MISSISSIPPI DIVISION OF
MEDICAID

Public Hearing Comments

May 3, 2017 at 2:00pm

Woolfolk State Office Building, Room 145

Home and Community-Based Services (HCBS)

Independent Living (IL) Waiver Renewal

Ms. Hollia Thompson:

My comments are more geared toward, although I work in the field with families of individuals with disabilities, but my comments today are more from a family member because my husband is on the IL Waiver. I addressed my concerns before and they kind of stemmed to community integration and recruitment by the family, so I kind of stated that. My comments as far as community integration that was one of my high hopes for my husband who had a stroke, being able to assess the Independent Living Waiver so that he didn't have to remain at home all day in the house. The first, I guess, I don't know if I want to say a barrier, but the first problem that we incurred was actually getting enough services to be able to even leave the house. When you look at two hours of services by the time a meal is prepared or what have you, that person doesn't have very much time for any community integration because that time is already absorbed. So we did have the opportunity to get another assessment and I was grateful for that opportunity which allowed him then to get four hours, and that was better than two hours.

So, again, I was concerned because the only community integration that I felt we had a choice for was adult day care, which he was not interested in. So without having the adult day care, he still goes back to having to pay because we were told that that's an agreement between the family and his direct care professional. In order to get them to go out in the community, you know, we have to pay for the gas to get them to go out in the community, which we have been doing and he has been getting out in the community, but I think that also it's something that should be a part of the service.

The other problem that I had was recruiting, recruiting by the family members. I work. He had a stroke which means he needs my assistance, and that took a lot of time. It took a lot of time away that he went without services because we could not find anyone to provide services for the amount of pay.

So, again, a burden falls on the family if we're going to find someone that we feel is going to provide quality care for our loved ones then that would provide another burden in supplementing money to the direct care professional. They didn't ask for that. I'm saying that. Because if we have a sheet, whatever you want to call it, the wait list, list of names, I don't care what you name it, that's what we had to go by to try to help us because we had waited and tried to find people on our own for quite a while.

So by the time all this time goes by he's still not getting the services, I'm still leaving my job. And so then when I contacted his support coordinator and said, you know, Can you guys help us somehow with this recruitment? So I got a list of names, which really didn't help us. We actually was blessed to get the person because the names were off line on the paper by the numbering. So everybody I called I had the wrong number. I was asking for the wrong person. They'd say they don't live here. So accidentally I spoke to someone who was a care giver to someone that we knew and that person called her and said, I think I was talking to Ms. Thompson but I'm not sure, what's her first name. And that was her sister. And so she said, yeah, she's looking for someone for Mr. Thompson. But, now, granted, this has been -- some months had gone by and we were still trying to find someone. And we found her thankfully.

But recruitment by the family, that is just something that really needs attention. You say that's giving us a choice, but it's not giving us a choice if we can't find anyone. And I'm out here in the field and run into a lot of people, and if I have a hard time you know it saddens me to think what other family members are going through.

So this is really -- I mean, it was an eye opener for me. It really was. And so I think it's something that you really should think about. That is not really giving us choice. Why can't we have other providers that we can look for services through?

For instance, a staffing agency that I could have contacted and they could have come out and we would know if they would meet our needs once we sit down with them and we would have had a choice to select from another agency. Instead it put all of that burden on the family and we still went without services for a length of time.

We are still at this point waiting on assistant technology, which really was something simple as some shower bars. Well, my husband is now a year out from his stroke so of course I have had to teach him how to take his shower, how to get in and out, how to get in and out of the tub because he was hard-headed and decided he wants to use the tub, but he should have that choice. So we still to this day have not gotten that.

So I am just really, really here to, as much as I can emphasize to you from compassion from my heart from my family and many other families that I talk to daily, the recruitment is not giving us a choice. It's very much limiting us in getting services and getting them in a timely manner. Thank you.

Ms. Jaylene Lose
Participant receiving services

I have had problems finding a care person, and I'm having an issue right now. The care person that I have right now, her car is sitting in my driveway and she is bringing someone to work with her. So I feel like I'm taking her time up, someone else's time up, as well as my care person's. So that's three people, and plus she brings her children to work, and that's not fair to me. So I agree with Hollia. There should be more choices out there for us because I can't do it on my own anymore. I'm sorry to say I broke my hip a couple of years ago. I didn't mean to do it. I did it on accident. I hate myself every day, but it will get better one day. Thank you very much. I guess that's my phone. Thank you very much.

