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Creating and Operating Services to Support Youth in Transitioning to Adult Health Care: Teaching the Importance of Health and Wellness and Medical Homes

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>> JUDITH: Okay. We need to get started again. We've still got a lot of really good information to cover, and I know that you have enough caffeine and nourishment to hold now to lunch.

So this section of the conference will focus on something I think, as I said, often is often overlooked. When you talk about health conditions and the issues that health status and wellness and prevention of secondary conditions and healthy lifestyles, those are things that I think we need to pay a lot more attention to, all of us, but especially with our younger population. I've been working on a grant, and I've been looking at a lot of the statistics. And when you look at risk factors, like smoking or not getting enough exercise or not eating healthy, people with disabilities have much, much higher risk factors. When you look at things like obesity, cardiovascular problems, asthma, lung problems, again, people with disabilities have more of those conditions and also need more equipment and services because of those conditions. Now there are a lots of things that we can't prevent, but we can really work on accessing good quality health care and getting good quality health care and helping younger folks, young adults, understand how important that is.

So we have three of our three presenters today for this session who have a lot of experience in this area. And, Christy, I'll let you start out and introduce Des. Now remember Des. He's the one that you contact if you're having boundary issues with young girls. Okay? Right? Okay. Got it.

>> CHRISTY: I asked you to let me introduce Desmeon because you guys have seen him in the room, but you've not heard from him yet. And so you're about to hear -- I mean, Augusta called him out yesterday talking about crushes and boundaries and all that kind of stuff. As you can see by looking at my colleague here that he is quite handsome, and, yeah, we have those issues. So you can talk to him about that at the break.

But we're going the talk about this morning is the whole concept of a medical home and teaching our young people the importance of health and wellness. So with that said, I'm going to turn it over to Desmeon Thomas.

>> DESMEON: Okay. First, and foremost, basically we're going to be talking about the medical home and how to transition into adulthood and getting the right health care that you need.

What is a medical home? That's the first question. First and foremost, it's a place where a person feels safe at home with a physician, a nurse, the staff, administrators and all of that. You usually want to set up a good relationship with the whole staff when you go into your doctor's office. You know, that's basically a medical home.

It's a partnership between a youth and their primary care clinic or physician. It's a relationship based on mutual trust. You want to go in and be completely honest with your doctor and let him know what's going on with you. And in return, they're going to do the same for you.

Connections to support and services to meet the needs of other individuals. It's respect for the youth's cultural and religious beliefs. After hours and weekends, you should be able to get information that you need even when the clinic is closed. If you have good medical homes, they'll give you numbers and things like that that you can call if you need any additional information as far as your care.

It's a place where you feel supported. You know that when you go there, the doctor is going to let you know about all the resources available. You're going to get the support services that you need, and more than likely they're going to work as a team. They're going to work with other organizations in the community. If you have a great medical home, they're working with the CIL in the community to make sure that the resources are available to you.

The benefits of having a medical home. Youth regularly see the same primary care physician and office staff who know them, who partner with them in coordinating their care. They exchange information with the youth honestly and respectfully as they learn from each other. They support the youth in finding resources for all stages of growth and development.

The benefits of having a medical home continued. Youth are connected to information and family support organizations in their medical home. The medical home partnership promotes health and quality of life as youth grow and develop into adults.

The tips for family and youth and building a medical home and partnerships. When youth visit their doctor's office, the majority of the time the best thing to do is bring a list of questions. Most doctors don't know what you need personally. So you want to come and let them know what you need help with. You have to ask questions so they can know where you're trying to get and what point you're trying to get at as far as your health care and things like that.

You want to share information on changes that is occurring on your health. The doctor is more than likely going to refer you to agencies and write prescriptions depending on the need. So you want to make sure that you ask questions and things like that and share information with your doctor.

Ask about the resources that may help the youth. Most of the time, I'm at the clinic the majority of the time. You always have to ask questions and let the doctor know exactly what you're looking for, and they'll share information back with you. They're going to always refer you to other resources.

Ask to meet the office staff that are going to be working with you. The majority of the time you're going to know the social workers there. You're going to know the lady at the window that's taking your information and your insurance card and things like that. The majority of the time you guys are going to have a great relationship if you have a good medical home.

Last but not least, the most important thing is to show appreciation because you want to let your doctor and staff know you appreciate what they're doing so they'll keep up the good work.

What works in Mississippi. I'm going to let Christy take this part on. Oh, we have one question.

>> AUDIENCE MEMBER: Fourteen years, I was a nurse. I thought I healed a person when I was doing a pre-operative workup. The gentleman was deaf. And part of the pre-operative workup was to give the individual an enema. When he started speaking to me, I thought that I had relieved a plug.

(Laughter)

>> AUDIENCE MEMBER: You have to do -- disability culture and education, even today, is not a part of any medical school curriculum for doctors or for nurses or CNNs. So you have to do a lot of education.

So I'd like to hear from y'all as you proceed with how you deal with educating a GP, about complex medical needs, and prescribing not only for the pharmaceutical protocol for those, but for all of the appliances and devices that may be required.

>> CHRISTY: Okay. We have another question in the back too. And we will talk about that. We're going to talk about that.

>> AUDIENCE MEMBER: I just wanted to say that in Florida for the last four years I've been on the governors working group. We've been trying to figure out how to transition adolescents into adult health care with disabilities.

And one of the things that we're doing now, we've got our matrix up and all that sort of thing. But we are trying now to work with the legislature to actually pass some kind of regulations that medical schools, at least within the state of Florida, are going to have to learn some minimum things about dealing with people with disabilities. That's where we are.

>> CHRISTY: That's great. We've taken a little bit more informal approach and simply approached our medical school, that happens to be right there in Jackson, to work with them and try to get in and do some classes, be a part of the curriculum for medical students and the nurses. We've not been terribly successful.

We've been more successful in getting in and working with the PTs and the OT students that are at that same medical school. We've not yet been able to get into the premed or the medical school students. We have gone, however, and spoken to the nursing school over there. So we've taken a little bit more informal approach.

But I like the idea of being a little more formal about it. In Mississippi we try not to involve our legislature unless we just have to. I'm not scared of them or anything. I think they're more scared of me. But I try to get it done in a more informal manner with working directly with the medical schools or with the services and systems that we're trying to change. Because once you start involving our state legislature it just becomes a big hot mess usually.

But thank you for that. And, Judy, we are going to talk a little bit more about the training that we do.

One of the things I'll just go ahead and say, that I think we do particularly well, and we'll get into it in just a second about how we're able to get into our clinics in Mississippi.

But one of the things that we really concentrate on -- again, we talked a minute ago about community integration, etc. Well, it's all about empowerment, as I said. And it's empowering the young people to ask the questions, to take control of their lives, to know what it is they need to live successfully in the community.

And that's one of the things we're doing in those clinics is empowering those young people. And, of course their parents, their primary care givers, to ask those same questions and to take control, not just their whole lives, but particularly their health and wellness aspect of their life so that they are comfortable and then going to a primary care physician and talking to them about what their particular needs are and not being hesitant to ask questions.

Doctors are -- obviously they're all very intelligent people, right, because they've gone through premed and med school, etc. But one thing that I learned for many years, and my husband always used to tell me this, it's a practice.

You just have to keep in mind that, yeah, they've all been to school and they're all doctors and they're all to be respected for what they've accomplished thus far, but you must remember that it is a practice. That's why they call it a medical practice and that they are constantly learning. And who better to learn from than their own patients, as far as I'm concerned.

