

Empowering Independence

Episode 6 Transcript

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(musical introduction)

Blaise Bryant: “Welcome to Episode 6 of the *Empowering Independence Podcast* presented by Consumer Directed Choices in Albany, NY. I’m Blaise Bryant.

BLAISE: “As we are taping this in the large conference room here at Consumer Directed Choices, and we have a gold-star panel because, well, there’s a lawsuit that we have to talk about that we won thank goodness; and we’re going to talk about the result and where we go from here.

So, from left to right order, Hermes Fernandez from Bond, Schoeneck, and King. He specializes in health and government law. Hermes, good to finally meet you, and thank you for a few minutes here with us.”

HERMES: “Thank you, Blaise, good to be here.”

BLAISE: “Bryan O’Malley from the Consumer Directed Personal Assistance Association of New York State – the Executive Director. Bryan, always good to see you. Thank you very much.”

BRYAN: “Thank you, Blaise.”

BLAISE: “My pleasure. And, Elizabeth Martin, the Chief Executive Officer here at Consumer Directed Choices. Elizabeth, always good to see you, and thank you for a few minutes.”

ELIZABETH: “You’re welcome no problem, Blaise.”

BLAISE: “My pleasure. Hermes, I’ll start with you. When you found out that the Consumer Directed Personal Assistance Association of New York State (C-D-P-A-A-N-Y-S) was thinking about seeking legal action, what went through your head?”

HERMES: “Challenging government actions is very difficult, and the fact that we were having a discussion about going into court meant that we were talking about last resorts. It really meant that the Consumer Directed program was in a very bad place, that the government action was so tremendously difficult and threatening, we had to explore what options were available. I was a reluctant warrior. As we discussed things with the association, with Bryan, with Elizabeth, with some other folks, we spent a lot of time talking about the challenges that a lawsuit would entail.”

BLAISE: “You certainly have been no stranger to C-D-P-A (Consumer Directed Personal Assistance). How long have you been working with the association? I mean, I know you have presented at conferences and that sort of thing.”

HERMES: “I’m not quite sure how long I’ve been working with the association, probably fairly close to the start of the association; because I actually started working in the Consumer Directed program with CD- Choices and its founder Constance Laymon. I was introduced by another client actually before CD Choices had served anyone, as it was still in its organizational phase.”

BLAISE: “Interesting. Now, Bryan, over to you now. What was the straw that figuratively broke the camel’s back in terms of wanting to seek litigation?”

BRYAN: “I guess the straw that ultimately broke the camel’s back would be the refusal of the Department of Health to look at any alternatives and ways to save money. When we first heard about the proposal in January, we fought it. However, when the budget was resolved and we had some small victories but for the most part still had a \$150,000,000.00 hole we needed to fill, we decided to try to work with the department to come up with ways to create savings that would not harm the program or the 75-80,000 people that rely on it. It quickly became apparent that that wasn’t a possibility, and that’s when we turned to looking at other options – and what were our options apart from just trying to get it reversed? Pretty much the only thing left was legal action.”

BLAISE: “Understood. Elizabeth, you run CD Choices here. One of the Fiscal Intermediaries (F-Is) that joined onto the lawsuit – How come?”

ELIZABETH: “We needed to save the program, and we saw it as we really didn’t have an option. To make the lawsuit as strong as possible, it needed to have individual FIs represented on it, because we were the ones with the biggest stake – actually the Consumers are the ones with the biggest stake – but through us – We had the direct stake in what was happening. In talking to the board, and in fact Hermes was on the conference call with our board to talk about getting onto the lawsuit, and it was – it was an immediate reaction of, “yeah, we’re gonna do this,” because we saw it as no other choice. The program was at an incredible risk.”

BLAISE: “We’re talking about what could have been 80% of the cuts. Now, I know there’s some bad news. But for right now, let’s just focus on the good news here. October 11, we won the lawsuit. Hermes, your reaction, and were you at all surprised? Because, as you said, taking action against the state is tough. It has been successful before, but I’m kind of getting the impression from you that it doesn’t happen all too often.”

