

## Empowering Independence

### Episode 4 Transcript

August 15, 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 4 of the *Empowering Independence Podcast* presented by Consumer Directed Choices in Albany, NY. I’m Blaise Bryant. We hope you’ve had a great summer and we’ve got a lot of catching up to do. On July 1, the New York State Department of Health, DOH, moved forward with guidance, laying out the future of Consumer Directed Personal Assistance, or CDPA. In the guidance, they say that on September 1, the new per member per month rate will take effect. By all accounts, no fiscal intermediary would survive, thus CDPA would be dead if these rates were to go in to effect. On July 26, which is the 29<sup>th</sup> anniversary of the Americans with Disabilities Act, the Consumer Directed Personal Assistance Association of New York State, or CDPAANYs, the New York Association on Independent living, NYAIL, as well as other independent living centers and fiscal intermediaries, including Consumer Directed Choices, have filed a lawsuit against the state so that the rates of the per member per month do not kick in on September 1. As of this taping, we don’t know how the suit is going to play out, but rest assured here at CDChoices we are doing everything possible we can to make everything work and save CDPA.

At the end of episode 3, I said that we would have two Disability Rights Hall of Famers to talk about disability rights and the independent living movement. Unfortunately, because of scheduling conflicts, things didn’t quite line up. Instead, courtesy of Voices of the Disabled, an ADAPT Chicago production, we have Marca Bristo speaking with Joel Margolis. Marca is from Access Living in Chicago. She talks about what they have been doing around employment as well as other initiatives, and disability rights.”

Marca Bristo: “In the 1980’s, uh, Congress passed a law that created centers for independent living, like Access Living. Um, when we first started, we were one of the first ten in the nation, now there are about 500. So back in the eighties when uh President Reagan had taken over and started to cut budgets like crazy, um the disability community organized through the centers for independent living and began to want to change the paradigm about disability, from a medical model where we’re looked at as people who are sick, and looked at through our deficits rather than through our assets, to a disability rights model. And then, in 1986, the National Council on Disability called upon the disability community to speak about our experiences with discrimination. Justin Dart Jr, the late father of the Americans with Disabilities Act, asked people, everyday people to write their discrimination diaries. Thousands of people

sent in stories about the wrongs that had been done to them simply based upon their disability. That all resulted in uh the drafting of the Americans with Disabilities Act, and Activism amongst the disability community to get the law passed. So in July of 1990, uh at a White House celebration, the largest that has ever existed, President Bush uh signed in to law the Americans with Disabilities Act. And I'd like to say that not only was it a legal victory for us, it began to transform our society physically and otherwise, but as Bob Kafka, one of the leaders of Adapt said, um it was really a victory for our Activism. It was the first time that we had truly exercised our collective power and it lifted up our power in so doing."

Joel Margolis: "What has happened since the American with Disability Act was passed?"

Marca: "Sure. Its readily apparent as you move around the community to see many of the changes - curb cuts on corners, um uh sign language interpreters at public events, ATM machines that now talk or provide access for people who are blind, um lifts on buses, not only here in Chicago, but all throughout the United States, trains that provide accessibility, Greyhound, um and most significantly, people with disabilities finally having the right to move out of instat institutions, costly institutions, to live in homes of their choice."

Joel: "Independent living."

Marca: "Independent living. And all of these things um would not have happened had it not been for the Americans with Disabilities Act, but um there's still so much more to be done. And some of that work has taken the form of subsequent legislation, uh expanded uh requirements for the telecommunications industry, for example, requiring that cellphones be useable by people with multiple disabilities.

Joel: "Speaking of expanded communications, I'd like to ask you, do you feel that the Americans with Disabilities Act ok, if assertively enforced, gives the disability community all the legislation it needs, or do you feel that there is still more legislation needed to protect and enhance the disabled?"

