

Empowering Independence

Episode 3 Transcript

July 15, 2019

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Blaise Bryant: “Welcome to Episode 3 of the Empowering Independence Podcast from Consumer Directed Choices in Albany, NY. I’m Blaise Bryant. Today is all about Electronic Visit Verification or EVV. This was mandated under the 21st Century Cures Act passed by President Obama in 2016. Basically, what you need to know is that every Medicaid-funded homecare program, including Consumer Directed Personal Assistance or CDDPA, needs to comply by January 1, 2020. As of this taping, New York is still in the process of figuring out which system or systems they are going to use.

We’re going to get two angles on Electronic Visit Verification. We’ll get it from the Consumer perspective and the policy perspective. We’ll start with the Consumer perspective with Kendra Scalia, who is leading the organization Stop EVV, a group that raises very real concerns about EVV and its impact on Consumers. Kendra and I caught up in early June. You can find out more information by going to stopevv.com. Kendra, thanks so much for joining me here on the Empowering Independence Podcast.

Kendra Scalia: “Thank you so much for having me.”

Blaise: “My pleasure. I gotta say I was uh on the site, and you have done one heck of a job with pulling together all the resources cuz you could see state by state where everything is on the site and you really have done an amazing job.”

Kendra: “Thank you so much. Well here at Stop EVV we’re a grassroots campaign lead by people with disabilities and our Personal Care Providers, and so there’s a small group of us that work together so it’s not just me. We also were started with an advocate in Ohio Alicia Hopkins, and so I’m very happy to have her on the team as well helping to gather all the information and spread the word about certain Civil Rights violations that EVV may cause for people with disabilities.”

Blaise: “There’s a lot of concern about GPS tracking and rightly so and Civil Rights violations that you just brought up. Talk about those?”

Kendra: “Absolutely. So, one of the largest concerns that we have from the Consumer perspective is ah one of the requirements of the Cures Act is that Electronic Visit Verification systems capture the location where services were provided. And so, there’s been a lot of misinformation really put out there by the EVV vendors themselves that the only way to track location is through GPS tracking of individuals or a biometric data collection system. And biometric means fingerprinting, voice recognition software, and facial recognition software. And so, they’re really um using devices to capture audio and video, and your location throughout your home and throughout your community. And so that’s very concerning for us

um as Consumers as well as our Personal Attendants, um and so we have gone through uh the Cures Act as well as all of the guidance provided through the Centers for Medicare and Medicaid Services (CMS), um which oversees the implementation of EVV in each state, and there's no requirement for GPS tracking or biometric use and CMS has actually written this in their guidance document. So we're really happy to see them putting out that information. So right now we're working on getting that word out to each state, Fiscal Intermediaries, and the Consumers and PAs themselves.

Blaise: "It's especially concerning given the fact that there's such an overall concern of privacy in today's day in age to begin with."

Kendra: "That's right. Um you know this is a huge violation of privacy in our opinion, and this would make disabled people the only population that's required to be tracked in uh a such a manner in order to receive a public benefit. And so that that's very concerning they're going to be essentially taking away Constitutional Rights to privacy in order to you know track where we are to meet this requirement for location. A and one of the really great things we've done at Stop EVV is we have some advocates um throughout the nation, and our California advocate worked with the Department of Social Services to create an EVV system. They have a Web Portal, a Telephony Visit Verification, and a Mobile App device with no GPS tracking, no biometrics, and there's also another issue which is the geofencing. Um and geofencing is where they put an imaginary perimeter around your home, and any service that goes outside of that perimeter is denied payment, so it really forces individuals to be isolated in their home and homebound once again. So we're really happy to have been able to work with the California DSS to create these standards and models that we're really putting out there as a really great EVV solution for many states.

Blaise: "Kendra Scalia here on the Empowering Independence Podcast. How receptive was the California DSS in terms of the willingness to work on all this stuff that really should be the model for the rest of the country to use?"