David says somebody always graduates at the bottom of the class. If you happen to get one of those doctors, you really have to do some education. That's right.

So this slide up here in front of you is what works in Mississippi. And what works for us is partnerships, obviously. And there's two pictures on this slide. You see a group of young people playing basketball, and you see another group of people doing a health and wellness class. And we're going to talk a little bit more about that. But both of those things that we do, we do them because we're able to do them because we have good partnerships.

Again, we've talked a lot about the fact that life is very unique and that we have one Center for Independent Living. We were established as the Part C Center for Independent Living in the state. We, of course, provide the four core services.

Eligibility, obviously, is simply anyone who has a disability of any age and any type of disability. And in an effort to serve any individuals of any age and any type of disability, we obviously have to seek other sources of funding because the Part C funds don't cover it all. Or if they do in your state, I really want to talk to you at the break.

One thing that we've learned over the years is that, of course, everybody has unique needs and what they need in the community to be successful. And what works for one person doesn't work for another.

The Part C funds give us the programmatic money that we need to establish our offices and pay our rent and hire our Independent Living specialists. What it doesn't do is provide us with the money that we need to -- thank you, Dawn -- is provide us with the funds that we need to purchase services that clearly so many people have that they've got to have. And that would be your home modifications, your vehicle modifications, and things like that.

So we've looked for other funds to meet those needs, and we've been fairly successful. I was feeling really successful before I came here, and I'm listening to some of y'all's budgets compared to mine. But I'm still proud of what we do with our $1.5 million.

So, anyway, in the course of looking for other funds, I mentioned yesterday that another organization called The Coalition For Citizens With Disabilities had written grant to HRSA back in the late '90s, early 2000s and specifically to serve children and youth with special health care needs. They had that funding from HRSA for several years, and then that grant ended.

So at that point, I applied as the Center for Independent Living. What I needed to give that money that I did not have, unfortunately, we had a new state health officer in Mississippi. This will just prove to you all how one individual person can change the course of history.

We had a new state health officer, real nice guy, but he didn't know us, and he didn't know what we did. So all I needed from him was a letter to put into that grant that would give HRSA permission or basically say are assigning life of Mississippi to be our out reach and coordination for children and youth with special health care needs under this Title V money.

Well, that's not the letter I got. What I got instead was a letter of support, a real generic feel good, warm, fuzzy, yeah, these are good people; we support their efforts. But HRSA had to see a letter saying we are designating LIFE of Mississippi to be our entity in the state that's going to do this, and he did not give me that kind of letter. As a result, we didn't get the money.

Health Resources Service Administration, I think. They've changed their name a few times over the years. It's the federal government, David.

So, anyway, we didn't get that. So what happened then, I thought, well, we're done for, and our youth program is coming to an end because we're not going to get this big pot of federal money.

Well, immediately what happened was under the state health officer and the person who was over part of the Title V dollars in the state, which is maternal and child health, he immediately approached me, and he said wait, wait, wait. Don't get discouraged.

As Judith said yesterday, one of the Title V's six performance measurements is to provide outreach and Independent Living services to children and youth with special health care needs. So they were charged with the responsibility of doing that, and quite frankly they had no idea how to do it; but he knew that we did. So that's when he came to us and said don't despair. We're going to give you some money. So that was the beginning of a really great partnership with the State Department of Health.

So let me quickly explain how the funds work there. State Department of Health in Mississippi gets the Title V money from HRSA -- from Health and Human Services, HHS now. They get the Title V money. It goes into what they call their Maternal and Child Health Bureau.

And I mentioned to you yesterday every state in the country gets Title V money. And that Title V money is going somewhere to some state agency in your state. It may be the Department of Health. It may be the Department of Human Services. It may be your services for children and families. I don't know, but it's going somewhere. So find it.

Because, again, one of their performance measures is to do outreach and Independent Living for children and youth with special health care needs. And who better to do that and who knows more about that than you guys, right? So find that money in your state and go talk to them and find out how they're meeting those goals.

We did that. And what has developed, and it's a little bit segregated, I'm going to admit, because what they've done for us in Mississippi, those Title V funds run a program called the Children's Medical Program. And the Children's Medical Program it's clinics. It's health care clinics for kids under the age of 21 throughout the state. The largest one, of course, is in Jackson.

I mentioned yesterday that I was a product of that. But when I was a kid growing up, it was called Crippled Children's Services or something ridiculous like that. It was not the Children's Medical Program.

So the Children's Medical Program brings kids in to these clinics from all over the state and provides them with basic health care. But the thing is they don't provide services to children and youth who have developmental disabilities unless there is a physical involvement that they need to treat.

So if you have a child who is born with Down Syndrome or a child who is born with autism or the like that doesn't have necessarily any physical involvement, that doesn't need a brace on one of their legs, or doesn't need a wheelchair, or an (indiscernible) device, then they're not going to be seen in those clinics.

So we're going into those clinics, and we're there as -- really they've let us come in as part of the staff. But we're not reaching all the kids that we need to reach through this clinic. So we've had to kind of back up and punt and reach out to those kids.

So what we've done at their request and with they're money, quite frankly, is we go into those clinics, again the largest one is in Jackson. And that's Desmeon, and he's going to talk a little bit more about that in just a second. But Desmeon is in this clinic usually twice a week.

Over the course of time, we convinced the director of the Children's Medical Program that they had to start providing some transition services because Dr. Green, who runs the clinic in Jackson, she's known me most of my life. She started there as an intern in medical school when she was very young, and I was a kid. And she's known me most of my life.

So I approached her and said when you kicked me out of the clinic when I was 21, I floundered around for a couple of years. I had broken prosthetics that I couldn't get fixed. I didn't know who to see, and it was a real problem for me. So we've got to fix this.

Okay. So we fixed it for me, but it was just for me because nobody really understood or knew what the term medical home meant at the time. So when medical home terminology was introduced to me years later, I said, oh, this is what I needed back when I was 21 years old. So I really jumped on the band wagon and started promoting the medical home.

So I went back to Dr. Green, and I said to her we've got to teach the young people in the clinics and their parents. They've got to be able to learn -- if they can possibly learn how to take control of their health care.

They've got to understand their bodies. They've got to understand their disability and how it impacts them individually. They've got to be able to discuss their needs, their medical needs, their health care needs. They've got to understand how to discuss that with their physicians in the community.

Because when you kick them out of here when they're 21, they're going to be really lost, and they're going to suffer the physical consequences and the health care consequences of not having the medical home that they deserve.

So they started the transition clinic at the age of 16 -- is that correct? And I begged them -- I'm still begging them to drop it to 12. Because we believe 16, quite frankly, is too old to start this process. So I think we've about convinced them to drop it to 14, hopefully, but I'm still going to advocate for 12.

So the partnership between the Children's Medical Program in LIFE, and remember the Children's Medical Program is funded by the Title V money. The partnership that we've created is called HOT, Healthy Opportunities for Transition in Mississippi.

At that point, I'm going to tun it over back to Desmeon, because he's going to give you a little more information about the HOT program and the Family to Family Center as well.

>> DESMEON: Okay. I'm going to tell you a little bit more about HOT first, which is Healthy Opportunities for Transition. And the way we kind of collaborate with the CMP clinic is very -- like she said, I go in twice a week; and once a month, I think, which is the third week every month for transition.

