

Episode 24: SDM4FL: Supported Decision Making in 2021

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Keith Casebonne: I'm Keith Casebonne, and welcome to this episode of You First. I hope you have already subscribed to our show because that's the best way to get alerted to new episodes each month. Just search for You First where you get your podcasts such as Apple Podcasts or Stitcher and subscribe today. You can also find us at disabilityrightsflorida.org/podcast.

In early 2017, our fifth episode of You First featured Michael Lincoln-McCreight. Mike was the first person in Florida to have a judge terminate his guardianship in favor of, what at the time was, a rather informal concept called Supported Decision-Making. It's now four years later, and Mike is back to tell us more about how Supported Decision-Making changed his life and what he's up to today.

My other guests are Viviana Bonilla López and Tyler Burns. Viviana is an attorney at Disability Rights Florida and an equal justice works fellow sponsored by the Florida Bar Foundation. She coordinates the supported decision-making pilot project at Disability Rights Florida, we shall talk about more shortly.

Tyler is a client of Viviana, who will be signing his supported decision-making agreement within days of this recording.

Thank you all for being my guest today. I really appreciate it. Mike, thanks for coming back. We did this four years ago. It was great conversation. I'd like to talk to you a little more about where you are four years later. Let's get a little synopsis of where you started. What you've done before you got to Disability Rights Florida.

Michael Lincoln-McCreight: I started back in 2016 where I was taken away from my father just because he wasn't able to take care of me or just was fallen through the cracks. I was taken away. I was put in foster care. I aged out of foster care when I was about 18 years old.

I was put into what you call this youth transition centers. I felt like I wasn't quite ready to be living on my own. I went into a financial guardian. It wasn't a full guardian but a financial guardian.

I was placed in a group home where I was able to come and go as I want. I had my rights fully taken away throughout that time. The right to vote, the right to get married, the right to sue, all of that. Then I contacted Disability Rights Florida, and I was able to restore my rights back in 2016.

Keith: Right, and then we talked to you pretty early 2017. You had just gotten to vote for the first time. I remember we talked about that a little bit. Now, it's four years later. What's changed? What are the goals have you accomplished?

Michael: I'm a security officer for ANS Security. I do bog yards. I do security for the New York Mets, when they're doing spring training.

Keith: That's great.

Michael: I do different security. I do the morning county fair. I actually got to see a sea lion do tricks while I was on duty. You can't see that every single day.

Keith: Nope.

Michael: I live on my own. I live in an efficiency apartment.

Keith: That's really great. I know you and Viviana...

Michael: I drive. I got a car.

Keith: That's wonderful. Nice. I know you and Viviana are co-chairs of the new coalition that we're going to talk about a little bit more in a minute. Tyler, tell us a little bit about your story.

Tyler Burns: Because I'm the CEO of Carpe Diem, because I want a job, a good job. I want money, a mansion, all that.

Keith: How did you meet Viviana?

Tyler: I met her, and she's my lawyer. She helped me a lot because I get sick. Mom's my assistant. I'm the CEO. I have mom helping me. I get sick. I go to the hospital. I need surgery, all that. That's it.

Keith: Viviana helped you become the CEO of your own life. Your mom and other family members are there to support you and help you make decisions?

Tyler: Yes.

Keith: Excellent, and that's pretty much what supported decision-making is all about. Right, Viviana?

Viviana Bonilla López: Yeah. I love that the way that Tyler has framed it. It's in his supported decision-making agreement. That way where he says, "I'm the CEO. My parents are my assistants." That's the way he likes to think about this. The first time that I met Tyler, which was over Zoom, and every time we've met since he's always wearing a blazer.

He says CEOs wear a blazer. He's someone who likes to call the shots. It's important for him to be in control of his life. I always love that framing, because we should all be the CEOs of our lives. SDM helps them do that.

Keith: I love that. That's a great segue into talking a little bit about supported decision-making, what it's all about. Viviana, why don't you tell us a little bit about what you do at Disability Rights Florida and the supported decision-making pilot project?

Viviana: I am an equal justice works fellow sponsored by the Florida Bar Foundation. What that means is that the Florida Bar Foundation was generous enough to give Disability Rights Florida some funding so that we could carry out this project.

I lead a pilot project in Miami-Dade County, where we are providing free legal services to people like Tyler, who would like to use supported decision-making either to avoid a guardianship or to get out of a guardianship.