Kendra: "We were very pleasantly surprised that we had fairly good reception from the California DSS, and they uh came forward through the stakeholder engagement process. Each state is required to have a stakeholder engagement process, and uh we even have uh CMS and Congress who put forth some bills to strengthen that stakeholder process to include Consumers and Personal Assistants, and California really took that...took that requirement and latched on to it and they did a great job working side by side with Consumers and PAs, but also with the Domestic Labor Unions that are out in California. (Blaise says "wow!") Uh their local SEIU as well as United Domestic Workers worked side by side with Consumers and CDSS to create these systems, and uh really develop uh a quality EVV system that meets federal requirements, and maintains privacy rights as well as maintaining the rights of the Consumer as the employer."

Blaise: "Well not only that but it gives people options and I think that's the other big piece to this too isn't it?"

Kendra: "Absolutely! You know one of the core tenants of Consumer Directed Personal Assistant Services is choice and control and flexibility, and that's really, really ah key with EVV as well. So any EVV system that's going to work for Consumers in CDPA needs to make sure that choice and flexibility is maintained, and what they've done in California uh they've gone a step further. Not only can a Consumer choose or a PA can choose between the Web Portal, Telephony, or Mobile App, but if your PA

chooses to use the Mobile App, and you want to use the website to verify the timesheet, they all work together...they're all interlocked so a provider can go in and clock their time on a Mobile App and at the end of the week when you pull up the website, you can see all the time they've tracked.

Blaise: "How do they work together?"

Kendra: "I'm not exactly sure how that technology works, but they have made it such that you as the Consumer can use any one of the three uh EVV systems at any time during the week. Um and and what they do in California is they also do not require that you clock in and out at the moment your shift starts and ends. This is also another piece of misinformation that EVV vendors have done a really good job to try and sell some of their more expensive EVV systems to states, so there's no requirement on the federal level that the time recording must happen at the moment the shift starts and ends. So in California you can have a provider uh use the Mobile App at the end of the week and clock every single shift they worked for you. And somehow their technology that they've built will translate that information from the Mobile App onto the Phone System as well as the Web Portal system."

Blaise: "And they're miles, and I mean miles ahead of the rest of the country."

Kendra: "That they are, and you know California uh really used their Consumer power to help them develop these technologies, and because of that it's helping develop it a lot quicker than many other states who are simply choosing systems off the shelf that don't really work and integrate well with the way homecare services are actually provided day to day."

Blaise: "Yeah uh Kendra Scalia here with me on the Empowering Independence Podcast. What I should have asked you at the beginning, and I did not was how come you are so passionate about EVV to the point where you are, when it comes to this, and CDPAP one of the faces of the movement?"

Kendra: "Well I've been a Consumer under Consumer Directed Personal Services for many, many, years, um I started using a Consumer Directed model when I was 14 years old, and um I have used it ever since. It helped me to get through High School, to get through College and Graduate School, um and now I live in New York State. I was very concerned when I learned about EVV and I just started using my education in Public Policy and really research the issue and come up with creative solutions and get out there and talk to other members of the community about EVV. And when I started Stop EVV uh with those other advocates, it just seemed very natural for me to step into the role as Director of Policy of the national organization, and uh last year the National Council on Independent Living (NCIL) created an EVV Task Force and Steering Committee so that they could track EVV issues and work on uh problems and concerns in the community and I now co-chair that committee as well. So I've been doing quite a bit of work on EVV for a number of years because it's going to impact me personally, and I'm also very concerned with um the way that the tech industry has really put themselves into the issue first by lobbying and getting it passed, and and now by providing a lot of misinformation so that they can make some money off of us.

Blaise: "I look at where New York is and they have just finished all of their input gathering. The Department of Health has finished all their Listening Sessions, including the webinar basically had to be advocated for because they were receiving... they were receiving all sorts of pushback on the fact these were all just all in-person sessions."