Mr. Micah Dutro
Managing Attorney
Disability Rights Mississippi

My name is Micah Dutro. I'm the managing attorney at Disability Rights Mississippi. We're the designated protection and advocacy agency for the State of Mississippi as established by federal law. And those federal laws tell us that it's our job to look out for the civil rights of people with disabilities wherever they may be found in the borders of our state.

Our organization has real problems with this waiver as it is proposed. And to illustrate why, I would ask you all to cast your mind back to the meeting that we had this morning about the elderly and disabled waiver. A lot of the changes in the waiver were prompted by concerns about conflict of interest and freedom of choice on the part of the participants, but we are saying, apparently as a state, that we don't believe that the people in this waiver need that freedom of choice. Now, that raises some real legal problems. Number one, I think it raises legal problems under the Home & Community Based Settings Rules that we're all going to be following here in about a year. Number two, it probably raises some constitutional legal issues, i.e., a violation of the Equal Protection Clause of the 14th Amendment of the United States Constitution. You've got two groups of people similarly situated, one on the Elderly and Disabled Waiver, one on the Independent Living Waiver. One group of people gets freedom of choice when it comes to the case management services. One group doesn't. Now, the Supreme Court of the United States says you can do that but you've got to have some real good reasons for it. I don't know what those reasons might be but I certainly don't see it. I cannot imagine why the folks under the Independent Living Waiver don't have the exact same concerns.

Now, the other issue that these nice ladies who spoke before me spoke about, personal care attendants, we have concerns there as well and they echoed many of those concerns that we have. I think that the restrictions on immediate family members being compensated as personal care attendants are too restrictive. We've got a lot of areas in this state where that's all you can find is somebody already living in your house, but the idea that that is somehow economically neutral for that family is preposterous. I mean, the nice lady sitting here on the second row who spoke first has been taking care of her husband. She's probably lost income. She couldn't work some that she would have been working. She's probably spent money on things that she had to do for her husband that she might not have if she had a personal care attendant during some of this time. That's an economic cost to these families. And that's not how these waiver services are supposed to work.

You know, I don't have anything against the Department of Rehabilitation Services. I'm sure there are lots of fine people who work there and I'm sure they do a good job, but, you know, you could forgive somebody for reading this waiver as it's currently written if they came to the conclusion that one of the main groups that benefits from the waiver is the Department of Rehabilitation Services. They've got the market cornered on case management services. They've got the market cornered on independent contractors for everybody on the -- excuse me -- PCAs who are independent contractors under this waiver. And by the way, independent contractors I assume they're being called because the department doesn't pay the payroll taxes, but if you look at the legal definition of what an independent contractor is there's way more to it than that. Just who pays the taxes that's the tip of the iceberg. And I would suggest to you all that the PCAs in this waiver would not qualify under almost any other part of that definition. They are essentially independent contractors in name only.

I worry that the folks on this waiver have freedom of choice in the same way that I have freedom of choice when my wife tells me that I can pick which restaurant to go to on Friday nights. She said, Where do you want to go? Well, we all know how that works, right? I get a choice as long as I pick the right thing, right?

So what I'm saying is is that we have the other waivers where people have more choice, why shouldn't they in this one? I don't see any reason.

Now, it's true that sometimes people with disabilities need help making decisions. Well, there are groups out there that can help them with that. The Arc of Mississippi does a lot of work with supportive decision making. Our organization can do some of that work, too. And, shoot, we all need help making decisions sometimes. I have two college degrees but I know better than to do my own taxes. And you won't catch me baking a cake. There's plenty of things I can't do, and I don't have any disabilities other than maybe being a smart-aleck that I know of.

So there's no reason why these folks can't have that same freedom of choice and it boggles our minds at our office why the state of Mississippi who is, apparently, with a straight face, submitting two waivers for renewal at the same time, one of which says we've got concerns that these people need freedom of choice and the other one says, hey, could you waive that whole freedom of choice requirement thing for us, please, that would help us out. That just doesn't make sense to us.

We urge the Division of Medicaid to reconsider some of this. The Department of Rehabilitation Services is performing a valuable service by administrating the waiver, but we don't believe that those concerns and the services that they're rendering override the rights of the participants and their concerns. Those are the people that the waiver is ultimately intended to serve. Thank you.