HERMES: “Victories against government actions don’t often happen. I’ve told people this analogy more than once which is, when you are challenging a government action, you are using their deck of cards, their card table, and their rules; and then you have to try to win that game. So, it’s – it’s always a daunting challenge. Courts, despite what people may hear about activist judges, are typically reluctant to rule against the governmental actions; and we can see that over, and over, and over again; and in case law, judges find one reason or another not to rule in favor of the challengers in what often look like meritorious causes. So, as this case developed, I was becoming more and more confident. But when I saw that we had won – In fact, before I saw that we had won, when I got the notice that we had a decision which arrived by E-mail – I was anxious, immediately flipped through the entire decision not reading anything until I got to the last paragraphs. (Blaise laughs) I was looking – I went backwards. First, I looked to see – did we win, or did we not? So, I was thrilled, really, really thrilled when I saw that the Judge had declared the Department’s action null and void. It was – it truly was a thrilling moment. It was something that we were hoping for. We knew – we knew what was at risk, and very often when government actions are challenged, they are not so central as they were in this circumstance. This one was really – you know – we had to land on the beach. The troops had to – the troops had to get there; and we got there.”

BLAISE: “The troops got there indeed.

Bryan, you called October 11 probably the best day of your professional career which says a lot. I mean, you have a lot of political background in terms of working with various members of the assembly in particular Richard Gottfried and other associations. How come you consider this – or you considered this the best day of your professional career?”

BRYAN: “I think it comes in large part because of the amount of work that so many people put into making it happen. From the Fiscal Intermediaries like CD Choices, to Hermes and his colleagues at BSK. I think most importantly, all of the Consumers and workers and family around the state who had worked so hard since January to try to stop this from happening, and just to know that that victory – that they had gotten this victory that was significant. It really afforded us the chance to go back and hit the reset button, and there’s not many opportunities in life to hit the reset button and try to fix something before – before devastating damage is done. I think – you know – there has already been some damage that has been done, but we have that chance and really for all of those folks who have poured so much into this campaign, it was good for them to get this victory, and it felt good from my perspective knowing that – you know – we had a second chance.”

BLAISE: “You along with the rest of the association did an impeccable job of getting people – Consumers, personal assistants, family members, Designated Representatives – to come to the court room, and we packed the court room. Is it safe to say that the Judge, just because of that alone, certainly understood what was at stake here?”

HERMES: “Let me take that one.”

BLAISE: “Sure.”

HERMES: “I think that the fact that the court room was packed with individuals who use the program did make an impression on the Judge. I don’t know whether it changed her legal analysis, but I think it helped to focus her on the fact that she had an important matter. You know, this program is near and dear to me. I’ve been involved with it for 20 years now, and the reason that it’s near and dear to me isn’t simply from the affinity of having worked with the program. It’s that this program has from its inception, been about dignity, respect, and liberty. It’s been about the ability of people to run their own lives, the way they want to run their lives. So, you had a nice, simple program that wasn’t encomPAssed... encomPAssed – or encumbered I should say – by a lot of different rules. But it was

allowing people to go about their lives as they chose; and these cuts, as devastating as they were, were putting all of that at risk. So, it wasn't simply a matter of simply saying here is a Medicaid program that may not survive. This was about dignity, respect, and liberty not surviving."

BLAISE: "Elizabeth, from an FI standpoint, what does winning the suit mean here?"

ELIZABETH: "It means we have a second chance, as what Bryan was saying, we have another – we have a pause in what was going to be an absolutely devastating cut that I did not see us surviving for very long, and in the process of not surviving, we would have been having Consumers having to deal with workers' wages and benefits being cut. I mean, it was just – it was looking like a nightmare. So, to have another shot at going back to the table with them – with the state, to try and talk about some other reasonable approaches to trying to create savings is – there's some relief to that. So, that's – it was – it was – it was a celebration, and it was relief."

BLAISE: "What does that mean for CD Choices specifically?"