Marca: "Well, you know our civil rights are an evolving concept um as individuals face issues and discrimination in areas that we didn't contemplate initially when the ADA was passed. For example, the Internet. The Internet didn't really exist in any major way when the law was passed, so the question of does the ADA uh require the Internet to be accessible to people who are blind has been an open issue that has been battled through the courts. And as I mentioned, there have been additional types of legislation as the disabilities community's voice has gotten stronger. So I think our civil rights are always a work in progress, I'm sure we will continue to see new areas that need attention as we go forward, but it's really important that people with disabilities learn what their rights are, and exercise those rights. Not all of our rights are embedded in the ADA. Some of them proceeded the ADA, such as the Individuals with Disabilities Education Act, the Fair Housing Amendments Act, the Air Carrier Access Act, so it's really important that people with disabilities understand that as disabled people, you are a protected class and you need to arm yourself with information so that you can properly request and demand that your rights be upheld."

Blaise: "You're listening to Marca Bristo talking with Joel Margolis, courtesy of Voices of the Disabled, an Adapt Chicago Production."

Joel: "With regard to employment, is Access Living primarily a legal services tool for the disabled or is there actual advocacy done by Access Living in the area of employment?"

Marca: "We're not a job placement site per say, although we do have some programs that assist people, particularly youth with disabilities in making the transition from high school in to the work world or high school in to post-secondary education. Um but we do do advocacy around the area of employment um and public education. So, for example, we have an organizing group that has um focused itself on making sure that sub minimum wage is not the law of the land, and that people with disabilities are paid a fair wage for the work that they do."

Joel: "For the benefit of our viewers, could you just give us a brief definition of sub minimum wage?"

Marca: "Certainly. Um there's a provision in the federal IRS law that allows certain categories of workers to be paid below minimum wage. These are typically individuals who work in what are known colloquially as sheltered workshops. Um these are often segregated work environments where individuals can be paid pennies on the dollar or two dollars as opposed to what the prevailing wage is. Um we believe that people with disabilities should be paid minimum wage like everybody else.

So, um back to your earlier point, it's it is accurate that Access Living's work revolves around uh services, advocacy, and legal work. But we take our lead as a Consumer-driven organization from the people we work with. And so the thematic areas that most people turn to us for for assistance are housing, employment, education, health care, long-term care, and some miscellaneous other things, for example, issues around immigration."

Joel: "We now see approximately 50 years of affirmative action for African Americans and Hispanic people. Do you think that a moral or possibly even a legal argument could be made affirmative type actions programs for the disabled?"

Marca: "Well, well in fact, um we've always had on the books, a federal requirement that people with dis people with disabilities are uh part of the protected class of affirmative action. However, we've never had strong regulations in this area. Um uh under the Obama administration there were new regulations that apply to federal contractors uh and people who do business with the federal government requiring a target of approximately uh target of seven percent of the workforce be people with disabilities. Um and that's across all job classes, so they can't only be looking at people in the mail room, for example. Um as..."

Joel (interrupting): "It has to be spread across."

Marca: "That's right. So uh corporate America is I think finally waking up to this incredibly talented workforce that heretofore has been slighted. And these new rules have given some teeth to uh require businesses to really do a better job of being culturally appropriate, having mechanisms to recruit people with disabilities, making sure that they have reasonable accommodations policies in place, etc. And that segues me to uh one of Access Living's new initiatives, understanding that uh American business was beginning to work on this and that this is an ongoing issue to tackle the terrible unemployment rate of

people with disabilities. Access Living made a decision to start uh a trainings and consulting arm that is set up to help build businesses become culturally competent in um employing people with disabilities and we're just about to launch it. We're sort of in the preliminary phases, but we'll be set up to provide uh trainings, uh consultation, a speaker's bureau, to help Chicago area businesses really embrace the workforce of people with disabilities."

Joel: "And all of that is geared towards the idea of finding salaried employment for the disabled."

Marca: "Yes."

Joel: "I'm wondering, looking toward a broader horizon, I'm thinking about the idea of self-employment. I have come across more than one or two presently disabled people who became disabled let's say in middle age and had long work histories, some of them as entrepreneurs. And I've heard them speak about a great frustration in being unable to launch a business that would be staffed by a cluster of if not all the disabled, primarily disabled people. However, I've heard several of them say that they have never been able to find any organization or center that has serves as an incubator for self-employment amongst the disabled."