We work with young adults who are 16 and older. The great part about it, even if the young adults aren't coming in to transition clinic, I'm still getting to talk to them the other two days a week and talking to their family about transition and trying to open up cases with them so they can still be more involved in the community and get the resources that they need while I'm there.

With me going into the clinics regularly, it gives me the opportunity to follow up on a regular basis with the families, and they come from all around the state. They're not just residents of Jackson. You have families coming from different parts. They come from Buloxi, Tupelo, Greenwood, and etc. They're coming from everywhere to these clinics.

So it gives us an opportunity to follow up. Even though they're not doing the transition clinic, if they're under 16, we're still able to teach them some transition services and able to do peer support and advocacy for them.

A lot of families don't know the services that are available for them. So it's good to have us there along with the social workers to let them know exactly what exists. So that's the great thing about me being in the CMP clinic twice a week and going to that transition clinic.

Now let me tell you the importance of the transition. It's always set up great. We had a Family to Family grant (indiscernible), which is Jackie Washington. She's basically a mother of a child with a disability. And she's been through the whole CMP movement. She's been through the clinics. Her daughter is just turning 21, so she's aging out. But she's able to peer other parents and talk to other parents about what she went through with her daughter and kind of give them a support system that they can lean on while they're at them clinics.

Me and her basically work together in them clinics. When we go in for transition, she's there talking to the family or attendant or whoever is there with the young adult and telling them her experiences and giving her advice on some of the things that they can work on as parents.

And I'm mainly trying to talk to the young adults. That's my job. I interact with the parents if the young adults are not cognitive enough to do it on their own. But for the young adults that's vocal and that's able to direct their own care, I try to teach them how to be better advocates and I peer support with them and let them know you can do more. I try to figure out their goals, and try to figure out what they want to do, and try to set up some things for them so they can transition into adulthood and get the services that they need as well.

We have a lot of problems. Especially once the kids are turning 18, 19, I don't have to talk to parents anymore. And I'm giving them the responsibility to do whatever you want to do. And a lot of parents are angry, and they don't want to do some of the stuff.

For instance, you have a kid, that they have a goal. Sometimes their goals are out of reach, but it is our job to kind of baby step them into getting what they want and doing what they want to do. Because once you're 18, you are a young adult, and we can't let the parents take over exactly what they want to do.

So that's usually a conflict that we go through, but Christy will tell you my job is to make sure that that kid is a young adult and they're growing into adulthood and they're getting services that they need and they want and not what their parents want all the time.

>> CHRISTY: I'm going to stop Des at that point and just say that, as any Independent Living Center, we're out there working for the consumer, not their mom and dad, not necessarily a primary caregiver. We're out there for them, and it's our job to ensure that they get the services that they need to live independently in the community. So, yeah, there are occasions when we might have a little bit of a conflict with the family. But that's the beauty of being in the clinics is because we've got Jackie, a parent, who wants her child to be independent and well taken care of one of these days when Jackie is no longer available. So Jackie understands the importance of it. So while Desmeon is over here talking to the young people about their goals and what they want to do with their lives, then Jackie is kind of steering the parents over here to do some peer support with them.

And while I have the mike, let me just say real quickly, we didn't discuss the funding situation here with the Family to Family Center. Again, what works for us is the partnership. What we've got is our university affiliated program in our center for excellence.

In Mississippi it's called the Institute for Disability Studies, and they are housed with the University of Southern Mississippi down in Hattiesburg, Mississippi; but they have two offices.

The Institute for Disability Studies wrote the grant and got funding for the Family to Family Center, and a lot of that money comes -- some of it comes from Family Voices. Some of it comes from CMS and HRSA. So we had already a good collaborative relationship with the Institute for Disability Studies.

So their director approached us. What they did was they went to the Department of Health and said we want to house a parent of a child with a disability in your clinics that can help us pull together No. 1, a parent support group, and No. 2, an advisory council of parents to tell us what we need to do better in Mississippi for parents with kids who have disabilities and how can we get the information and referral out there to them.

The health department didn't necessarily want to add -- it's state government bureaucracy. For whatever reason, maybe they didn't have a pin number. I don't know, but they didn't want to add another employee to their rolls. So they turned around and came to us and said you guys hire her and house her here with us.

Yeah, that leads to some of its own little issues that we have to deal with, because she's an employee of LIFE, Jackie Washington is as Desmeon said. She's an employee of LIFE, but she's housed over in the health department next door to the clinic in the resource library.

So she's there every day to meet with and talk to parents and also to help the Institute for Disabilities Studies and the Children's Medical Program to gather the data that they have to submit to the feds to continue getting their money. And she's good at that. But she's also very readily available to parents who are coming through that clinic.

And in her role of pulling together the advisory council for parents, she has been able to branch out to parents whose children may not be necessarily coming to the clinic, which, of course, is one of the six performance measurements that Title V says you've got to meet. And that is to do outreach and community living for all kids with disabilities, not just ones who have physical involvement.

So the Family to Family Center, the Children's Medical Program and LIFE of Mississippi have all worked beautifully together to have this partnership that works, and it gives us tremendous access to young people throughout the state.

And one more thing I want to add is that most of the clinics are in Jackson. But I'm skipping through these slides because I've already talked about it. Most of the clinics are in Jackson, but there are actually clinics all over the state.

Now the way the Children's Medical Program is set up, their clinics are designed for specific types of disability. So they'll have a clinic for cerebral palsy. They'll have a speech clinic. They'll have a mylo clinic. They'll have an orthopedic clinic. They'll have a neurological clinic, and then they have the transition clinic.

So Desmeon is an all transition clinic and they meet once a month, and then he's often at the orthopedic and the mylo clinic as well. And then he's available because they're not far from us. They're just around the corner from our office. So he's available any other time that a parent might be coming in that needs some talking to or with a child.

So that's how we tie all of those partnerships together, and I know that's a lot of information to swallow. Do you all have any questions about the funding or how we tie those partnerships together before I move on and let Desmeon talk about the services provided? We have a couple of questions back here.

>> AUDIENCE MEMBER: Okay. My question is really that I don't understand the term medical home. Is it medical home services or medical services at home or is it an actual place? I don't get it.

>> CHRISTY: It's not an actual place and it's not services at home. It's really a concept. It's a philosophy more than anything. When we talk about a medical home, I guess the best way I can describe to you it is just to give you an example, and I'll just use myself.

I was born with my disability as I've mentioned. So these triple amputations, and I wear prosthetics. Well, I've always known -- I didn't believe it until I turned about 35. But I've always heard I was going to have all these secondary complications as I aged.

What I needed to find was a physician, preferably a general practitioner that knew me, that understood how my amputations affect me personally, that understood the concept that occasionally that prosthetics would break or that I would need to get new ones.

He didn't necessarily have to understand what to write the prescription for, but he just needed to know that, okay, Christy has come in. She needs a new prosthesis, a new leg. So if she tells me that she needs it and she shows me what's wrong with the old one, I believe her. I'm going to write the prescription for her to go on and get that done.

He also -- my general practitioner also happens to know my family's history. So besides the disability related issues that he helps me work through, he also knows my family history. And by the time I was 40 or -- well, 45 really, he's tested me for high cholesterol, which I have. So he's treating me, the whole person. He treats me if I have a cold. He treats me if I need sinus medication. He treats me -- he takes my blood work annually.

He gives my, what we call a healthy you checkup. Are you familiar with the healthy you checkups? Do your insurance companies provide that for anybody here? No? Yes? Okay.

