

You First Podcast - Episode 5: Supported Decision-Making

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Keith Casebonne: Hi. I'm Keith Casebonne. Welcome to "You First," brought to you by Disability Rights Florida. The purpose of You First is to discuss the rights of individuals with disabilities, putting your rights first.

This podcast is produced by Disability Rights Florida, a not-for-profit corporation working to protect and advance the rights of Floridians with disabilities through advocacy and education. You can learn more about Disability Rights Florida on our website at disabilityrightsflorida.org.

Our guests today include Mike McCreight, a young adult who was previously under a very restrictive guardianship, and is now able to make decisions on his own, and Amanda Heystek, Director of Systems Reform at Disability Rights Florida, and Mike's attorney.

In this episode, we'll talk about Mike and the guardianship situation he dealt with, how Amanda was able to help Mike by removing the guardianship, and how Mike's life has changed since that time.

Thank you, Mike, for joining us today. I look forward to talking to you, and thank you, Amanda, for being here to talk about the work you did to help Mike gain back his right to make independent choices.

So, Mike, I'd like to start with you. Tell me a little bit about yourself before the guardianship.

Mike McCreight: Well, um, I was in foster care, um, for almost, I think, two years, um, where I got taken away from my dad, um, by DCF.

I also enjoyed volunteering. I volunteered with various, various of, um, organizations, such as, uh, Sheriff's Explorers, Guardian Angels, um, hospitals, the whole nine, and I loved to go to church.

Keith: It sounds like you had a pretty active life...

Mike: Yep.

Keith: ...before the guardianship kicked in.

Mike: Yep.

Keith: So, what happened after, uh, uh, after foster care, after you turned 18?

Mike: Well, I was on my own. Um, I aged out of foster care, where they put me in, um, in a less-restrictive, where I could come and go as I want. Um, how do you put it? Like a transition center type of setting.

Keith: OK.

Mike: But I felt like I wasn't ready for that, so I decided.

They said I should be put in a group home, just for, like, a couple of years, just so I can get some learning of...

Keith: Mm.

Mike: ...you know, of getting some adult learning. And it turned out that I was actually being there for more than two years. It was actually four years.

Keith: Oh, wow.

Mike: And then it kept on going, and going, and going. And then, it turned out I was being petitioned by the court, where they took all my rights away and provided me an incapacitated guardianship.

Keith: Wow, and that meant you couldn't do any more of the volunteer work you enjoyed, or...

Mike: Exactly.

Keith: ...or any of that. Gosh.

Mike: And I also had to ask permission from the guardian just to do the things I wanted to do.

Keith: Wow. I heard it was even restricted for you to get a ride somewhere.

Mike: Yeah.

Keith: Like you had to...

Mike: They had to be put on the Safe list, um, and if they weren't put on the Safe list, they could not pick me up.

Keith: Wow.

Mike: Yeah.

Mike: So, along the way, though, fortunately, you did the help of some friends and family. Uh, and I know you sort of became your own advocate, as well. Tell me a little bit about that.

Mike: Well, I was in a group home, where it was completely, completely restrictive.

Keith: Mm-hmm.

Mike: I could not go see my family, couldn't go see my friends, couldn't do my phone to work at all, couldn't even call people.

So, when I got some privileges back, I bought me a cell phone, and then, I contacted a good friend of mine, which is Coleen. And, um, we started writing letters to the sheriff, um, of St.

Lucie County. We also started writing the letters to, um, APD and then, she also said I should also call Disability Rights Florida.

So, at that time, I googled it, [laughs] the old-fashioned way, googled it, and, um, I got the intake number, which is the 800 number.

Keith: Mm-hmm.

Mike: And I did the intake, and not in a matter of minutes -- oh, not minutes, but a couple of days, um, Amanda called me and said, you know, she would like to meet up with me to talk about, you know, what was going on.

And at the time, you know, I wanted it, but also, you know, the [inaudible 04:51] wasn't that much of a, accepting about it. So, you know, we went, moved forward, and I said, "No, I'm doing this. This is my decision." And, um, we got the ball rolling. And, you know, um, Harold was also, um, was also a big help, um, and also, um, Melody was also a big help, so.