Ms. Patricia Carson
Participant’s Mother

MS. PATRICIA CARSON: (Telephonically)
May I please speak?
MS. BUCHANAN: Could you state your name and what organization you're with?
MS. PATRICIA CARSON: Yes. I'm Patricia Carson and I'm not with an organization. I am Baker Carson's mom. I received these e-mails to call -- and, sorry, we were up all night. We sleep during the day because Baker keeps me up. We were on the first ID/DD Waiver. MS. BUCHANAN: I'm sorry. Could you hold on just a second. We're not able to hear you. I'm sorry.

Our volume is all the way up. I apologize. Could you maybe speak just a little bit louder for us. Thank you. You have the floor.

MS. PATRICIA CARSON: Yes. Excuse me for being late. It's a little difficult when you're in the middle of stuff and you stop. I am Patricia Carson. My son is Baker Carson. He got out of the institution and he got -- I didn't know anything about the ID/DD waiver. That all came later. It was someone from there that we know about it because we had gone through a terrific, horrific storm and Baker would come with us. Anyway, I thought it was full because this kind of diagnosis that he's had since he was three. So 30 minutes later I get a call that he's on the waiting list. It was an answer to prayer. I never wanted to be in this position. And I never would have turned him over as a ward of the state so I can't qualify for Medicaid so that -- you know, I was reared that you pay people. Or you find a way for people to receive payment for their services. I didn't realize, you know, what was going on. I could not find public education for him. I could not find a waiver to get him speech and he needed that. And everywhere we went it was worse and worse. At first it seemed to be a good idea but then it became not a good idea after the storm.

It was a circus to say the least. I was asked to -- I was asked information about the waiver. It was as if I was writing it for them. But just somebody with a GED, somebody he knew gave them my piece of paper, you know, let them call in and they'll interview him. I was thinking okay. But we were in shock from this storm and I was just so grateful. And both children were here. I moved in with their father. We had been divorced. And we had a daughter that needed direction. So with that said, it was a good thing for everyone.

We didn't get a transition period. It looked as if he would have to go back and it was a wonderful company that came to the state. Just showed up at the door one day out of the blue with our case worker who offered and he actually offered to see Baker. Nobody really ever cared because Baker was kind of like an afterthought like that sweet lady that I heard blamed herself. That's been the language, that I've got to let them know if everything I presented would you still see everything. And we were going through trying to keep a 15-year-old girl with such a horrific thing to lose everything she had and living such a horrific event headed toward her goal of school and college. She's a good girl at this vulnerable age, and leaving Baker where he felt secure and safe where he wouldn't have a blow-up reaction.

Anyway, all that said, I thought about it and I did call them back and he put his stuff with me and I wasn't understanding. I was just so excited that somebody wanted to know about my son and asked. The state had never done that. Not even when he was in high school they didn't once ask us point blank needs, what he does, his responses. And this is a big problem. Like I just heard two women who were begging and looking through horrible things and no compassion. It's the lack of compassion from our state from the people that give the services.

But that said, the support of living came in. I could rest. I could recover. I could have been home with my children. I still had to guide and help them with Baker, but I had someone for them over the employee that wanted to help them because a lot of our Mississippi PCAs or whoever they are, they have no training. They have no degree. Our own behavior people didn't have a degree. Most people just had a social service degree and that was a friend, that somebody knew. And if there was a problem they were there to guide their employee through it. It took so much pressure off the family. I actually felt like maybe I could go to McDonald's and drink a cup of coffee and get five miles away, you know, in case Baker had an offset or a meltdown because of the change of circumstances. I actually felt that there was hope, which there wasn't much before that. And Baker going back to the institution and feeling like I had just thrown him away for, you know, wanting to be with his family because of our circumstances and the trauma we had been through. It was just a really, really tough thing. So that said, we had somebody for three years with supportive living, and then the state pulled the trigger on us. You know, she had every bit of her documentation. She could have fought that. She was so offended. And then the state recognized the people that claim to be over Oxford Health or take the application and I'm thinking that he's not qualified for that –

MS. BUCHANAN: Ms. Carson, listening to your comments, and, of course, we're taking notes and the court reporter is writing down everything but in listening to your comments, I believe that you are referring to the ID/DD waiver.

MS. PATRICIA CARSON: The ID/DD waiver? Yes.

MS. BUCHANAN: Yes, ma'am. This public hearing is about the independent living waiver.

MS. PATRICIA CARSON: But it is also still applicable for –

MS. BUCHANAN: Right. I just wanted to clarify for you and everyone else in the room and our court reporter. But please continue if you would like to.