In Mississippi with Blue Cross Blue Shield, which is the largest health insurance in the state, a healthy you checkup, it's a wellness checkup, and it's free. If you've got Blue Cross Blue Shield, you go in once a year, and they do a complete checkup. They do all of your lab work, your blood work. They run a mammogram for women, a Pap smear for women.

If you're over the age of 50, they'll do a colonoscopy for men and women. They do a prostate exam for men. It's just a full complete checkup that's done annually, and it's a wellness checkup. And I think that ever insurance company should offer them.

So Dr. Altman, being my general practitioner, he treats me for everything. If I come in with a situation that he can't handle as a general practitioner, he will refer me to a specialist. And he can get me in to see a specialist much faster than I can get in to see a specialist myself.

For instance, several years ago, I developed bursitis in one of my elbows. What it meant was basically my left elbow was so swollen, I couldn't get my arm on, my prosthesis on. I called the orthopedic that I usually see and was told by the receptionist he'll see you in May. This was the beginning of February. I was like, no, that won't work.

So I was kind of panicky, and I was really angry and frustrated. And then I remembered, wait, I have a medical home. So I called Dr. Altman and explained the situation. I went in and saw him. He looked at it. I didn't even have to go to the orthopedic because he knew what it was. He's like this is bursitis. Here's some medication. This should work. If it doesn't, at that point I'll send you to an orthopedic. So I got treated much faster, and he understood what the problem was, and he knew that it was related to wearing the prosthesis a lot and that kind of thing.

So I kind of went around the world to answer that question, but does that help? Again, it's not a place that you're treated. It's not a place. It's a concept. It's a philosophy.

>> AUDIENCE MEMBER: It's like a designation?

>> DAVID: It's a service model.

>> CHRISTY: It's a service -- yeah, thank you, David. It's a service model as David said.

>> JUDITH: It's becoming more popular now. It started in pediatrics when you had kids with disabilities that got shipped to multiple specialists, and nobody kind of was coordinating and caring about the whole person. So it's called medical home, but it really means a way of doing practice. And sometimes you hear it referred to it as patient centered care. Same thing. It means that somebody is looking at you holistically. They know you. They follow you so you're not seeing different people all the time. They kind of have a better sense of who you are and can make adaptations and adjustments as needed. They're in every state this initiative is moving. And I will find a good reference for you for practices that are doing medical home. Everybody does it to a degree. Some are just better than others. This is kind of the way they want medicine to happen right now is through a medical home.

>> CHRISTY: And there's a link in this power point, too, for medical home as well. Richard.

>> RICHARD: This is probably oversimplifying, but it is like a primary care physician plus, plus. It's thought of as being better than primary care because it is more encompassing. It is more holistic. It's a term that's being used in a lot of the new health care legislation.

And another way to look at it is at TIRR, The Institute for Rehabilitation Research. That's what ILRU is part of. Our CEO Carl Josehart realized that a lot of people with spinal cord injuries were not really getting their needs met by physicians in the community because they didn't understand spinal cord injury. So not only did people with spinal cord injuries have needs specific to spinal cord injury but all of their medical needs.

So, the approach that TIRR is taking is we're going to be the medical home for people with spinal cord injuries. So we'll be their primary care physician for everything that they have to deal with as far as their medical needs are concerned.

Certainly there will be specialists that there will be referrals, but it is a way of getting most of someone's if not all of someone's needs met through one door, through one channel. Is that close?

>> AUDIENCE MEMBER: Yeah.

>> CHRISTY: Does that help?

>> AUDIENCE MEMBER: Yeah.

>> CHRISTY: The best example and the most benefit I've ever gotten from medical home was not for me. But it was actually for -- my husband was hospitalized last year, and we were at the Medical Center at the University of Mississippi Medical Center in Jackson, is where he was.

It's a medical center. It's a teaching hospital. So not just one doctor comes in that room. They come in in teams, like flocks of sea gulls, we call them because they'd come in in five and ten -- you know, they bring an intern or residents, etc. They come in and look at the patient, and then they talk to him a little bit, and they walk back out, and they consult in the hallway, and they write stuff down in their chart. And you're like, what is going on?

And then a nurse would come in a few minutes later and say, okay, this team prescribed such and such. Okay, well, after that had happened two or three times, I was like wait just a minute. We've now been prescribed two or three different medications. I don't understand what any of them are for. I don't know if they're going to interact with one another. I don't get this.

And I was getting kind of scared because I felt like there was too many people involved. And I know they were trying get to the bottom of the issue, and I was grateful for that. But because it was a teaching hospital, they weren't teaching me and my husband. They were teaching each other.

So I finally just picked up the phone and called Darrell's general practitioner and said this is what's going on, and I'm really scared. We've had two different medications prescribed today, and there were two yesterday. I'm worried. I'm worried about the situation. And I can't get them to listen to me because they come in here, like I said, a flock of seagulls, and then they run back out. Unless I chase them down the hallway, I can't get them.

He took it from there. He picked up the phone, and he called the hospitalist [sic] who was sort of overseeing all of this, who we had not yet met, and talked to him and kind of got to the bottom of it, and then he called me back.

From that point forward, when I had a question and I couldn't get a doctor at the hospital to tell me, I picked up the phone and called Darrell's GP, and he would get that information for me. And that was the beauty of having that one primary care physician that was willing to work with us on that. So it's a good example of great benefits that can come from having a good medical home.

Any other questions about that? Have we answered y'all's questions? Okay.

Judith.

>> JUDITH: Just one other point. In our state, in each state, the children with special health care needs, the Title V folks decide which types of disabilities that they'll treat. So in Utah, we see a ton of kids with autism. We also see kids with physical disabilities, and we see kids with developmental disabilities.

So you need to find out in each of your states as you begin this partnership or exploring this partnership which types of children they have kind of prioritized to provide services to. And it does vary from state to state.

>> CHRISTY: Thank you.

Okay. At this point, I was just telling Desmeon, he's really already talked about this peer support.

Do you have a question? Is it Joey? Okay.

>> AUDIENCE MEMBER: I just want to know what the difference between the home medical/home philosophy is now in comparison to what the relationship I already have with a doctor would be.

>> CHRISTY: If you already have a good relationship with a general practitioner and he's somebody you can contact when you're having a problem and he can refer you to a specialist if need be or he knows you well and understands the injury that you've had and how it's affected your body, then you have a medical home. You just don't call it that.

>> AUDIENCE MEMBER: I was trying to figure out the difference.

>> CHRISTY: There's no difference. You have a medical home, Joey. Good for you.

Okay. At this point, I'm going to turn it back over to Desmeon.

>> DESMEON: Okay. Well, I already talked to you about the peer support and how me and a parent coordinator go together to the CMP, which is Jackie. She's on the photo, if you can see it. And that's who I work with on a regular basis at them CMP clinics.

We also go to different events. We don't only just work in the clinics. Once we get a client on our caseload and we start working within them, we visit them with peer support, one-on-one in the community. We set up group meetings and things like that, basically, depending on the need of the family and the person.

All right. Outreach and information to families regarding medical homes. I just said that besides the clinics seeing people, we do things one-on-one, group meetings. Like I was saying, we kind of have socials out in the community sometimes.

Lately we've been trying to set up peer support with bowling nights and going the bowling alleys and getting the bowling house to donate us lanes where we can come in. They already know if we come, we're probably going to order food from them. We kind of do it monthly as a peer support meeting. That's one of the things we do in the community as an example.

