

## Empowering Independence

### Episode 5 Transcript

September 18, 2019

Disclaimer: The following is a presentation of Consumer Directed Choices. The views expressed by guests appearing on the *Empowering Independence Podcast* do not necessarily reflect the views of Consumer Directed Choices or its management.

(musical introduction)

Blaise Bryant: “Welcome to Episode 5 of the *Empowering Independence Podcast* presented by Consumer Directed Choices in Albany, NY. I’m Blaise Bryant.

Before we get into the main substance of the podcast, I have some sad, breaking news to tell you. Last month you heard a conversation from 2017 with Marca Bristo and Joel Margolis. On September 8, so about a week ago, Marca lost her battle to cancer. She was 66-years old. In 1977 she was in an accident. She became paralyzed from the chest down. Three years after that, she founded Access Living in Chicago. That was 1980. That is the agency that you heard her talk about. Access Living is an independent living center. They do a lot around policy and employment and peer advocacy for people with disabilities. In 1984, Access Living sued the city of Chicago’s transit system. They won the suit. Busses were put on lifts before the American’s with Disabilities Act was passed, which Marca was an integral part of making that happen; so much so, that in 1994, then President Bill Clinton not only appointed her to be the Chair of the National Council on Disability. He gave her an award for her work as an integral part of the passage of the American’s With Disabilities Act. In 2017, Marca found out she was diagnosed with cancer and left us on September 8, at 66-years old. From all of us here at Consumer Directed Choices, we extend condolences to Marca’s friends, family, and colleagues. Rest in power, Marca.

Now, we talk about the main substance of the podcast here – the Empowering Independence podcast. You can get it wherever you get your podcasts.

There is a lawsuit we’ve been telling you about, with saving the Consumer Directed Personal Assistance program (CDPA) as we know it. We’re going to hear from two fiscal intermediaries. We’ll start with Elizabeth Martin, the CEO here at Consumer Directed Choices

I caught up with her here in her office. We go over a timeline of the lawsuit.

Elizabeth Martin: “On July 1, the New York State Department of Health issued guidance, in which they had announced the per member per month rates that they were planning on reimbursing fiscal intermediaries for their operations. They were incredibly low. We were looking at cuts that could be as much as 60, 70, 75% of our costs. We decided that we really had no other recourse other than to file an

Article 78 Proceeding lawsuit against the state. An Article 78 Proceeding basically challenges a state's decision on something. So, it's basically our attempt to appeal a state decision; and, the grounds or merits or complaints on this Article 78 of what this state decision is – we're arguing that they didn't follow their rule-making process as they are supposed to, and we're also arguing that they – their rates were set in an arbitrary and capricious manner.

We filed that at the end of July, and the petitioners on the lawsuit include our state-wide association CDPAANYS. They're kind of the lead in this whole thing. There are also two state-wide associations on it – the New York Association of Independent Living and HCP which stands for Health Care Providers. They are all associations that represent fiscal intermediaries across the state. In addition to those three associations, there are also twelve fiscal intermediaries that are also named on the suit. Consumer Directed Choices is one of them, and the rest of them are various independent living centers across the state that do fiscal intermediary services. So, we filed the lawsuit in July.

In August there was a hearing in which the state was listening to a couple of requests from both sides. We had a request on our side – We had a request for a preliminary injunction. We were asking the court to basically prohibit the state from moving forward on implementing rate cuts until the merits – our complaints could be heard and decided upon by the court. The state had asked for a Motion to Dismiss. They wanted the court to say – you know – “dismiss the case,” and say, “we're not looking at this on the grounds that the fiscal intermediaries did not have standing; so, they weren't being harmed; or, they didn't have any right to sue the state, as the argument that the state's doing everything fine.

About a week ago, the state – last Friday – the state – the court excuse me – the court came out with a decision. Judge Ryba came out with a decision on both of those requests. It was a mixed bag for us. So, first, our preliminary injunction was denied. The reason why it was denied was because we really – she – she stated that we could not prove that we were going to experience irreparable harm. The reason behind that was none of us were going out of – if the cuts get enacted, we're not going out of business right that moment. We are – She felt as though she could handle these court proceedings come up with a decision on the merits of the case prior to any of us going out of business. On top of that, if the court were to find in favor of us, basically the state would then be paying us the rates – They would be nullifying the cuts at that time, and we would be paid our rates. So, therefore, any money that we lost for a short time we would get back.