We'll represent them in drafting a supported decision-making agreement and any documents that they might want as part of that process, like a power of attorney, or healthcare surrogate designation, or we will represent them in court and filing what's called a suggestion of capacity.

Which is where you tell the court, "Listen, I can exercise my rights. This is how." You ask the court to reevaluate that original guardianship decision, which is what we did with Michael Lincoln.

Keith: I know four years ago, when I was talking to Mike. I remember his attorney at the time referring to supported decision-making as a relatively informal concept. Something that, it hadn't happened in Florida yet. It hadn't in a couple other states. It was still pretty new. It's four years later, and it seems that's not the case anymore.

In fact, if anything, we're looking to make this a pretty standard thing as there's a bill in front of the Florida Legislature right now. Tell us a little about that, how this concept has changed over the last four years and where we're at now.

Viviana: Supported decision-making is still something that you can use informally. Really, the answer to that is, it's up to every person. It's up to every decision maker. I use supported decision-making more informally, where I ask my parents for advice, and other friends who I trust, when I have to make big decisions, like where I'm going to live, maybe medical decisions.

Every time I have to get my car fixed, because I never understand what the mechanic is saying to me. I use it in a pretty informal way. Then Mike uses it in a more formal way, where he's written down who his supporters are. How they're going to help him. He has a power of attorney and a couple other documents.

Tyler also has opted for a more formal way where he has written down a supported decision-making agreement. His is pretty cool, because it has pictures in it. There's an audio recording as well. He said, who he wants to help him, how, and has some other legal documents, also power of attorney, etc. that accompany.

It's a question of how do you want to use supported decision-making. Then we want to make sure that that is available for you in Florida. The same concept remains true. We're just trying to create more opportunities. We've presented a bill, Senate Bill 1010, and House Bill 681, that will make supported decision-making more uniform, regulated in the State of Florida.

There's already 12 states and Washington DC that have supported decision-making laws in place. We want to be the next. What this law will do is it will say, "OK, what is the supported

decision-making agreement? What needs to be in there? Who can be a supporter? Who can be a decision maker? Who has to accept a supported decision-making agreement?"

"If I'm going to take it to the bank, do they have to accept it?" The answer is yes. "What things can you authorize using a supported decision-making agreement?" It's making it available to everybody and so that we're all on the same page about how these documents work.

That doesn't mean that you can't continue to use supported decision-making without a supported decision-making agreement, like many of us are doing and have been doing for years. It's just going to create more uniformity, more guidance for judges to say, "You should consider supported decision-making before appointing a guardian."

Also, one thing we're pretty excited about is that it's going to require schools to give parents information about supported decision-making whenever they talk to them about guardianship. I'm happy to go into little more details about the bill if you'd like, but that's the idea.

Four years ago, we were talking about supported decision-making as something that could make the lives of people with disabilities better in Florida. Now we're taking more concrete steps to make sure everybody knows about it, and that we have a good base to start and build on.

Keith: You mentioned guardianship in there. Guardianship is a much more restrictive option, and unfortunately, one that gets used much more frequently than is probably necessary for many, many people. The idea of supported decision-making is to give a much lesser restrictive option.

Is some of that written in this bill? Does it explain guidance as to what's more restrictive and what's not, and why maybe you should use supported decision-making instead of guardianship?

Viviana: Yes. Florida law already requires that judges, once they found that someone is incapacitated, that they consider, "Is there something other than guardianship that would meet the needs of this person so that we don't have to do guardianship?"

Because guardianship is restrictive. You lose your rights. They're given to someone else, and that other person makes all of your decisions for you. Judges are already required to do this, but we don't give them very much guidance on what could that be. What could that alternative be?

We've already seen Mike use supported decision-making as an alternative, but it was because he had an attorney who knew to bring this up to provide evidence to the judge.

What we're going to do is have that guidance, that was provided in this instance by the attorney, be in the law. The law is now going to say that when someone is found incapacitated, judges should consider the less restrictive alternative and they should consider alternatives to guardianship.

Now there's going to be a list in the law that says, "What are those alternatives?" It's going to include supported decision-making, healthcare surrogate designations, powers of attorney, trusts. All these tools we're already familiar with. It's going to be very specific about how this comes in which will be helpful.