Keith: Good. Well, since you contacted Disability Rights Florida at this point, we'll turn our attention to Amanda. Uh, tell me a little bit about yourself and your experience and work at Disability Rights Florida.

Amanda Heystek: Sure. I've, um, I've worked at Disability Rights Florida for eight years, since 2008. I've been a lawyer for about 16 years. Um, throughout my work at Disability Rights Florida for the past eight years, I'd say I've primarily worked with people with developmental or intellectual disabilities.

And so, I'm familiar with the issues, and when Mike called, uh, after our first conversation, it was just clear to me that the guardianship had, no longer served a purpose for him, or he had outgrown it, um, one way or the other, and he kinda something that was less restrictive where he could be in charge of his own decisions, 'cause he's capable of making them.

Keith: So, what did you think about Mike when you first talked to him? I mean, obviously, you did, you just said you felt he was, you know, capable of making decisions, and that this guardianship was a bad idea.

Amanda: Right. And I think, you know, I don't want to cast blame or anything. So, it's, it, it might have been a good idea at the time. When Mike was first in the guardianship, he was in a limited guardianship, which was just covering his financial affairs.

And I think that was maybe, um, appropriate at the time. He was aging out of foster care, and he didn't have a, a large family network of support. That limited guardianship, however, became a plenary guardianship, which is what we refer to in Florida statute as sort of a full guardianship.

In other words, all of the statutes that are...all of the rights that are listed by statute are actually removed from the person at that point, so he went from not having control over his finances to not having control over anything.

And that included, um, decisions about where to live, uh, decisions about his social environment, what kind of friends he could have, and who he could be with, and that sort -- you touched on that with the who was on the Safe list to be able to provide him rides.

Um, all the way down to rights such as the right to vote, was removed from him, and he's clearly capable of watching the news, just as well as anybody else...

Keith: Sure.

Amanda: ...and forming opinions and voting on his own.

Keith: Sure, sure. And, and the court is, is supposed to explore, uh, least restrictive options before making a decision to put someone in a guardianship. Uh, did they do that? Did they, did they explore that any?

Amanda: So, I wasn't at the original court hearing, because we didn't know Mike at the time. Um, the court...you, you were present for that, right?

Mike: Yes, I was.

Amanda: OK. And so, he, he voiced his opinion, and I believe you even had a chance to speak, right?

Mike: I had a chance to speak, but the attorney, at the time, thought, you know, just to let me speak a little bit.

Keith: Right.

Mike: So, and the judge, to me, didn't even listen to what I said.

Amanda: OK.

Mike: So.

Amanda: So, a lot of times, um, while it says in Florida statute that the court has to consider less restrictive alternatives than guardianship before establishing the guardianship, there's nothing delineated in statute as to what those might be.

Keith: Mm.

Amanda: The obvious choices are power of attorney, um, trustees if there's a monetary issue going on, um, health care surrogate forms and the like. Um, in this case, we used supported decision-making to get him out of the guardianship.

And that's really nothing more than an informal way of relying on those around you to provide you with guidance and advice.

Keith: Good. And we'll talk a little more about the, the, the remedies that were put into place. Uh, Mike, how did you feel when you first to-, uh, excuse me, when you first spoke to Amanda about this issue?

Mike: I felt that she could actually help me, um, because just like other people, she felt determined on getting me out of the guardianship. Even though I called her 50 million times of the day, but...

[laughter]

Mike: Um, I was kind of persistent on wanting to get this done, because I was sick and tired of people...

[crosstalk]

Mike: ...controlling...

Keith: Sure.

Mike: ...all of my life.

Keith: And, and your persistence is, is probably what helped get all this going.

[laughter]

Mike: Yep.

Keith: Yep.

Amanda: It surely did. It kept me on track.

[laughter]

Amanda: I can tell you that much.

Keith: Very good. Very good. So, um, Amanda, let's talk a little bit more about where you started to go with the, uh, the, the remedies we provided, uh, of course, the supported decision-making, which of course, I want to get into a little more specifically later.