Kendra: “We have um spoken with the Department of Health (DOH) um regarding their stakeholder process in June and let them know we do not feel that this was a robust stakeholder engagement process as required under the federal uh requirements. And so we are requesting that there are more stakeholder engagement sessions, that they are to be attended not only in-person, but some way for individuals to call in and either listen in as well as to be able to have two-way communication to voice their concerns or to have more webinars on this topic. And really the state needs to be having stakeholder sessions throughout the entire process of designing, developing, implementing, and training EVV at every level. One of the things that we did learn through the stakeholder engagement process was that the state does plan to submit for a delay in the EVV requirements, so uh CMS does have a method for states to request a good faith effort delay of one year, which means for one additional year states will not have the penalty of losing Medicaid dollars if EVV is not fully implemented. Um you know as much as the state really believes that they’ve done enough to reac...meet the requirements of the good faith effort delay, the Consumers really aren’t sure. And so we’re really relying on CMS here to make a decision on whether or not New York State has done enough in the past month to prove that they’re on the road to implementing EVV.

Blaise: “What do you think Consumers can do in addition to participating in these listening sessions and webinar sessions?”

Kendra: “Um so one of the first things we recommend is to get connected with the other individuals, Consumers and Personal Assistants in your state who are working on these issues, And you can do that by going to stopevv.com. There’s a form at the bottom of our website where you can sign up to be on our mailing list and receive a lot of information. You can also go on ah Facebook if you are a Facebook user, we have quite a few different Facebook groups. One is “Help Stop Electronic Visit Verification”, and that is a nation-wide group for all Consumers, Personal Assistants, Designated Representatives, and Family Care Providers to talk about their concerns as well as their experience. And we also have a Facebook group specifically for “New Yorkers against Electronic Visit Verification”. You can certainly join those groups and get connected to communities so that you don’t feel so alone and you can feel more empowered about ah advocating for a quality fair EVV system in the state. And the Department of Health has set up an e-mail line, so you can e-mail <mailto:evvhelp@health.ny.gov> and voice any of your concerns as well as anything you’d like to see in a system at any moment by e-mailing DOH.

Blaise: “Kendra Scalia from Stop EVV, stopevv.com is where you can get more info. Kendra you are just a wealth of info and I cannot thank you enough for taking a few minutes here with me on the Empowering Independence Podcast I really appreciate it.”

Kendra: “Well thank you so much for having me I it’s been quite a pleasure to speak with you.”

Blaise: “Because of the advocacy efforts of Kendra and other Consumers, the Department of Health did expand the number of listening sessions, including an exclusive webinar listening session in July. There are still two listening sessions. July 17th in Buffalo and July 18th in Syracuse. That’s the Consumer perspective, we’ll take a quick break and we’ll get the policy perspective here from Bryan O’Malley from the Consumer Directed Personal Assistance Association in New York State here in just a minute on the Empowering Independence Podcast.

Break: “Consumer Directed Personal Assistance supports seniors and people with disabilities. It gave me an opportunity to hire my own assistants, be able to direct my own care, they could help me live an independent life. To learn more visit cdchoices.org.”

Blaise: “Welcome back to the Empowering Independence Podcast I’m Blaise Bryant. We got the Consumer perspective now it’s time to get the policy one. Since 2011, Bryan O’Malley has been the Executive Director of the Consumer Directed Personal Assistance Association of New York State. To spell that out in acronyms for you that’s CDPAANYS. Bryan also worked in the Assembly and also did some policy work for the Mental Health Association of New York State before coming to CDPAANYS. And we caught up in early June literally from my desk phone in my office at Consumer Directed Choices so the recording system we used sounds a little bit different just to give you that heads-up. Bryan as always good to talk to you and thanks for coming on the Empowering Independence Podcast.

Bryan O’Malley: “Not a problem Blaise thanks for having me.”