Keith: This doesn't necessarily replace guardianship?

Viviana: No.

Keith: It gives another option for people to choose, or judges even, to recommend or choose. We mentioned schools, so teachers can also recommend it. It sounds like it's going to be a wonderful, wonderful option.

Viviana: Yeah. It's an addition tool to the toolkit. A new tool in the toolkit. You still have guardianship. You still have guardian advocacy. You still have those powers of attorney. You still have the healthcare surrogate designation. Now we're saying you also can add supported decision-making as one of the other tools that you can pick from.

This is good for judges. It's also good for parents, for people with disabilities. For older adults. For people assisting older adults. It's adding another alternative, another option.

Keith: How is that going? I know that it's got a little bit of bipartisan support right now. Is it looking good? What's the status?

Viviana: Yeah, we're excited. We're very optimistic. Our House Bill 681 is sponsored by Representative Allison Tant. She is the former head of the Democratic Party in Florida. Our Senate Bill 1010 is sponsored by Senator Joe Gruters who is the current head of the Republican Party in Florida. You can't get more bipartisan than that.

We've seen a lot of interest in support from both sides. Right now, we're doing pretty well. We had a meeting today with one of the committees. That's our last stop in the House and they're already interested and want to talk about our bill.

We've had other representatives express their support to the chair at the first committee that we're at. Things are looking pretty good right now and we're hoping that that will remain the same.

Mike has been sharing his story with a lot of these representatives, and out there talking about the bill as the co-chair of the coalition pushing this bill. Mike, it's going well, right?

Michael: Yes, it's going well. What I love about this bill is it gives people with intellectual and developmental disabilities a chance to live their life to the fullest.

As you heard me say, Keith, four years ago, I wasn't able to go to church. Well, with supported decision-making, I'm now able to go to church. I met some awesome people like Pastor Jerry which is my pastor. I got to meet some cool people and you don't get to do that when you're in a guardianship.

It also brings out a lot of opportunities to be successful, to live your life. To be able to be successful.

Viviana: That resonates with people, and it's not just developmental intellectual disabilities. It's any disability at all.

Keith: Mike, tell me about some of the other things, that you asked for advice, some of your people to support you with making decisions.

Michael: Well, I asked for advice from a lot of people. My number one is my pastor. I mentioned him, Pastor Jerry. He advises me even though I'm stubborn sometimes. I'm not going to lie, no one's perfect. He advises me about a lot of stuff. I also ask advice from Colleen, Harold. Sometimes my dad, my uncle.

Different people that's in your support team that...I even keep in touch with Amanda sometimes. Sometimes I call her and say, "Hey. What do you think? Good idea, bad idea? What?"

Tyler hits a good point. He calls him the CEO and the associates. With me, I call it like, "I'm the chief of police," or, "I'm the chief." They're my officers underneath me which is a good way to look at it. You make fun out of it, you know what I mean?

Keith: Yeah. Everyone goes to people for advice and asks questions. No one's expected to know how to do everything. It's a very natural process and I'm glad that some of this can be made a little more official and documented with the court. It's exciting to see where this is going and the opportunities out there.

Viviana, we've had a number of people now that you've helped get supported decision-making agreements in place, correct?

Viviana: Yeah. We have served over 85 people as of yet, and that number is growing every day.

These are people that we've either given them advice on how to do a supported decision-making agreement on their own. Assisted them with drafting a supported decision-making agreement and any other legal documents that they need, or we're helping them get out of a guardianship.

We've had an incredible reach, and I'm grateful for all the clients I've been able to work with.

Keith: That's amazing, and it's come a long way from when we had our first client there, Mike. No one even knew what supported decision-making was. That's wonderful.

Let's talk a little bit about the coalition. I know again, Mike, Viviana, you guys are both co-chairs of the coalition. I know a lot of the goal of the coalition was to get the bill going and get some traction behind it.

Either one of you going to talk a little bit about some of the progress coalition has made with advancing supported decision-making?

Michael: I love talking about our coalition. Our coalition has come so far from such a small amount of time. When I first got a call saying that, "Oh, we wanted to start a coalition." I'm like, "Oh, Lord, here we go. I'm getting myself into a big predicament." It turned into so much more.

We're technically family. We have Florida SAND which is a group of self-advocates throughout the State of Florida that's helping us draft this bill, Developmental Disabilities Council, so different organization.