Marca: "Yup, you're you're right to point that out. There are uh for example, there are gender based organizations that are working to promote the employment of women with disabilities in the entrepreneurial space. Um a couple years ago, the state provided a grant to the University of Illinois at Chicago to establish an entrepreneurship program. Honestly, uh I'm not aware of uh whether the funding for that will continue, but it was an important first step in looking at how do we promote self-employment by people with disabilities, and while we're on this, if you go back to that federal affirmative action rule that I mentioned, one of the things that businesses are being asked to do is include contractors who have businesses run by people with disabilities. Um and in the the Federal, the state, and the local government all have slight, and the county, all have slightly different rules by this. But it is, um, in order to be counted in those statistics that I mentioned earlier, the company has to be certified that they are in fact a disabled owned business. And the city of Chicago um as well as the United States Business Leadership Network operate uh certification programs that will verify that people aren't just trying to scam the system and pre you know, pretend that their sister-in-law is the president of the company cuz she has a disability when she has no involvement whatsoever. So, there are some uniqueness unique issues related to this."

Joel: "Now with regard to the question of employment and legal services, ok, is Access Living there primarily to provide information to the disabled individual as to what their legal rights are in seeking employment and redress for discrimination?"

Marca: "No. Um uh if you'd like, I could segue into what our civil rights team does. Uh currently we do not work in the area of employment law. I could suggest that you're uh listeners and viewers uh reach out to Equip for Equality, which does have a um employment related legal component. Our civil rights work right now is focused in two primary areas, maybe three. Um fair housing, and there we see um complaints on the basis of disability uh across the board, so it could be rental denial, it could be mortgage denial, um inaccessibility of buildings that should be accessible, failure to allow somebody to

have an assisting animal, it's a pretty wide spectrum. We also run a testing program where people with and without disabilities are paired and go out to a place where we've heard there might be some discrimination and we evaluate....

Joel (interrupting): "Testing the market for housing?"

Marca: "Well, we're testing to see if there's a difference in the way the landlord treats the disabled person compared to the nondisabled person. And we can use that evidence as long as it's been very carefully collected, and we train people to do that, um as evidence in court should we need it. The other part of our civil rights work is focused on the Americans with Disabilities Act, Titles Two and Three. Title Two is uh public sector, so we are one of the organizations that brought the big lawsuit against the state of Illinois, uh three lawsuits in fact, to uphold a Supreme Court decision called Olmsted, which uh the state was reluctant to implement, even though the court directed them to put in place a plan to get people who were unnecessarily institutionalized out of institutions. The final area of our work is in Title Three and that it applies to public accommodation... museums, movie theaters, um and we we mostly look for impact cases where uh we think by bringing a case, we could have an impact in a broad area. Most recently, the the um the case we might be most noted for is a case against Uber. Um, as you may know, Uber has begun to transform the world of transportation.

Joel (distorted): "Definitely."

Marca: "Even though they claim that they are not covered by the Americans with Disabilities Act, uh they claim they are just an app, uh we think not. And so we are um bring, we've brought this matter forward on behalf of wheelchair users who are unable to transfer in and out of a regular sedan. And um we'll wait to see what the court decides, but this is uh a case that I think has been um uh on the minds of a lot of people with disabilities all over America because we've had the same problems with the transportation network providers like Uber all around America. Um they were sued previously for failure to provide appropriate accommodations for people who are blind, and reached uh a national settlement in that case, um so you know there and and I do know that Uber and some of the other companies have uh uh reached out to the deaf community to be a good place to employ people through driving. Uh we're in support of those things. We just want them accessible to all of us."

Joel: "All of, including all in the disabled community."

Marca: "Especially as the taxi industry is being so hard hit as Uber has come in, the industry is shrinking, and we only just won the right to have accessible taxis. And we don't want to see that disappear and leave us with no other uh option for private pay transportation."