ELIZABETH: "Well, it was a pause – again, it was a pause in the funding cuts; so, we're kind of at a status quo right now with things. We know that there are cuts that are looming though still that we're going to be working with the state. So, there's still tension. I'm not going to say that I'm fully relaxed. I'm not going to say that anybody should be sitting back and thinking, woohoo we're done here, and everything's going to be the way it was; and there's a reality that although this was a huge victory and gives us a chance, no one should be thinking that the program is ever – We're not going back to before January. It's not – that's – that's done. We're going to have to think of some ways that we can do things a little differently, and so, that we can assist the state in meeting some of its goals, but doing so in a way that does not jeopardize Consumers' programs and doesn't harm their workers. I mean that's – that's something that everything that we've done at CD Choices has been always about as much as you can do no harm; and that's what we're hoping that the state takes the approach of. We don't want them making a budget cut just to make a budget cut, because they're looking to make a budget cut."

BLAISE: "Absolutely."

Hermes Fernandez from Bond, Schoeneck, and King; Bryan O'Malley from C-D-P-A-A-N-Y-S; Elizabeth Martin from CD Choices are here with me, Blaise Bryant, on the Empowering Independence Podcast.

Now, before we go into the woods, because as all of you have said, there is still work to be done, what's your level of optimism in being able to work with the Department of Health to make sure that CDPA can exist as it does? Bryan, we'll start with you here on this one."

BRYAN: "We're committed to working with the department on this issue. They were in an understandable spot. Every time they issue any kind of cuts, providers and others start yelling that the sky is falling. They hear this over, and over, and over again. I think they're in a unique position now, where they saw firsthand in this six-week period that these cuts were in place that we weren't just yelling that the sky was falling; that – you know – indeed, chaos did rule supreme during that period. So, I am hopeful that they will come back and engage with us – engage with all of the stakeholders in this program to figure out ways that we can save money while not harming the program, and in fact, possibly even strengthening it. Because, I think that there are some things that we can do that will save the state a significant amount of money but will overall make the program better for those who rely on it, not worse."

BLAISE: "I'm going to ask you to elaborate on that if you can."

BRYAN: "Sure. You know, one piece that was highlighted by a number of Consumers was the fact that assessments have to be done twice annually. You know, assessments cost a lot of money. They require a visit to your healthcare provider, that's usually going to bill Medicaid between \$80.00 and \$100.00. They require a visit from the nurse who is going to do the assessment on site. That generally costs about \$150.00. So, we're talking \$250.00 per visit for 90,000 people by the D-O-H's estimate for this program by the end of the year. That's a lot of money. As I've generally said on this topic, if a quad starts walking, you're not going to need a plan to come to somebody's house to find out about it. It's going to be on the front page of the New York Times. In most instances, folks will be just fine with a once-annual assessment. That is the norm in any number of programs. Home care is really the outlier, and as long as we have mechanisms in place where Consumers can request new assessments if they feel they need more hours, or if the plan is obligated to come do an assessment if they know about a change in the situation, there's no reason we need to require two per year."

BLAISE: "Elizabeth, let's get your barometer here."

ELIZABETH: “Well, it’s definitely more optimistic than it was October 10 – right before the decision came out. I am hopeful that – you know one of the things that happened over the Summer was that there was a state-wide FI workgroup; and the Department of Health was there – there were a bunch of FIs there including us. Bryan was there, and there were plans there; and we were supposed to talk about – you know – we’ve talked in the PAsT about this RFA process – this procurement process the state was going to do for Fiscal Intermediaries. Each time, there were discussions about all the things that FIs do, and all the things that the program is supposed to do, and how it’s supposed to operate. One benefit of it, I would say – or what I would say is a silver lining that I’m thinking happened based on certain conversations I’ve had with people – is it did provide education to some key people in the Department of Health and even with the plans as to what the program was about; and that’s helpful, because I think there’s at least a greater level of awareness. There’s probably still more that we have to talk to them about in terms of really trying to make sure that everybody really understands how the program is supposed to operate and what the needs are; but it’s a starting point. So, there was – So, I would say that’s appositive. I think that the stories of just what Bryan was talking about during those initial six-week periods before the decision came out – what we were warning the state – to the state was going to happen was starting to happen. We were seeing cuts coming in way deeper than anybody had anticipated. We were seeing cuts to funding that went to direct care, which is basically workers’ wages and benefits. We saw FIs cutting wages and benefits to workers. So, those were real experiences, and I think that the Department of Health might have been taken a little bit aback – kind of – just like what Bryan was saying – There’s a lot of times where they’re all – you know – the sky is falling. But the sky was starting to fall.”