The importance of outreach and information to physicians regarding medical homes. Finding a doctor to serve as a medical home for both pediatric and adult health care can be kind of hard. We all know that many families don't have private comprehensive coverage due to cost.

Many individuals and family, therefore, rely on Medicaids a their only form of primary coverage. After a certain age, most people age out of Medicaid and go over to Medicare. So they won't be able to see the same doctor unless they're taking added insurance.

Many doctors and private practices don't accept Medicaid. I just said that. This often leaves health care groups and hospitals as the only means to get health care. They have to go to ER's, and you don't see the same doctor every time you go to the emergency room. So that's going to make your health care a little bit worse off than it would have been. You want to go where you can see the same doctor every time you need some assistance.

The Family to Family Center in Mississippi, I'm going to let you talk about that part, Christy, if you don't mind.

>> CHRISTY: I don't mind. What we're doing in Mississippi to outreach to physicians to convince them that they should be medical homes. Again, as Desmeon said, one of the issues we have in the state is that a lot of physicians in the state don't accept Medicaid. And yet Medicaid may be the only form of insurance or health care that an individual has. So what happens, as he said, is they end up going to emergency rooms or to these big clinic, the MEA clinics or whatever, and you may not necessarily see the same doctor over and over again.

So the American Academy of Pediatrics, the Mississippi chapter of the American Academy of Pediatrics has begun working with not just pediatricians, but they're also outreaching to adult health care providers to, No. 1, tell them that they have got to -- they need to start -- they're trying to recruit more physicians to accept Medicaid. And, No. 2, they're trying to recruit more physicians to serve as medical homes for individuals with disabilities.

So we've got a good relationship with the American Academy of Pediatrics Mississippi chapter, and they're helping us with that issue.

Judith is telling me I have five minutes. Okay.

>> DESMEON: I will do the tips. Okay. From a consumer to advocate standpoint, medical homes are imperative to promote health and wellness. Understanding your body and your disability is critical. When you're trying to have a good medical home, you want to be able to tell your doctor exactly what's going on with you. And if you study your own body and your habits, you'll have a better understanding of different changes that may occur in your health. No one knows your body as well as you do, hopefully.

(Laughter)

>> DESMEON: You are your own best advocate. So you have to advocate for yourself to make sure you get the services that you need.

Sticking with the same physician allows them the opportunity to really get to know you and your disability. So that's why it's important to stick with the same doctor and not have to go to the emergency rooms and see all these different all the time.

A good medical home ensures that you have an advocate in your doctor, that you get timely and appropriate referrals to specialists. The central location for all medical records and information, it's probably going to be with their primary physician.

Less likelihood of drug interactions. You don't want to take all these different medicines with different side effects that may affect you in a different way. You're more likely to have good health and wellness without all of that.

>> CHRISTY: Okay. Before we turn this over -- back over to David, I have to put a plug in for one more thing. The hospital stay that my husband had last year, unfortunately, he didn't come home. He passed away.

AUDIENCE MEMBER: Ahh.

>> CHRISTY: Thank you.

But before that, we had started -- because of his issues that he was having, and he had a spinal cord injury. I don't want to scare anybody in here with a spinal cord injury, but Daryl had a spinal cord injury. He lived with it very successfully for 42 years.

And all they could tell us -- and this was a university Medical Center. All they could tell us was we think it's metabolic and his (indiscernible) system are shutting down and that his body can no longer fight off illness or infection. His body can't handle it.

Okay. So before that I had seen changes in his body. And I had seen him gaining weight and being unable to stop that process. I had seen how he was emotionally reacting to that. I had seen that he was just not eating, which I knew good and well wasn't healthy, etc.

So we started a whole new health and wellness campaign in our office. It's like my new passion now, to get people with disabilities healthy. So it's no longer, for us, it's no longer just about medical home, and it's not longer just about teaching people with disabilities to understand their bodies and how their disabilities affect them. Now we're really passionate about teaching people with disabilities you have got to understand your body.

You've got to understand how your disability affects you personally and what kind of secondary complications it can cause and the importance of the general health and wellness goal. Maintain your weight. Start young. Don't smoke. Don't drink to excess. Watch the medications that are being prescribed for you. Make sure that there's not going to be interactions. Pay attention to your body. Exercise is important. Healthy nutrition is important.

So it started this whole new health and wellness campaign in our office. And I want to tell you all, we contracted with the Mississippians against Obesity Foundation. And they've never worked with people with disabilities before, but we're really excited to get involved. And they helped us to develop a whole course instruction. And we meet once a week for an hour, and it's an eight week course. And we've held that class three times now.

And I'm going to tell you that the individuals who have the most significant disabilities in terms of most physical, most of them were people who had higher level spinal cord injuries, like Desmeon for instance, did the best. They got it immediately. They followed their instructions. They started to lose weight. They started to feel better. They started to get healthy.

So as a Center for Independent Living, again, it's our new passion. And I want to encourage all of you, Centers for Independent Living out there, to keep in mind that when you're treating the whole person, that includes their health and wellness.

So please consider putting a health and wellness spin on a lot of what you're doing so that individuals with disabilities can live a healthier and a longer life than we're currently seeing now. So I just want to encourage you to do that. And if you want more information about that program, I'll be glad to talk to you about it or Augusta will be glad to talk to you about that.

With that said, I'm going to turn it over to David.

(Applause)

>> DAVID: Nicely done.

I'm going to stand up again because I don't sit well. Thank you very much. Nicely done.

I'm going to take a little bit different approach. We don't have quite that same kind of home -- medical home kind of model in our Center for Independent Living. So I'm going to take a slightly different approach and just describe some of the activities we engage in with young people with disabilities as they transition into adulthood from the health care perspective. So it will be just a little bit different.

Just to kind of set it up a little bit, we have two core IL staff that work in this arena, in this area. We have two personal assistant staff on the administrative side, and then we have one systems advocate. And all of these individuals play a key role in helping individuals disabilities transition into adulthood and to take over a greater role and responsibility in their own health care decision making practices, etc.

In addition to this, we also have between 250 and 300 direct service professionals working at any given time. It varies a little bit because of staff turnover and increase and decrease in the number of consumers that use the personal care attendant program, et cetera. I will tell you that of the eight centers in the state of Minnesota, five of the centers for Independent Living operate personal care attendant programs. And we'll get into a little more detail on that.

We provide some of those services. The IL core service staff are paid for out of the core services budget, so our core service allocation that we receive in the state and federal dollars, like Christy talked about.

And then the PCA staff people are paid for out of the proceeds of the PCA program. And that program approximately generates about $3 million a year in cash flow. Now I will tell you as we move in here that there are -- well, I'll come back to that in just a second.

We also participate in our center -- a big part of our focus on health care is on the public policy side. So we participate with other disability focused organizations to promote public policy that supports the needs and wants of people with disabilities.

You heard Christy talk about the Coalition for Citizens with Disabilities. We have a coalition like in the state of Minnesota as well that really provides a keen focus on those public policy issues and promoting favorable public policy decisions that benefit people with disabilities.

We have a very active role in the CCD organization. I actually sit on the executive committee of the CCD in our state. And the CCD in our state is regularly recognized as being a very strong driving force on the public policy side of health care and development in the state of Minnesota, especially when it comes to serving people with disabilities.

This also ensures that a youth perspective is included in those discussions that are leading to those policy decisions. So we made sure that there is not only an infusion of that IL philosophy in those public policy discussions, but we also made sure there's a youth perspective there as well, because that's a huge part of that.