So, that was the basis for why we did not – why we were not able to establish irreparable harm in the eyes of the Judge. The Judge also denied the state's motion to dismiss. She was very clear to say that we all had standing. Even the associations had standing and had grounds to pursue this lawsuit; and, she also seemed to indicate that the merits, or our complaints were very valid for her to have to review to determine if the state is indeed violating certain aspects of the law. The state also had their Motion to Dismiss denied, and the state wants to review our complaints and wants to make a decision. She is also, Judge Ryba, recognizing the urgency of this whole thing, because she has put it on a fast track to be reviewed by her. So, normally, from what I've heard the courts might take a month or so to get – you know – arguments put in or what not. She wants us back September 13, and she wanted the state to

give their arguments in ten days. So, she's really trying to speed this up so that she can come up with a decision fairly quickly, which is helpful."

BLAISE: "Understood. I also want to note that in New York State, contrary to what we're taught in grade school in terms of the way the judicial system works, the Supreme Court in New York State is the lowest court. It is not the highest court."

Elizabeth: "Yes."

Blaise: "So ---"

Elizabeth: "Yes – The – Is it – The Court of Appeals or Appellate Court – one of the other."

Blaise: "Yes, the Court of Appeals is the highest one."

Elizabeth: "yes."

Blaise: "This would still be reviewed then in Albany Supreme Court on the 13<sup>th</sup>?"

Elizabeth: "Yes. Yep – it – with the same Judge."

Blaise: "What are the scenarios here that we're talking about?"

Elizabeth: "Well, the – and I'm not an attorney, so – you know – just from – don't take this as – like – legal – legal advice or anything. The way it's been explained to me is that there are a few things that can happen. One is that the Judge could find in favor of the state and say that they're doing everything lawfully, in which case the state can continue on their merry way with what they are doing with the PMPMs and then the cuts to the plans and things like that. The other thing that can happen is that the Judge could find in our favor, and – you know – we have a few complaints in there; so, it is possible that she finds on some complaints but not others. But essentially, if she were to find that the state didn't follow their rule-making process or was acting arbitrary and capricious, it could nullify the cuts for now and the PMPMs for now. It doesn't necessarily make them go away forever. It does make New York, the way I understand it – New York to have to take more time to go through the proper process and reviews and that kind of thing before they can put through the PMPM. So, we're hoping that if that were to happen, that the states a more thoughtful approach to what they're doing."

Blaise: "So, they could still – meaning the state – do whatever they want."

Elizabeth: "Theoretically, yes, just delayed, but what we – again what we're hoping for is that the state would – and we're still advocating for this quite honestly – that the state takes a more thoughtful approach to a PMPM so that it doesn't jeopardize the program. Right now, our biggest concern is that the way that this is moving forward is that the program is at risk. The cuts:

A: are too, too deep for any fiscal intermediary to consider sustainable, and then the other thing that we're very concerned about is that it could have an effect on worker wages and benefits which affects consumers' care. I mean – if a worker has a cut in their wages and benefits, they're much more likely to

leave for a higher paying job, and it doesn't help the consumer; and, there's a home-care shortage out there. Consumers are recruiting off the street. There's – More than half our consumers hire people they never had a relationship of any sort prior to employing them. So, they're not family or friends. They're hiring off the street. So, they, in effect, are competing against retail, fast food, any of those other occupations that quite often at this point pay more than what they can earn as a Personal Assistant. So, the idea that there could be wage cuts or benefit cuts just exacerbates that; and, it just makes it even worse. So, we're really concerned with the impact that these cuts – even though they're trying to focus it just on fiscal intermediaries, there's only so much cut you can take before it starts to sort of hit everywhere else. That is what we are very concerned about.”

Blaise: “I've been getting a lot of calls from consumers who are, rightly-so, very confused about everything that's going on. Because, while some of them understand what's going on, there are also some that are under the impression that hours are being cut ---”

Elizabeth: “Eligibility for the programs' are not being cut; hours are not being cut by what the state's doing. That's not – that's not where their services are being – going to be affected. That will all stay the same. So, when that – the state is accurate with that aspect of it. Where we see the impact on services is just the fact that funding for services is almost entirely worker wages and benefits; and, so, when cuts get very, very deep, it's – that's actually – that's almost 90% of the program itself – is PA wages and benefits. In many cases it's almost 90% of the program. So, it doesn't take much of a cut before it starts to bleed over into what's the funding for the services. So, while the hours may stay the same, the eligibility may stay the same, the consumer's care plan might stay the same – they are going to have difficulties staffing it.”

Blaise: “What can consumers do to help out and make sure this doesn't happen?”

Elizabeth: “They can contact the Governor's office and share their stories about how Consumer Directed Personal Assistance has helped them, and to share their concerns about the cuts, and to ask – urge the Governor to stop the cuts and to have the Department of Health take a much more thoughtful approach to implementing PMPM.”