BLAISE: “Absolutely.

Hermes, I know not all of your job is necessarily litigation and lawsuits. Part of your job is also giving advice. I mean, you provide advice on and you specialize in health law, and government law, and that sort of stuff. What sort of advice can you give here?”

HERMES: “Well, it’s actually a compliment what Bryan and Elizabeth said in terms of what can be achieved with the Department of Health. I think we can achieve that also with the division of the budget and the state legislature. It’s vital, and Elizabeth framed it appropriately, what we’ve won here. What we’ve won is breathing space. We’ve got an opportunity now to try and move to other, better adjustments to the program. I’m still alarmed at the number of people I spoke to who I would have expected by now, who understand the mechanisms of the program, who are either refusing to believe what they’ve been told or are clinging to prior beliefs.

I'm alarmed by the number of people I've spoken to, who have still said to me that a Fiscal Intermediary is really just a payroll agent. I spoke to a state senator two days ago, a respected state senator who I think usually does a very good job of getting her arms around issues, who said to me, "Well we still have to get rid of – what do you call 'em?"

I said, "Fiscal Intermediaries."

She said, "Yeah, the bad Fiscal Intermediaries." What made her remarks so ironic, is who we would regard as the bad Fiscal Intermediaries are the Fiscal Intermediaries who really only see their role as being a payroll and doing nothing else. Yet, I've had other people say to me – you know – in government positions – "Well, that's all a Consumer Directed program – a Fiscal Intermediary is, is a payroll agent."

So – you know – what are people looking to get rid of? The good Fiscal Intermediaries who do more than be payroll agents, or the bad Fiscal Intermediaries who only act as payroll agents? So, there's a lot more work to be done here, and the C-D-P-A-A-N-Y-S, along with the other litigants – the other associations that are involved with the Consumer Directed program all have to be putting forward a joint message with joint proposals to really be able to effectively change the thinking."

BLAISE: "You lead me perfectly into the final topic here, Hermes. Now, where do we go from here? Because, while we won the lawsuit, I've kind of been liking – likening it to we've won the battle, not the war. Bryan, I'll start with you. Where do we go from here?"

BRYAN: "Well, I think Hermes wrapped up his comments perfectly with – you know – what's next. We need to continue to put forward joint proposals. We need to continue to work together. I think that's been one of our biggest strengths throughout this process. We have stuck together at every turn in the road. Every time there has been something that really could have divided us as agencies, divided us from Consumers and workers and FIs, we have stuck together; and I think moving forward it's more important than ever that we continue to do that and work together to identify and advance real solutions. You know, I don't think it comes as a surprise to anyone long term care costs money. You know – we're not talking about insuring children who need to go see a pediatrician once a year and get immunizations. Long term care is a daily service that folks use. It costs money. It costs a lot of money. We've known that these costs are coming, that the long-term costs in Medicaid are going to go up for the better part of 30 years. We've been talking about the – you know – looming baby boomer Medicaid crisis for the better part of 30 years. It shouldn't come as a surprise that more people are utilizing CDPA

and other long-term care services. That doesn't excuse us though. We need to look at how we can make these programs more cost-effective, how we can strengthen them, how we can build them while still saving money. I think if we continue to work together, present a unified voice and present real solutions, we have a great chance at doing that."

BLAISE: "Elizabeth from the viewpoint – or standpoint here at CD Choices, what else can we do?"