We also participate with the Minnesota Department of Human Services on developing a youth in transition curriculum. So we work with one form of partnership. And, actually, I was just appointed to a statewide quality assurance committee, that is we have been given a task by the governor's office to come up with a new set of quality assurance standards for health care and related services for people with disabilities. And we will be delivering that to the state legislature in January of 2013.

So, unlike Christy, I'm not afraid of going to the legislature.

>> CHRISTY: I'm not afraid.

>> DAVID: They're afraid of you is what you said. That's right.

So there's a very, very active partnership between the legislature and the disability community. And the outcome of that partnership is not always favorable for us. We're not always pleased with some of the outcomes. There are some shortsighted people in our legislative body. I'm sure many of you can address that in your own states and identify those kind of individuals there as well.

But at least we have a dialogue, and we have an opportunity. And we have some of the members of the leadership in both the House and the Senate that are very, very friendly to our issues and are very accommodating and welcoming of our opinions. So that's very helpful.

Some of the other services that we use to assist individuals in that transition from a health care perspective, I mentioned earlier this morning the Disability 101, the DB 101. It's an online resource to identify and secure appropriate adult benefits for individuals with disabilities.

And it also has a module built into it specifically for youth in transition, and the individuals who are working with you to teach kids about work and benefits. So to make sure that as they transition into adulthood, that they're being connected to all of the appropriate benefits that might be available to them, whether it be a medical home or consumer directed services, we call it in Minnesota, or if it's some other type of community-based or benefit program.

It might be workman's comp or it might be social security or SSDI. It might be one of the waivered programs that exist in Minnesota that they might not be aware that they are eligible for. So using the DB 101 process and walking them through that really helps get them connected to those services that they might be eligible for.

We always provide a lot of one-on-one assistance. For example, working with young adults as they're becoming emancipated. And I mentioned this earlier this morning as well, in providing skill training to teach individuals how to successfully supervise, manage, recruit, hire, their DSPs.

Because for adults with disabilities or young people with disabilities who use a direct service individual, that's a huge part of their health care circle. So being able to make sure that their needs are being met in an effective way and that they're communicating those needs in an effective way and getting them satisfied is critically, critically important.

And we also provide personal advocacy that supports health care needs. So our individual advocate works a lot one-on-one with individuals as they are seeking to better understand their health care needs or to gain access. If they're, perhaps, having difficulty with a physician, like Christy talked about, that maybe they're not getting their message through or they're not being heard or the physician isn't listening well.

Then our individual advocate can work with that individual on a one-on-one basis to develop new strategies so that the individual can be more effective in communicating their needs and getting their needs satisfied, quite frankly.

Now in the state of Minnesota -- and this may be familiar with some of the other states. But in case it's not, in the state of Minnesota, there are primarily two different types of personal care attendant services. We have what we call traditional PCA services, which is a very much a full service model of personal care attendant services.

So the agency takes on the role of recruitment, hiring, training, maintaining the staffing, scheduling the staffing, etc. It's a full service model. So the consumer really does nothing except receive the services. And for a lot of adults with disabilities, I'm sure many of you here, that's not particularly satisfying. You'd like to have a little more control of scheduling and who you hire, et cetera.

So in the state of Minnesota we have what we call PCA Choice. And, again, you may experience something similar to this in some of your state. But the PCA Choice program really places the consumer in the driver's seat.

So the consumer is responsible -- it's not just an option for the consumer. The consumer is responsible for recruitment, for hiring, for training on their care and delivery. We may provide some orientation from a personnel standpoint in terms of our company policies in that, but it's really the consumer that takes the active role with our support and assistance when requested.

But it's really the consumer that takes on that role of training, supervising their day-to-day cares, managing the time sheets, scheduling when the person comes to provide their services and when they don't. It's their responsibility to get the time sheets in on time so their staff gets paid. And they work with us to set the pay levels.

One of the beauties of the PCA -- and that's the -- the PCA Choice is the model that we utilize at the Metro Center for Independent Living. One of the reasons that we choose this is because, as you noted, we have minimal staff on the admin side. We have 250 to 300 DSPs, but on the admin side we have two staff people that manage the program.

And because we can keep our admin rate low -- our admin rate for this particular program is 4 percent. That's low. I mean any of you that are in administrative roles, you know if you can run a program on a 4 percent admin rate, that's cheap. I mean that's low. It's almost too low. That's what my accountant keeps telling us. That's a little too low, David. It's getting to the dangerous level.

But, conversely, what that allows us to do is pay DSPs, the direct service professionals, a higher wage, a higher hourly wage. And we think that's the critical piece because we recognize that DSPs are on the very bottom rung of that health care delivery ladder.

So in order for consumers to effectively recruit and retain quality DSPs so that we can kind of change the perception a little bit of as working -- I worked as a DSP myself. My background is in direct care. So I understand the importance of developing that career ladder of perception within that community.

And by being able to pay a higher, competitive wage, that's one really, really important piece in that process. Our average wage -- our reimbursement rate in the state of Minnesota is $15.40 an hour. It's what the agency gets reimbursed for provision of personal care attendant services.

Our average wage for a DSP is 12.25 an hour, and that's just the hourly wage. That's before add on of any benefits or anything. We're able to pay a higher average wage than a lot of other providers in the state of Minnesota because we commit to that to being a practice.

Yes, Mike. We're getting to know each other pretty well here, Mike.

>> AUDIENCE MEMBER: Is your CIL able to provide health benefits for your personal care attendants?

>> DAVID: Yes. We do provide health care benefits. It's interesting, though. Only about 20 percent of our DSPs actually participate in our company sponsored health care plan. Many of them have a spousal health care plan or something like that. But only about 20 percent, but it is available to them, yes.

And our DSPs, also, they accrue vacation time, sick time. They have personal days. We provide both long and short-term disability insurance and, of course, worker's comp.

Did you want to say something, Christy? Please.

>> CHRISTY: Actually, I have a question.

>> DAVID: Great.

>> CHRISTY: Do you all use -- when you're training the DSP, do you train the DSP or do the consumers train them themselves?

>> DAVID: That's a really good question, and it's actually both. We provide some orientation and training to best practices to consumer relationships and so some of our company policies. But the intimacies of the actual care that the consumer is desiring from the DSP, they actually take the front hand in doing that training. We'll provide support and assistance if they request, but it's the consumer that provides that orientation.

>> CHRISTY: Do you use the college of direct support?

>> DAVID: Yes, we do.

>> CHRISTY: Okay.

>> DAVID: In fact, I'm on their board.

Yes, please.

>> DESMEON: you got the PCAs, and that's completely different than waiver services, right?

>> DAVID: Yes.

>> DESMEON: Okay. And -- let me think. I have to come back to it if I can remember it. I lost track.

>> DAVID: Okay. Just interrupt me, and I'll be happy to do that.

In any event, the PCA Choice program is what really works for us and we believe better fits with the overall IL philosophy and model than a traditional PCA program. So that's why. And, actually, all the five centers for Independent Living in the state of Minnesota, the five of the eight that actually provide personal care attendant program, we all do the PCA Choice.

>> DESMEON: Does the client that's receiving the PCA services, do they have to direct their own care?

>> DAVID: Yes.

>> DESMEON: Okay.

>> DAVID: That's a requirement -- for the consumer to qualify to be in a PCA Choice program, they have to be able to demonstrate the ability to supervise and manage their own care on a day-to-day basis.