Blaise: “Governor Cuomo's phone number is 474-8390. You hit option 2 to speak with an actual human being to listen to your story as of – as a consumer of how CDPA helps you. Personal assistance, I think, would also benefit from calling too, wouldn't they?”

Elizabeth: “Yes – yes, they can. Family members – anyone actually who has a concern about this – and it's area code 518 too for those that might be outside the area code.”

Blaise: “Again, that number is (518)474-8390. I meant to ask this earlier; but, do we have any sort of clue as to when the Judge will have a decision after September 13?”

Elizabeth: “That’s a hard guess. I’m assuming it’s going to be some time this – not this month – it’s still the last couple of days of August. I’m assuming it’s going to be some time in September, but I can’t guarantee anything, simply because you never know. But we’re hopeful it’s sometime in September.”

Blaise: “Elizabeth, as always, thank you very much.”

Elizabeth: “You’re welcome.”

Blaise: “We’ll take a quick break and be back with another fiscal intermediary, this time from the western part of the state here on the Empowering Independence Podcast.”

(Commercial for CDPA)

Voiceover: “Consumer Directed Personal Assistance helps seniors and people with disabilities.”

Consumer: “It gave me an opportunity to hire my own assistants, be able to direct my own care. They can help me live an independent life.”

Voiceover: “To learn more, visit [CDChoices.org](http://CDChoices.org).”

Musical introduction)

Blaise Bryant: “Welcome back to the Empowering Independence Podcast presented by Consumer Directed Choices in Albany, New York. I’m Blaise Bryant. Kathryn Carroll is the manager of Government Affairs for the Center for Disability Rights (CDR). They have an office in Albany, but their main office is in Rochester. They are also an independent living center That is an FI. I spoke with Kathryn about a week-and-a-half ago. I started off our conversation by asking her why the Center for Disability Rights joined onto the lawsuit.”

Kathryn Carroll: “So I think I can answer your question in two ways. The first is more of a philosophical reason. Basically, we see – we in the disability community, see the per member per month rate methodology and the cut that it represents to Medicaid funding in New York state as a threat to the independent living of disabled New Yorkers. The idea of Consumer Directed Personal Assistance, or home care, was actually begun in New York; and, it is incredibly important to people with disabilities – abilities who live independently – not only because we can get the services that we need, but also we get to direct our own care, and we have the freedom to hire who we like; and that, again, is part of the independent living philosophy – being able to make decisions and have control in your own life. The other reason is a – basically no-nonsense factual numbers reason. The per member per month rate methodology is unsustainable. Fiscal intermediaries cannot perform the functions that we need to perform to ensure that the Consumer Directed Personal Assistance program can continue. Like the other plaintiffs in the suit, we knew right away that the numbers that the Department of Health proposed would not allow us to do our job. That’s where it became necessary for us to file suit with all of the other plaintiffs.”

Blaise: “You are FI primarily in the western part of the state. We’ve heard a lot, and certainly, we’ve focused on the eastern part just because of where we are here in Albany, but not too much in the western part of the state. I understand that the climate is a little bit different in terms of how people are served and the number of FIs in the Rochester area?”

Kathryn: “Right – I think that’s fair. I mean- we know that there are many FIs operating downstate and in New York City. So, we know that going into this the Department of Health intended to basically reduce the number of FIs operating in New York State; and if you’re downstate where you currently have more options, the idea of a – of a smaller number of FIs may not be as scary, but up in – and the flip side is that upstate, the idea that – you know – the FIs around you – the fewer choices that you have are considering ending their operations is very scary.”

Blaise: “Absolutely. Kathryn Carroll here with me on the Empowering Independence Podcast. We go back to court, Consumer Directed Choices, Center for Disability Rights, CDPAANYS, NYAIL, and other organizations on September 13, even though on September 1, the state did go through in implementing per member per month rates for people who receive fee for service Medicaid, which is Medicaid that people receive through the county departments of Social Services. You have an attorney background. What are the scenarios here?”

Kathryn: “So, we actually just got an update on a court date. We are supposed to be back in court – we being the plaintiffs and our counsel, on the 13<sup>th</sup>. It was just shared with us that the Department of Health HAS asked for an extension and to go back to court on the 20<sup>th</sup> instead of the 13<sup>th</sup>; and our legal counsel has opposed this. So, of course, we would like to be heard in court as soon as possible and that the Judge understands that this needs to be taken care of quickly. So, we hope that 13<sup>th</sup> date stays and that there’s no delay.”

Blaise: “So, at this point, on the 13<sup>th</sup>, it’s now a wait and see.”