ELIZABETH: "Continue advocating, speaking to trying to get into see D-O-H, working with Bryan and the state-wide association on those potential solutions that we can advocate for, talking to our state legislators. Consumers can talk to their state legislators. It's not a dead issue. It's still alive. For Consumers to – and for FIs to help Consumers if they need to, but for Consumers particularly to share their stories, share their workers' stories, as much as they are willing to be possible. They were integral to, I think, some of the tone change that's been happening. I think while we still have a fight and there's still a battle, there is a growing awareness that's happening throughout the state, and that is directly related to those stories from Consumers. I can talk about the technicalities, but I am just a non-profit executive, and we're sometimes not totally listened to or believed. Consumers are the ones that can really bring it home and bring their stories and make them really relatable for people to be aware of the importance of the program."

BLAISE: "But you are a very active non-profit executive –

ELIZABETH: "Well, yes –

BLAISE: "who does hear a lot of Consumers' stories, and you interact with the Consumers as well."

ELIZABETH: "Yes, absolutely. So that's why FIs can help and – you know – provide resources or tips or information who is their legislators and stuff like that. So, FIs can play a role in that. But again, I think that – you know – and FIs play a role because it is important to also communicate the technical aspect of things. The people – the decision makers have to understand that as well. But that human element of really understanding the impact and bringing it close to home for everybody – that has to be done by Consumers, their representatives, their workers; and the more they get out there, the greater success we'll have."

BLAISE: “But, how do we – and this is the final thing here. Because, in talking to Consumers, I’ve noticed they are certainly willing to share their story, but they don’t know how. So, Bryan and Elizabeth, in order here, talk about the #SaveCDPA efforts that we’re doing here with Berlin Rosen.”

BRYAN: “Right. So, I think – you know – we are, at C-D-P-A-A-N-Y-S, building a new campaign aimed at taking advantage of this moment, where we are able to get a second chance. We want to bring together everyone – FIs, our allied organizations throughout the healthcare field, Consumers and PAs and as a part of that effort, we’re committed to helping people tell their story; and it really is just that simple. It is telling – Consumers telling their story. Many people have their own video camera right in their pocket with a cellphone, and – you know – you can film yourself answering three basic questions: What is CDPA? What does it mean to you? How has it improved your life?

Just that basic act and send that to us – you know – send that to us at Info@CDPAANYS.org and we will help you spread that word. We will help you tell your story to policy makers, to the Department of Health, to Governor Cuomo and make sure that your voice is heard. While you’re looking at C-D-P-A-A-N-Y-S, go sign our petition to save CDPA. Tell your story directly to the Governor. We make everything very easy, right off of our website for Consumers to take action, tell their story, and be heard. Because, at the end of the day, this is about Consumers. This program is about the people who use it, and that is the beauty of this program, and if we win, it’s the voice of Consumers that will allow us to do so.”

BLAISE: “Elizabeth, we are doing stuff here at CD Choices. We have staff that are helping Consumers do videos. Right?”

ELIZABETH: “Yeah, if a Consumer does not have a cellphone, does not have access to a cellphone or mobile device, we can assist them with providing that.”

BLAISE: “Great.

(Exit music)

Hermes Fernandez from Bond, Schoeneck, and King, Elizabeth Martin Chief Executive Officer here at Consumer Directed Choices, and Bryan O’Malley, Executive Director at C-D-P-A-A-N-Y-S, I cannot thank all three of you enough for a few minutes here with me on the Empowering Independence Podcast.

Thank you so much.”

ELIZABETH: "Thank you."

BLAISE: "My Pleasure."

The Empowering Independence Podcast is a presentation of Consumer Directed Choices. You can get more information:

Hermes: www.BSK.com

Bryan: www.CDPAANYS.org

Elizabeth and us here: www.CDChoices.org.

Denise DiNoto is Executive Producer of the Empowering Independence Podcast, transcribed by Loreal Lavigna.

Let us know what you think at info@CDChoices.org and we'll see you here next month on the Empowering Independence Podcast