We've actually, over the years, we've had some instances where we've had to go to the consumer, and we've had to say you know what? We really think that you would be better served by a full service traditional PCA model. Because, for whatever reason, they just have not demonstrated the ability to successfully and effectively supervise their own cares, and they're placing themselves in health care danger.

We can't support that. Like any other agency, we have mandatory reporting responsibilities. So rather than report them as a vulnerable adult, which is required in our state, we'd rather take the first step of going to them and saying, why don't you let us help you transfer to a more full service PCA program?

So good question. Other questions? Yes, ma'am, in the back.

>> AUDIENCE MEMBER: How long have you been providing the PCA?

>> DAVID: Our PCA program has been in place since 1991. It has not always -- it's kind of funny. It's not always been qualified as PCA Choice because in 1991 PCA Choice, that model didn't exist, but we've always operated that way. So in our state when PCA Choice came along as a model, as a design, we kind of sat back and said this is what we've been doing all along. So it wasn't a big transition for us. We've been doing it since 1991.

The other thing I should share is we try to be very conscious of our PCA program that it doesn't become too big. There's one -- we have one organization in the metro area that serves over 500 people in their PCA program. We don't want to be that big. And the reason for that is we don't want the PCA program to overpower or overshadow the larger efforts and mission of the Center for Independent Living. So we intend to keep our program at about 100 to 120 consumers, and that's purposeful.

Yes. Joe, is it?

>> AUDIENCE MEMBER: Yes.

>> DAVID: Please.

>> AUDIENCE MEMBER: How long of a waiting list do you have? I know in Connecticut we've got like a two-year waiting list for our PCA waiver program.

>> DAVID: In the state of Minnesota, for PCA services we don't have a waiting list. And at our specific Center for Independent Living, there's no waiting list.

The one frustration we do have is every consumer and every direct service professional has to have a unique provider number, what they call an UPIN number. When we apply for that, it generally takes four to six weeks to get that number issued by the Department of Human Services. And there's no logical reason why it takes four to six weeks to get that number. The background check has already been done when we submit that. We can't submit the application.

Very briefly, a little story that kind of frustrated me. Last summer, we had a batch of new applicants. And the other thing is you can only fax the application. You can't send it electronically. You can't mail it. And God forbid you should want to hand deliver it because they have no idea what to do with you if you show up with, you know. So you can only fax them.

We faxed this batch of 14, and you have to wait several days before you can call in to see if they've got them. Because they, internally at the Department of Human Services, have a policy that they are allowed ten days to scan the application into their database.

So they receive it by -- it's a one-page application. But their policies allow them ten days to scan this one page. And you have to wait a certain number of days before you can call. So we wait those prescribed number of days, and they're like, no, we didn't get that batch.

Okay. We'll fax them again. So we fax them again. So now we're already seven days out. People are waiting to go to work. Consumers are waiting for services. So now we're already seven days behind. We had to wait the seven requisite seven days again.

We call. No, we didn't get those. So now we're 14 days behind. So I get on the phone, and this young lady on the other end, and I said, ma'am, I said this is really, really frustrating. We have people waiting to go to work. We have consumers waiting for services.

And she said, well, you know we have a ten-day policy. We're allowed ten days to scan this into our database. And I said, all right, well, I get that. While it's frustrating, can you at least -- I'm going to fax them right now. We'll resend them right now. Can you walk over to the fax machine and just tell me if they arrive. She giggled. She giggled at me and said, well, I'm sorry. I don't even know where the fax machine is.

(Laughter)

>> DAVID: So that conversation came to a very abrupt close. At that point, you just have to start working up the ladder.

The other thing that we do is we provide advocacy supports to youth and their families as they make choices regarding that transition from youth to adult services. So we try to work one-on-one with youth and their families.

Again, as Christy said, keeping the priorities of the youth in the forefront. We involve the families in the discussion, but it's our responsibility to represent and to support the decisions of the youth.

Yes, Judy.

>> JUDITH: I was interested in the PCA Choice. Do you have young adults that are receiving -- that have their personal assistance through the PCA Choice?

>> DAVID: Yes. Absolutely.

>> JUDITH: And how do you support or assist them in that process?

>> DAVID: Excellent question. Thank you for asking it.

We do have -- we have served people as young as 3 in our PCA program. For the young adults, if they're under the age of emancipation in the state of Minnesota, then they have to be represented by a responsible -- what's called a responsible party.

Most often that's a family member, a parent, although not always. It may actually be a guardian of some nature. It may be another relative or whatever. But they have to be represented by a responsible party. But, yes, youth are eligible for the PCA Choice.

Other questions? Yes, in the back over here. I think it's table 3.

>> AUDIENCE MEMBER: Is that me?

>> DAVID: Yes, ma'am.

>> AUDIENCE MEMBER: Okay. Two questions.

>> DAVID: All right.

>> AUDIENCE MEMBER: Are all of the consumers in your PCA program Medicaid recipients?

>> DAVID: About 85 percent are Medicaid recipients. The other 15 percent are either insurance company or private pay.

>> AUDIENCE MEMBER: Okay.

>> DAVID: Very, very few private pay.

>> AUDIENCE MEMBER: I forgot my other question, and it was actually better.

>> DAVID: Did you just stun you with your answer? Is that why you forgot your question?

>> AUDIENCE MEMBER: Maybe so.

>> DAVID: All right. Well, you think of it and raise your hand again. We'll come back to you. All right?

Also, as I mentioned earlier this morning, but it comes into play again in this context of our transition program, is that MCIL manages the Disability Linkage Line, which is that one stop call center for any questions that are disability or chronic illness related.

And we serve all ages and demographics through the Disability Linkage Line. Last year, in our last reporting year, about 4 percent of the people we served through the Disability Linkage Line were under the age of 18. So I don't know what 4 percent of 40,000 is.

Oh, the hand is back up. She remembered her question. Yes, ma'am.

>> AUDIENCE MEMBER: Are family members allowed to serve as the DSPs in your state?

>> DAVID: That's an incredibly, incredibly timely question. What a great, great question because we're having legislative battle on that subject right now. Yes, to the first part, because it's a two-step answer to your question.

The first step is, yes, family members are allowed to work as personal care attendant or direct service professional for a family member. There is a measure working through our state legislature right now. However, that will allow a provider -- require, not allow, but require provider agencies to pay 20 percent less. We will be reimbursed 20 percent less for family members providing DSPs services as opposed to a nonfamily members.

The rationale on the part of the Chair of the Health and Human Services Finance Division in the House and supported by several committee members, the rationale is that the family members have a moral obligation.

This is written -- I'm not translating. That's what is actually written into the legislation, is that the family member has a moral obligation to provide these services, and that's not the worst part. And that by providing a 20 percent reduction in the reimbursement rate for family members, they will very, very likely continue to provide the services anyway. So it's kind of like let's give it to Mikey. He'll eat it. He'll eat anything, right?

So we're challenging that. We're battling that now saying that this really isn't a question -- it's a question about quality service delivery. And the decision that the legislature is making has nothing to do with competency, has nothing to do with skill or availability. It has to do with a perception of moral responsibility.

I was talking to the chair of the committee, and I said I was raised in a household where we were taught that you have to give back. Both of my parents were very involved in the community, in volunteer capacities, and so on and so forth -- taught to give back. So I believe it's a moral obligation for us to give to our community. So I think members of the legislature in giving to the community should serve without pay.

(Applause)

>> DAVID: It didn't go over real well. I didn't get the same reaction that I got from you guys.