Kathryn: “Right. I hope that we will hear soon on whether the extension has been granted. When we are heard in court – So, I say heard – so, heard has particular meaning here because there will be arguments on the substance of our lawsuit. It’s referred to as an Article 78 lawsuit. We’re basically arguing that – We are opposing a policy decision by a state agency, the agency here being the Department of Health, and at the same time arguing that the Department of Health did not follow proper procedure in adopting the per member per month rate scheme.”

Blaise: “Now, what exactly is supposed to be the proper procedure as you understand it with your background as an attorney?”

Kathryn: “I don’t have personal experience with these types of – these types of lawsuits, but I can help explain what – by kind of analogy – what happened VS. what should have happened. The difference here is between informal and formal adoption. In this case, the department just went ahead and decided that this was the rate scheme that they were going to do, rather than putting the rate scheme out to the public as you would with other things that require public comment – a public comment

period – and giving people the opportunity to – the public to weigh in on the proposed changes. So, we’re arguing that by just going ahead with this rate scheme they did not follow proper procedure.”

Blaise: “Understood. In terms of the scenarios, from my understanding, if we win the lawsuit, we’re able to get the money back from the rates – from the per member per month for fee for service. It is still a mystery at this point as to what managed care plans are doing. But if we are not successful, what happens and where could we go from here?”

Kathryn: “So, right. There’s as you mentioned earlier, there is a difference between how this affects payment and fees for service and in managed care. The threat to CDPA has been particularly apparent in what the managed care plans have done in response to the budget cuts and the per member per month proposal. Just to give you an idea, under the per member per month rates, the spending by fiscal intermediaries is on administration of the program, so not wages, would be about 4%. Currently, it could be upwards of 12 ---”

Blaise: “Whoa.”

Kathryn: “so, a significant cut there; and one example of – Meanwhile, one managed care company has proposed to reimburse us at a rate that would only allow us to spend between 2 and 3% on administration. So, even less, shockingly, than what the state rates would allow. So, I just wanted to emphasize that it’s just become very clear to us that the threat to the program posed by these changes. I worry about spending too much time thinking about what happens if we lose. I think based on what was said in the hearing – not the formal hearing, but what was said by the Judge when she was hearing arguments about whether to grant a preliminary injunction, that she understands the issue. She asked wonderful questions that really got at the heart of what’s really going on here with the Department of Health. So, I am very hopeful that even – even while not granting the preliminary injunction, that the Judge will make a fair and right decision when it comes to the substance of the lawsuit.”

Blaise: “Understood. I have been asked if things don’t go as planned, is there the possibility of an Olmstead case.”

Kathryn: “I think there should be. I would hope that at least among the plaintiffs and also among the FIs and other organizations who were not able to join us in the lawsuit, that we would – we would seriously consider that option. There is a fairly – in my mind – a fairly direct – direct connection between the funding for this program and its ability to function and the ability of disabled New Yorkers to live in the most integrated setting possible. I guess that’s all I can say. I would hope that that would be a serious option for us on the table.”

Blaise: “Kathryn Carroll, the Manager of Government Affairs for the Center for Disability Rights here in Albany, as well as the larger office in Rochester. Always good to talk to you, and thanks for a few minutes on the Empowering Independence Podcast.”

Kathryn: “Thank you.”

Blaise: “We have an update on the court date. Elizabeth said the 13<sup>th</sup>, which a couple weeks ago was true. Kathryn said that the date is up in the air – not anymore. We will be in court on Tuesday, September 17, in Albany Supreme Court. There is an event for people to come and show their support for the court hearing. It is not intended to be an ADAPT action. That would not look good for us quite frankly, and this is just for Consumers, Designated Representatives, and Personal Assistants to come and show their support for CDPA. You can find out more information about the event. It is from 9:00 a.m. to noon on our Facebook page: [www.facebook.cpom/CDChoices](http://www.facebook.cpom/CDChoices).

Thank you so much for listening to Episode 5 of the *Empowering Independence Podcast*. Thank you to my guests, Elizabeth Martin and Kathryn Carroll, also to Loreal Lavigna for our podcast transcription. Your comments and feedback are welcome at [info@CDChoices.org](mailto:info@CDChoices.org)

Make sure to call Governor Cuomo, area code (518)474-8390. Hit option 2 so you can speak with an actual human being who is able to listen to your story whether you’re a consumer, designated representative, personal assistant, family member, friend, or neighbor about how CDPA impacts your life.

Again, thank you so much for listening. We look forward to talking about disability and employment as part of Disability Employment Awareness Month in October, here on the Empowering Independence Podcast.

*(Exit music)*