Uh, w-, w-, what else? Uh, uh, just some basic education, even for family, and, and himself, and...?

Amanda: Y-, sure. So, um, as a person with a disability, he also received some benefits, so another obvious, less-restrictive alternative is a representative payee through Social, Social Security, where the, the monies received are actually paying for life necessities -- rent, food, clothing, etc.

And then, it goes to the individual, to the beneficiary. So, there's different ways to go about this, and, um, it, in the process of es-, re-establishing his rights, he would have to see a physician, and the physician would have to evaluate him.

And in this case, we had a really good physician. And they met, and he convinced him that he is capable of exercising most or all of his rights, and that's what the report said.

Keith: Wow, th-, th-, that's great. So then, you mentioned supported decision-making, and I know that's the, the, the big topic here, uh ,a, a new direction perhaps, that, uh, at, at least in Florida, for a least-restrictive option over guardianship.

So, can you tell me a little bit more about what that is, and what the process was to get that set up for Mike?

Amanda: Sure. So, supported decision-making really isn't, um, a formal concept.

Um, it's, it's the notion that people who have a disability and may lack capacity to make certain decisions can otherwise inform, influence, and make those decisions if they're presented with the right information from the right people, people they trust, people who have proven themselves to be loyal to their best interests, and, and help them make those decisions.

And so, in, in certain cases, um, the person might actually lack capacity, and the court can make that legal determination. However, you don't have to go that extra step to a guardianship if there is a support network around that individual that can help them make those decisions.

And that's a less restrictive alternative to guardianship, so in this case, it was a combination of, you know, "We could do a power of attorney, we can do a [inaudible 11:59] , and we can do supported decision-making."

There's different ways to go about it. Um, some countries and states actually have it in statute, and have formal agreements that people enter into.

In this case, we kind of molded an agreement from all of those different sources and created one agreement where, uh, Mike acknowledges that he's going to need some assistance and some support in making certain types of decisions.

And he actually signs onto it like a contract, um, and names who those supports are going to be. And the court is aware and presented with that information, that these individuals have been in his life. They've been proven to be loyal and honest with him, and in support of his decisions, and they're going to be there for him.

So, he signs off on it, saying, "I'm going to consult these people," and these people, um, sign off on it, saying, "We're going to support him."

Keith: It, it almost sounds like what we all do every day when it comes to, uh, this s-, uh, knowledge we don't have. Like if you, you feel sick, you don't diagnose yourself, you go to a doctor. If you need legal help, you go to an attorney. It sounds...

Amanda: Exactly.

Keith: ...not much different than that.

Amanda: It's not. It's the same concept. It's just a more formal wy-, formal way of presenting to the court that the guardianship isn't necessary, because he's aware of his surroundings, and he knows what's going on in his life. And he's going to seek the guidance of others, just as anybody else would. If you're going to buy real estate, you might talk to a realtor.

Keith: Right. Right. This sounds about as, as, as least restrictive as, as, as you can be with, while, while still having some, you know, some level of agreement in there.

Uh, well, since this is the first time that we know of that this has been used in Florida in this, in this particular way, uh, are we hoping for maybe setting a precedent, or doing this more often, or pushing for maybe some legislation, or...? What's the, what's the future look like, uh, as far as supported decision-making in Florida?

Amanda: So, I think the first thing really is, um, I think we have to acknowledge that there's some precedent here, and that a court has signed off on an order, um, restoring Mike's rights, saying that he's going to use supported decision-making as a less restrictive alternative.

Keith: Mm-hmm.

Amanda: Um, other courts don't necessarily have to follow that, however, in Florida, but I think it's certainly a guidepost that they can look to. And Mike is sort of going to be the pioneer of this idea.

[laughter]

Amanda: And so, we're hoping for good things. And he's already far exceeded our expectations, with having two jobs, and being back in the community and volunteering.

Um, I think there's a general lack of education or knowledge about it. We've gotten into a situation in Florida where guardianship, although we s-, we, we pay lip service to this notion of less restrictive alternative, it doesn't always come into play.