Blaise: “My pleasure. So as we know from the 21st Century Cures Act and the extension and everything, New York has to implement EVV, well the whole country does by 2020 on January 1, and it looks like it would be a bit of a disaster from an FI standpoint right now doesn’t it?”

Bryan: “You know that really depends on who the FI is that you’re talking about. Um a number of FIs have had EVV systems for a decade or more due to contractual obligations or system efficiencies they have put in place. Many others do not. I think the biggest unknown right now is the fear that uh DOH may go with one statewide EVV system which frankly whether or not an FI has a system in place, they have invested in the beginning infrastructure. A a move to a singular EVV system throughout the state would cause tremendous and financial resource hardship for every FI.”

Blaise: “But that’s interesting to me. I didn’t know that there were some FIs that have been using this stuff for a decade now.”

Bryan: “In Long Island, New York City, and a lot of downstate as well as uh in Western New York. Many FIs have either voluntarily or contractually been obligated to use EVV systems for a long time. On Long Island they are just the norm they’re accepted. Every homecare agency, every FI utilizes an EVV system primarily due to contracts that existed with the counties, the same with out west. Almost every FI west of Rochester has an EVV system in place.”

Blaise: “And that’s really interesting. You talk about how the state there’s a fear a very justifiable fear that they’re looking to do a one size fits all approach. They’re exploring as far as I understand it from what I know from the various listening sessions and whatnot maybe doing another approach where it’s not so much of a one size fits all?”

Bryan: “Well I think you know they maintain that they do not know as of yet. They are going to be looking for the Good Faith Exemption that CMS is offering to allow them additional time to implement what they choose. Um they seem very confident that they will receive the good faith exemption. From a Consumer and I think an FI perspective that’s a positive, the longer we can go without EVV, for those who don’t have it, the happier everyone is. However, the uncertainty and the fact that DOH has opened this up when they had previously indicated to others that they were moving forward with a Provider Choice system is causing a significant amount of concern.”

Blaise: "Interesting. Bryan O'Malley with us here. Talk about that CMS extension?"

Bryan: "Well there is a good faith exemption that is available from CMS, the application itself is not available until to be filed until July, however, the state does think they are in a position to receive that good faith exemption. It does require unavoidable delays, and there are several categories under which an unavoidable delay could be filed. Most of those seem to be generally in the range of your state legislature doesn't meet every year, you can't appropriate money or something along those lines. I'm not sure where the justification for New York's would be coming from, however, it is something that they are looking at and frankly at this point given the timing, hopefully receive."

Blaise: "I just can't help but shake my head."

Bryan: "Yeah. You know, I think given that they just had the first listening session last week and realistically once an FI chooses an EVV vendor, will take six to eight months for them to implement a system, I think it's shocking that they've waited this long frankly. It, this isn't sneaking up on anyone. It's been in the works for several years, and frankly it was an act of Congress that kept it from being a requirement this past January 1st. So it feels like there's some catching up to do from a state level and that is certainly so causing ripples and um fear throughout the provider community."

Blaise: "I would think I mean you know how the state works better than most given you've been with CDPAANYS for eight years, worked in the Assembly for a few years, and did stuff with the Mental Health Association. Why in the world would they wait so long to get this done?"

Bryan: "I'm not going to hazard a guess on that. You know it strikes me as odd, given the financial penalties that go along with not having it done. However, this is where we find ourselves. And so we're in a position of having...FIs are in a position of having to wait for the state, and then Consumers are in the in unenviable position of having to wait for the state and then wait for their FI and will hope that there's sufficient time too for adequate training and education on these systems."

Blaise: "But yet for all that to happen by January 1st, it sound kind of like Mission Impossible."