So in any event, it went to a court case, and it was the implementation of that law, because it was actually put in place in the last legislative session. And very quickly lawsuits popped up based on discrimination, because, again, you're making the decision not based on skill, talent, competency, etc. You're basing it on a familial relationship. That's discriminatory.

Well, the court ruled in the legislatures favor, and the court used their language in their ruling saying, yes, we believe that the families do have a moral obligation. So now it's back in the legislature, and we're -- and, of course, the other thing they're saying to us is if this is reversed and we don't implement it, then we've got to find $24 million somewhere because that was the proposed savings they were going to be able to acquire by making this cut.

So the battle continues. The battle continues, and we're going to see how it works out at the end of this legislative session. The governor believes that he can find the money somewhere else. So we'll see. But that was a really good question.

I mentioned earlier this morning, also, the living well with curriculum -- or living well with a disability curriculum. We also use that in this context as well. This curriculum travels to various programs within MCIL. So you'll hear me repeat it a few times. I won't run through the list again because I've done that before.

Yes, sir.

>> AUDIENCE MEMBER: You all were trying to limit the number of people who have participated in your PCA program. So, of course, there being some program income (indiscernible) What you look at it as. With more resources, you're able to serve more people.

>> DAVID: Correct.

>> AUDIENCE MEMBER: So help me understand the board's thinking there.

>> DAVID: Okay. All right. Well, thank you for that question. It's a really good question.

Several years ago the board of directors at the Metropolitan Center for Independent Living made a conscious decision to keep our PCA program at about 100 to 120. And the reasons for that, as I mentioned earlier, is because they didn't want the PCA program to become larger than the core service programs. They didn't want it to overshadow our core service operation.

Essentially, as a Center for Independent Living, our fundamental responsibility is the delivery of those four core services. The PCA program is a nice add-on. It's a nice ancillary because it provides an incredibly valuable service to people with disabilities. But we also have a responsibility, it's reflected in the federal regs, that the core services cannot be subordinated by other overarching services in a Center for Independent Living. So that's why we have decided at our site -- this is not statewide, it's just at our site -- that we've decided to manage our PCA program at about 100 to 120 individuals on an annual basis, on a regular basis, for those reasons.

Now, does it produce revenue? Sure. There's some net revenue gain from that, and those net revenues from the PCA program get poured back into the PCA program. That's how we provide the benefit package and so forth. We don't regularly use the proceeds from our PCA program to shore up the other core services. Again, that's a conscious decision on the part of our board.

>> CHRISTY: David, I would assume that since it's not connected to a Medicaid waiver that you don't have those rules and regulations that have been put into a waiver.

>> DAVID: Right.

>> CHRISTY: So you can do -- I mean, you guys set the program up. And you've designed your rules and regs the way you wanted to because it's not connected to a Medicaid waiver. If it were connected to a Medicaid waiver, you would have to follow whatever rules and regs they wrote into the waiver when they sent that waiver into CMS.

>> DAVID: Yeah. It is Medicaid reimbursed, but it's not through a waiver. It's not on a waiver, yeah.

Yes, ma'am. I've got five minutes here. So I'll take a couple more questions.

>> JUDITH: Well, a couple of -- you've got about six or seven minutes, actually.

>> DAVID: Oh, okay.

>> JUDITH: But I thought there might also be questions that people still wanted to ask Christy. So I just wanted everyone to know that we're kind of wrapping up this session. The questions are great.

>> DAVID: And I'm done with my slides, so that's fine.

>> JUDITH: Okay.

>> DAVID: Because the curriculum was listed again, which you've all seen before.

Yes, ma'am. Your question, please.

>> AUDIENCE MEMBER: Can you go into a little more detail about what you teach the people at the center who are interested in the PCA --

>> DAVID: Sure. Absolutely.

>> AUDIENCE MEMBER: The teenagers, more specifically.

>> DAVID: Sure. One of the things that we do with the youth is preparing them for, again, how to effectively supervise a DSP. We teach advocacy and self-determination skills.

As Christy was talking about and Desmeon were talking about, is when the young person begins to more actively participate in their health care decision and health care discussions around their lives, that they're going to be more knowledgeable about their disability.

And they're not just going to be more knowledgeable, but they're going to be able to talk about their disability in a meaningful way. And they're going to recognize when something is not working quite right, and that's the most critical piece.

A lot of people, no, I'm just getting these aches and pains. I'm just getting older. I'm just this. Well, they don't realize that it might be symptomatic of something bigger, and you don't ignore those kinds of things. So those are really the self-advocacy skills, the self-determination, being willing to speak up.

And, you know, the other thing is, as part that, is encouraging the individual not to allow themselves to be seen as a mono dimensional individual. One of the things that people with disabilities -- and I know many of you know this because you live it every day -- is that one of the challenges that you face is -- and Mike made this point earlier, you know, what do you like to be called? Well, so often people with disabilities are treated in a very mono dimensional way because they're seen as their disability first.

I do a lot of work with parents. And we'll go around the room, and everybody introduces themselves. And I say tell me a little bit about your kids. Well, I have a 7-year-old, Down Syndrome. Doesn't tell me anything about the kid.

I can tell you about someone in my life. Her name is Rosalind. She's 21 years old. She's graduating from high school this year, and she's so excited. She is stubborn. She loves cheese and hot dogs. She is a great athlete. She loves volleyball, and she's an incredible basketball player and a very good swimmer. She likes to go hunting with her grandpa.

She can be very stubborn and very strong willed. She'd like to go to school. She can't decide whether or not she wants to be a beautician or a veterinary assistant, which I think would make a wonderful mix.

(Laughter)

>> DAVID: But we'll get back to that.

>> AUDIENCE MEMBER: A groomer.

>> DAVID: Yes, exactly. She would be a great groomer.

And, oh, she happens to be diagnosed with Down Syndrome. You know, the point is one of the things we try to instill in youth with disabilities is don't allow yourself to be defined by your disability. It's part of the who you are, absolutely, but you're so much more than you're medical label. Rosalind, who is incredibly dear to me, is absolutely a multidimensional individual. She's so much more than that medical diagnosis, that medical label. I always tell people that two weeks before my grandfather died, he had a gall bladder operation. Now for the remaining two weeks of his life, we didn't refer to him as the gallbladder.

(Laughter)

>> DAVID: You know, when somebody contracts a venereal disease, we don't refer to them as the syphilis, right?

(Laughter)

>> DAVID: It's silly. I know, it's funny, isn't it? It's silly. We wouldn't do that. But we do that to people with disabilities all the time.

So one of the things we try to instill with youth with disabilities is an understanding about their disability and the way to talk about it in an effective way, but not allowing themselves to be completely defined in that mono dimensional way by their disability. Because people with disabilities are incredibly multidimensional.

One last question? Two more questions? Oh, she's cutting me all kinds of breaks today. I love it. Anybody? For me or for Christy? I'm not hogging the stage here. Really, we've answered every question you can possibly have? Really?

>> CHRISTY: They're hungry David. They're hungry.

>> DAVID: Oh, that's what it is. Okay. You're tired of me. All right. Fine.

>> CHRISTY: Well, thank you all for your attention.

(Applause)

>> JUDITH: Just a reminder, we'll do the same routine that we did yesterday. That is pick up your things, leave the room. Now you've got -- actually, you have 17 minutes of free time. Okay? Come back in. The place will be here waiting for you. Thanks again to the panel.