And that's not necessarily a good thing or a bad thing. It's just sort of the way things are, where the courts are presented with all of these cases of people who need help, and they don't really have formal alternatives out there.

And so, lacking any formal alternative, they tend to go with the guardianship, and that becomes costly for the person, it becomes restrictive, and it's, you know, in Mike's case, demoralizing.

Keith: Right. Well, so, Mike, tell us a little bit about how your life has changed since the supported decision-making agreement was, was put into place.

Mike: Well, um, I get to see my supports a lot more -- Coleen, um, my friend Mike, which was also a, um, friend I've made from the Explorers. Um, I also get to do some activities like going to the mall. [laughs] I'm a movie addict, so I go see "Fast and Furious" whenever it comes out.

[laughter]

Mike: So, I'm going to go see "Fast and Furious 8." But anyway, um, voting for the first time, which was awesome.

Keith: That must have felt great.

Mike: Even though it was a long line, but yes, it was awesome on voting day.

Keith: It was a big election.

[laughter]

Mike: And then also, being able to go back out in my community and serve with Guardian Angels, keeping the community safe, um, and also my two jobs.

Keith: Right. Wow. So, it sounds like life has totally turned around for you.

Mike: Yeah.

Keith: Uh, well, give us an example of maybe what, uh, some of the daily things that you do that involve using your supports that you, uh, agreed to use in the, in the supported decision-making agreement.

Mike: Vacation. [laughs] My very first vacation trip was actually coming to Tallahassee, to be honest. Um, you know, and I actually used my supports for that.

Keith: Good.

Mike: Um, because, you know, when f-, Amanda first told me I was coming to Tallahassee, I was like, "Hmm. Maybe I should call my uncle and tell him, and see what he thinks."

So, I called my uncle, and then, I went through channels. I called my uncle Steve, which is also...um, as you know, I did a radio show with him, as well. Um, and basically, um, you know, I asked him what he thought, and then I contacted my friend, coach, in Orlando, um, you know, to, you know, plan it out.

And, you know, it went through supports, you know. I went through the channels, um, to get money for Greyhound, you know? Um, I asked Coleen to, you know, "Hey, can we do this? Do you think I can get a ticket to Greyhound so I can go to Orlando?" and she was like, "Yeah, why not?" So...

Keith: Great. That's a great example. That's a, there's a lot of different moving parts there that you had a lot of support...

Mike: Yeah.

Keith: ...and help with. Great. Well, what advice would you give to others in situations similar to what you went through?

Mike: [sighs] Stand up for yourself. Don't let people run over you, because there are people out there that'll run over people that has disabilities...

Keith: Mm-hmm.

Mike: ...and really does take advantage of them.

There are people such as jobs, such as the legal system, such as attorneys, such as anybody. Anyone in the world will take a, take...uh, how do you put it? Take just advantage of people with disabilities, and it really does get me upset.

But, um, that's why in the future, I'm going to be a s-, uh, advocate for people that has disabilities. So, I'm planning on joining Family Care Counsel of my area, area 15, and my goal is to make a difference. My goal is to actually, um, stand up for people with disabilities, because there are people that runs over them.

Keith: So, I don't think anyone could put it any better.

[laughter]

Keith: Mike, thanks so much for taking the time to tell us about your incredible story.

Mike: It's a pleasure to be here.

Keith: And Amanda, thank you, as well, for the work you do for Mike and other people with disabilities in Florida.

Amanda: Thank you. It's an honor.

Keith: If you or a family member of yours has a disability, contact Disability Rights Florida. We provide free and confidential services including information and referral, advocacy, legal representation and negotiations, and investigation and facility monitoring.

Our goals include access to education, employment, and independence, better laws, policies, and practices, and elimination of abuse and neglect. You can learn more about the services we provide, explore a vast a-, array of resources on a variety of disability-related topics, and complete an online intake on our website at www.disabilityrightsflorida.org.

You can also call us, as Mike did, at 1-800-342-0823. You can also learn more about supported decision-making at www.supporteddecisionmaking.com.

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