Bryan: "It does. You know I think fortunately many FIs are in the process, they chose not to wait for the Department of Health, uh they started moving forward. We had an EVV Vendor Fair last year so that both FIs and Consumers could talk to some of the vendors and find out what's out there, find out the strengths and weaknesses of different systems. However, a lot of that depends on what rules the Department of Health puts out. Of course, as long as they don't go with a single vendor I'm sure that every EVV system will be moving and moving quickly to meet the rules the Department establishes, assuming that they're not already compliant. But, it is a game where one is forced to play catch-up and guess work as opposed to moving forward based upon strong guidance from the Department."

Blaise: "Bryan O'Malley here with us on Episode 3 of the Empowering Independence Podcast. I remember reading a report last year back just a week or two after I started here at Consumer Directed Choices about an EVV report with some recommendations that you guys put together. Talk about that report and those uh recommendations."

Bryan: "CDPAANYS Consumer Advisory Committee uh met several times, uh that was chaired by your previous guest Kendra Scalia. That group put together a series of recommendations of what an EVV system should look like from the perspective of Consumers. Those positions have generally been

adopted as CDPAANYS positions on EVV at this point in time, but they really speak to the needs that are particular to the CDPA community in many respects. The need for flexibility to avoid having to lock in a schedule in advance and then call to adjust it, um they speak to the need to recognize that Consumers are not criminals, they should not be tracked wherever they go. Biometric and GPS tracking systems represent an invasion of privacy, and you know from CDPAANYS perspective systems should not incorporate those measures, there are other ways to go about gathering the information needed by CMS. And then you know an important piece that often will get overlooked is making sure that the systems are accessible...ADA accessible. All too often systems are built for able-bodied individuals and you know the Consumers themselves cannot utilize the system that's you know generally overseeing their services."

Blaise: "Well and I think you hit on the accessibility point and why. I mean that's just another reason why I would think a one size fits all system isn't gonna work."

Bryan: "Well yeah I think that and...I think uh I think the one size fits all system doesn't work from the perspective of CDPA. You know for the better part of two decades, CDPA was traditionally shoehorned into any number of systems be it EVV, or billing, or other systems that were designed for traditional homecare, and then just made to fit without any real adjustments. With the growth of the program we have seen vendors in a realm of spheres including EVV design programs and design software that aren't intended for this program and really meet the needs of those utilizing this programming not homecare. So to go backwards to a time when we are really forced to respond to software and systems that are not made for the program that they're being used in, would be a disservice to everyone that utilizes and relies on this program."

Blaise: "What else are you guys going to be able to do if anything from a policy level to make sure this is implemented the way it should be, in a way where biometrics and tracking aren't being used aside from just the listening sessions that DOH is doing?"

Bryan: "Well I think that's a key piece. Um we are making sure that Consumers and FIs are aware of every listening session and have the opportunity to go out and speak to the needs of this program. We wanna make sure that you know this program is well represented and the Department of Health understands the special needs of this program from those who use it. To that end we are also working with NCIL as well as um NYAIL on the state level, we're working with the Stop EVV campaign that Kendra is affiliated with, and others to you know in inform Consumers inform Consumer's Personal Assistants, and drive that discussion forward in a positive manner. Um we also will continue to have conversations with the Department of Health separate and a part of the listening sessions to make sure they understand the ramifications of this on the program itself."

Blaise: "Bryan O'Malley, Executive Director of the Consumer Directed Personal Assistance Association in New York State. Bryan always good to chat with you and we'll have you on soon."

Bryan: "Great thank you very much Blaise."

For more information about the work that CDPAANYS is doing, go to cdpaanys.org. Thank you so much for listening to Episode 3 of the Empowering Independence Podcast. Thanks to Kendra Scalia and Bryan O'Malley for joining us, as well as Shawna Nunziato for our transcription. Subscribe to the Empowering Independence Podcast wherever you get your podcasts, and let us know what you think

<mailto:info@cdchoices.org>. We will get those suggestions and bring them in. Coming up next month, we'll talk all about Independent Living with two Disability Rights Hall of Famers. We look forward to talking with you in August here on the Empowering Independence Podcast.