What it is, is the coalition is to create a bill, so we can get it passed in the local and state legislation. Basically turn it into basic law. The bill is 35 pages. I believe 35 pages. The coalition,

we all put the bill together. I have good faith because we worked hard on the bill. Anything you want to add, or I left out?

Viviana: It's nice as Michael said for this bill to be one that comes from the community, that comes from people who were directly impacted by the guardianship system. It's one that was put together by people with disabilities, by their parents, by people who've been guardians, by disability advocates.

It's come from the people who are most affected by this saying this is what would be great for us and for our community. That is wonderful. We don't always see legislation be created that way. We're very grateful and happy that our sponsors wanted to amplify that.

Representative Allison Tant is the mother of a person with a disability. It's really important to her to stand with people with disabilities. The same with Senator Gruters. This is a population that it's important for him to stand by. We're very grateful and proud of the way that this has come together.

Keith: On the website if people want to take action or help get something going here with the bill, contact their legislators or push on social media, I believe there's tools to do that on the website, right?

Viviana: Yeah, go to www.idecideflorida.org. Everything is written out. We have a lot of different pages to learn about SDM, read people's stories about SDM. Then there is an Act Now page that will tell you what to do if you want to help us get this past.

Michael: You can also look us up on Facebook and Twitter, called IDecideFL.

Keith: Great. I'm sure there'll be updates on progress of the bill and information on what SDM is and why this bill is important. That's really great. Tyler, I know very soon your agreement is going to be official and in place. You have some big goals that you're looking forward to or something that you want to do on your own as soon as this is ready?

Tyler: I want a house by myself and my dog. I can be happy. Before [inaudible 21:48] goes away, better. I want a good job and be good.

Keith: Is there a specific job, something you would like to do?

Tyler: Well, I want to be a cop one day.

Keith: If Mike's the police chief, then maybe you can work for him.

[laughter]

Viviana: Mike is the person to talk to if you are interested in careers related to that, because Mike is a security guard. Tyler, you have a pretty cool supported decision-making agreement, right?

Tyler: Yes.

Viviana: It's cool because it has pictures in it. Why did we put pictures in your supported decision-making agreement?

Tyler: Well, because my decision is because mom's my assistant. The whole family is my assistant.

Viviana: Your mom and your dad and your sister are your assistants? What do they help you with?

Tyler: Say I go to the hospital. I get sick. For that I have mom, because CEO of Carpe Diem.

Viviana: Yeah. You've told me that your mom works at Carpe Diem and you help everyone there. So, they know you as a CEO?

Tyler: Yes, they behave good. They behaving.

Viviana: I'm [laughs] glad you keep a tight shift. You run a tight shift.

Tyler: I do, I do.

Viviana: Tyler, why do you trust your mom? Why is it helpful?

Tyler: Because she's a good mom. She helped me a lot, just to help me. Because she's there for me. I need her to help me make my decisions.

Viviana: Are you excited about signing your supported decision-making agreement soon?

Tyler: Yes.

Viviana: What will it feel like, you think, when you sign it?

Tyler: I'll feel happy. I'll feel happy.

Viviana: Do you think you'll also be proud of yourself?

Tyler: I'll be proud of myself. I'll be happy and proud.

Viviana: That is awesome.

Keith: That's what it's all about, right?

Tyler: Yes.

Keith: Well, thank you all for being my guest, I appreciate it. Hopefully, we can talk about this again a little sooner than four more years from now. Looking forward to keeping track of the performance of this bill. Hope this becomes a law in Florida and would be the...Was it the 13th state that would get it?

Viviana: Yeah. 13th plus DC, so kind of like 14th. [laughs]

Keith: OK. 13 and a half.

Viviana: [laughs]

Keith: Very good. All right. Thank you all again, I appreciate it. Good luck on the bill.

Tyler: Thank you.

Viviana: Thank you so much, Keith.

Keith: Thanks again to Viviana, Mike, and Tyler for being our guests today. You can learn more about supported decision-making and the SDM for FL Coalition by visiting www.idecideflorida.org. On their site, you can read more about the bill and take action by downloading their advocacy and sharing tool kits to spread the word and contact your legislators.

To learn much more about supported decision-making, types of guardianship, and other alternatives to guardianship, you can visit our website at www.disabilityrightsflorida.org/sdm.

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