MS. PATRICIA CARSON: Well, as I said -- and I'm sorry for calling at the wrong time. I couldn't call our –

MS. BUCHANAN: No, this is fine. I wanted to be sure that we all understood.

MS. PATRICIA CARSON: Thank you. Yeah. I'm just needing a voice to be heard. I don't care what waiver it is. Because my son in one of those two is real. And right now we're stumped because of Social Security Administration making it impossible for me to keep the ID/DD waiver open. And gave Mr.- -- I mean, I think he just got frustrated and left. The man that's so successful everywhere else and then the employee wouldn't work for me because she's seen the battles that I was going through between the department. So all of that said -- and I know that Baker's Medicaid has been charged for services Baker never got. And we weren't a part of a waiver after the ID/DD waiver was closed for us by finally helping us financially get Baker on Social Security. I know it's been a problem and I don't know if these other people have a problem, but, you know, jacking money around, it's just really sad. And I accept your review, you know, as what you're entering and saying, but I just want to say to anybody thinking about this waiver and helping these people if you can hear these stories and sleep at night, God love you.

The employee bringing the car and leaving, I get that one. Bringing the kids to work. She's sick. And there's nothing you can do. Because I lived on purpose for Medicaid, I looked at them and said I -- I live on purpose. For you to get paid, for you to work with them so you can leave. That wasn't like that. Anyway, I'm going to end with that. And the state of Mississippi is like a lot of people in a horrible, horrific place.

Another friend of mine whose son committed suicide with drugs, and that was a bad thing, by the power of God alone are all of us that are reaching out to the cold voices in that room for help and offering -- I mean, we could complain all day that doesn't do any good. Speak about what works is good. I'm just going to throw my voice in the camp. And God doesn't like ugly. I know that the state of Mississippi could do better. I remember my state and I miss my state. My state wasn't always so corrupt. My state wasn't always like this.

And I don't really care that I'm off topic right now, but thank you for listening. And when Baker does qualify, when y'all don't cast him out because of 25 supportive lending and all that I didn't even know I was a part of, when all of that is settled I hope you'll reach out to us and these others. And I'll end there. Thank you.

Ms. Vicki Killingsworth

My name is Vicki Killingsworth, and I have been an advocate for 30-something years for people with disabilities. I would like to address the portion of the Independent Living Waiver that talks about directing your own care. And in order to qualify for the Independent Living Waiver you're supposed to be able to direct your own care, however, it is limited directed care. You are allowed -- once you're assessed, you're given so many hours. However you can't move those hours. They have to be done in that day. They cannot be moved from one day to the next.

It would not cause a budgetary problem if you are allowed, say, 100 hours a month but today you're out late with your PCA and you have an incontinent issue, well, you've got to be cleaned up right then. At that point you cannot just say, okay, stop. And even if you do when you get home, what, you just cut them off at that time because you've met your time frame? And then how are you going to get in the bed.

So I think that needs to be adjusted. There's no reason that it can't. It will not cause a budgetary problem because you're still using the same hours. There's always going to be extenuating circumstances and unplanned events. It is in everybody's able bodied life, as well as it is in people with disabilities. Unfortunately we just have a few extra. So I really would like to see that addressed.

I also think that it would be an excellent idea to put a buffer amount of hours when somebody first transitions out from a traumatic injury or whatever into the community because when they first get out in their mind they're thinking, I can do this, this, and this based on their previous lifestyle. Then they get out and they think, oh, well, they're only getting four hours, well, gosh I can't do that, I can't do this. So possibly if there was a buffer then they would have those extra hours when they needed them until they learned. From the way I understand it now, if there is an incident like that they can call their case manager and say, you know, I went over my hours or whatever, and then that can be rectified, but that is not done on a regular basis.

And you don't have, you know, back to back to back incidences where you would need that. You could, let's say for instance, if somebody had to go out over their hours on one day, the next day if they chose they could tell the attendant not to come in early, to rectify the amount of the time that's allotted for them every month.

So I think that's pretty much -- I agree with some of the things that people have said, but that one right there seems to me causes problems. And it causes more problem for people that are out and in the community on a regular basis. And they are all very grateful -- let me say this. They are all very grateful for those hours, regardless of the amount, but the ones that it bothers the most are the people that are going to therapy on a regular basis, going to doctors' visits, wanting to go shopping and heaven forbid that they want to go do something for fun. That's my comments. And I have a little statement that I wrote up about it and I'd like to give it to you.