Blaise: "You're listening to Marca Bristo talking with with Joel Margolis, courtesy of Voices of the Disabled, an Adapt Chicago Production."

Joel: "Now with regard to housing, I have often heard members of the disability community say that there's simply not enough housing that is specially equipped for the disabled. In seeking to augment the stock of specially adapted housing, is Access Living playing any advocacy role in that area?"

Marca: "Of course. Um..."

Joel (distorted): "And what do you do in there?"

Marca: "Well, first let me say that since the day we opened, the number one service that people with disabilities turn to us for is accessible, affordable housing."

Joel (in background): "Housing."

Marca: "And it's all three... accessible... the third one accessible, affordable, available housing, the three A's. Um... the housing that does exist is often taken by people who need it. Um for the people we work with, who are often on fixed incomes, they need not only affordable housing; they need affordable housing that's subsidized in addition to being affordable. Traditional affordable housing uh prices out people with disabilities who live on SSI or SSDI. In fact, in all of America there's no place in the United States where a person on SSI or SSDI can afford market rate. So in many respects the link between poverty and fixed incomes is a precursor to people having no place to live. Add on top of that the issue of uh accessible housing and it's a pretty significant barrier.

That said, we have a long history of advocating for policy reform, for uh for working with the Chicago Housing Authority to allocate uh greater per percentages of their uh subsidized housing to people with disabilities, working to ensure that IHDA the Illinois Housing Development uh Agency, which finances a lot of housing is incentivizing uh the construction of accessible, affordable housing. We've worked with the city of Chicago, the Mayor's office, with people with disabilities to make the building code, the Fair Housing Law, and the ADA all harmonize, so that when a developer gets his building permit in the city of Chicago, it's also um uh vouching to the fact that if they build to that permit, they are complying with these laws.

We also say for people who are looking for accessible, affordable housing, um don't give up. You know you you have to go under every rock. And while we can't find that housing for you, we can tell you the best way to go about making sure that you're putting your name in on all the waiting lists. We have a list of those um uh housing complexes that are uh accepting applications, so it is uh worthwhile to be in touch with us, uh but you have to do the work. We can't do it all for you."

Joel: "The disabled individual has to get out there and search."

Marca: "Yes. That's right. On on the issue of health care, um most of our work has been in the area of health care reform, trying to make sure that the health care system serves the needs of people with disabilities. A lot of our early work in the early days of Access Living was to create the state's first home services program. In fact, that was my very first advocacy letter to the Governor of Illinois way back when. And we were involved in the very early days of creating the state's home services program, um now our work is to monitor that that program is being run properly, that cuts or changes to policy don't harm people with disabilities, such as the current proposal by the Rauner administration to limit overtime hours of workers, um which we think puts disabled people at serious risk. It's very difficult. Uh one of the things we do in direct service is run a Personal Assistant training and referral program. So if

a person um we we can help people get connected so they get assessed to be um determined if they're eligible to have state sponsored support for home services, um we can help them identify a list of people who could be home service workers for them.

In health care, people with disabilities are the canary and the coal mine. You know, if you make a system that meets our needs, it will meet everybody's needs. And if you make a system that doesn't meet our needs, you will make a system that serves no one's needs because eventually, almost everybody in this country will acquire a disability and they will need the things that we've been advocating for, especially as the population ages."

Blaise: "Marca Bristo speaking with Joel Margolis, courtesy of Voices of the Disabled, an ADAPT Chicago Production. What Marca has been talking about with the work that independent living centers do, is work that just about every independent living center throughout the country does. To find out where your local independent living center is, just do a Google search of your area and type in the words independent living center.

Thank you so much for listening to Episode 4 of the *Empowering Independence Podcast*. To listen to this, as well as other episodes of the podcast, be sure to subscribe wherever you get your podcasts and let us know what you think, [info@cdchoices.org](mailto:info@cdchoices.org). Thank you so much for listening. We hope you have a great rest of summer, and we'll see you back here in September on the *Empowering Independence Podcast*.

*Exit music*