FMS pays the payroll then bills the state. Anything that was not used is not billed to anyone because it was never spent. The whole Medicaid budget is huge. A budget is a projection and a lot of the money is billed. It is not like the money is sitting there waiting to be spent and then there is extra money at the end of the year. Some lines may spend less than projected and other line items may cost more. In any case, it is not like money is sitting in a pot waiting to be spent and then returned somewhere if anything is left over. There are no funds sitting anywhere, they are spent as services are provided. The budget is solely an estimate.

Debbie Miller: She said that last month something was said at the meeting that was highly offensive to her and others. She had been upset about it all month. She was offended when a comment was made about “family members getting high wages to sit around and watch TV” and insinuating that family member caregivers are overpaid or somehow cheating the system. Debbie reminded the group that this was the second time this issue came up—the first time it was said by a case manager and Debbie and other families were “shushed” and not allowed to fully explain how inappropriate that comment was. Debbie said that those comments were hurtful and damaging. She said she needed to address what was wrong with the comments so this does not happen again. Debbie said that before she was drafted into being a caregiver she never made less than \$30 an hour in her job and often made as much as \$40 or \$50 an hour. She was a blackjack dealer and loved her job. She usually worked 4 days a week and had ample breaks during her day. When her son was hurt she tried to keep her job. First they wanted to put her son in a nursing home—the place he was at—supposedly rehab—was killing him. She could not let that happen so

she brought him home and tried to continue working. Every time she got to work she would have to come home. Often she would not get to work because the home health agencies would not send people even though they were scheduled. She had to quit her job and lived on almost nothing for years trying to make this work. Even when she was a parent C.N.A. she could not make ends meet. She fought hard to get this program through. She went to the capitol and spoke to numerous people in the legislature, CMS and HCPF. She even put spreadsheets together showing how families were being ripped off and shared horror stories of various dangerous or inappropriate behaviors by agencies. She and her son got on CDASS and finally things were OK—they had adequate services and could get by. Then they were hit with the 5% reduction. The reason the money is so important is that in addition to having to support her and Brian, she pays for all of Brian's extra supports out of her salary. This includes supplements, alternative medicine such as acupuncture that really helps a wheelchair accessible van, etc. He had to quit some of these therapies after the 5% reduction and he went downhill—it was really hard to watch him lose gains that he had made. She went into \$30,000 worth of debt trying to keep him healthy. When the tax rules changes and the family caregivers got the tax returns she paid off the debt. She said that is what most family caregivers did with the additional money—either that or bought necessary equipment or services that Medicaid does not cover for their family member. She said finally they are surviving—but still almost all of the money goes to pay for things her son needs—the rest to keep a household functioning so they have a home.

She said she would give her job and the pay that goes with it to anyone willing to do the job. She read the job description—it includes the following required skills:

- ✓ Certified nurse aide
- ✓ Personal care provider
- ✓ Homemaker
- ✓ Psychotherapist

- ✓ Physical Therapist
- ✓ Occupational Therapist
- ✓ Speech Therapist
- ✓ Doctor
- ✓ Nurse
- ✓ Pharmacist
- ✓ Secretary,
- ✓ Scheduler,
- ✓ Authorized Representative
- ✓ Lift mechanic for the Hoyer lift, wheelchair lift,
- ✓ Troubleshooting wiring on equipment
- ✓ Carpenter to do bolting and repairs to walls and doors
- ✓ Emergency Medical Technician
- ✓ Translator to help other people figure out what he is saying the few times he is with others.

You have to be able to do the following

- ✓ Run a small business
- ✓ Understand and address repetitive behaviors—being asked the same question or told the same thing hundreds of times a day for years on end
- ✓ Tolerate being called nasty names on a daily basis
- ✓ Manage sundowner syndrome and confusion
- ✓ Deal with seizures
- ✓ Deal with choking (Heimlich)
- ✓ Clean up after bowel accidents in the middle of the night
- ✓ Clean feces off of the wiring of the wheelchair
- ✓ Trouble shoot with all sorts of technical issues and breakages
- ✓ Manage rules, preferences, and quirks of at numerous agencies, providers, and companies and develop positive relationships with all of them

#### Other characteristics

- ✓ Must be able to solve any sort of problem at any time

- ✓ Must be able to learn multiple rules of multiple systems
- ✓ Must be willing to have all aspects of private life open to wide variety of people
- ✓ Must be able to be pleasant and perfect all of the time,, and supportive of the other caregivers and people in his life and in our home
- ✓ Patient
- ✓ Incredible coping skills
- ✓ Psychic to figure out what he needs when he is unable to articulate it
- ✓ Must be able to do all of this on limited sleep

#### Hours and Compensation:

Hours: The required hours of this job are 24 hours a day, 7 days a week. Every week you might get a couple hours to do errands on your own. Every 10 years you might get a few days of respite. . The most we can make is \$39.30 and most of us do not make that. No outside work. No insurance, no short or long term disability, no life insurance (I bought some in case something happens to me so my son would be provided for), no paid holidays, no paid vacation or unpaid vacation, no sick days.

You have to be able to respond when your other daughter says "I want my mom back". You have to accept that you cannot be a full parent to your other child and cannot be a grandparent to your grandchild.

Do I watch a lot of TV? Yes –I have watched the same game shows on the game show channel several hours a day for 19 years. If there is a show I want to watch I can sit down and watch it—but have to get up to do something every ten minutes..... Yes the TV is on constantly but I do not get to sit and watch it without interruption. I would love more intellectual variety than game shows.

Agencies are saying they have overhead—so do we. We have to maintain a home, pay for food for Brian and attendants. When we go in and out the door is left open making it easier to maneuver the wheelchair, causing

skyrocketing heat and cooling bills. It is not only us going in and out but numerous people in and out of the house. I have to pay for a van with a lift, constant repairs, supplements, recreation, home modifications, copays, office supplies, printer ink, cell phones, and more. This is in addition to maintaining a home that works for someone who needs a wheelchair, a ceiling lift, roll in shower, an extra room for medical supplies, etc. We have overhead also.

***Conclusion: So---if anyone wants my job and the salary that goes with it I am offering it to you right here, right now. I never want to hear anyone every again in this meeting say that family caregivers have it easy or even hint that we are overpaid. We earn every penny we make.***

Several people commented that she made excellent points and that her comments were a good reminder that we should not be judgmental or make assumptions about what family members do. Christina Johnson asked if they have looked at best practices in other states concerning FEA model and open enrollment issues. Answer was yes and specifically they have talked with Kansas and Wisconsin but without much feedback. The best source is the National Center.

The meeting adjourned at 4:15 pm.

Respectfully submitted

Julie Reiskin