

You First Episode 39: 2023 Disability Policies on Our Watch

Maddie Crowley: You're listening to "You First," the Disability Rights Florida podcast. On this episode, we're chatting with our staff about what disability-related topics to watch out for this legislative session.

[music]

Maddie: Hi there. I'm Maddie Crowley.

Keith Casebonne: I'm Keith Casebonne.

Maddie: We're the hosts of You First. Happy New Year, everybody. We hope you had a good start to your year. With a new year comes a new Florida legislative session.

Keith: That's right. Each year, Florida legislators and advocates meet to discuss and pass new laws and regulations. This year, Florida's legislative session is starting in March, but the conversation around what bills and topics will be talked about began months ago.

Maddie: Yes, definitely. Disability Rights Florida staff has been following these conversations and keeping track of what potential topics will come up next month. Issues that are up for debate and discussion can greatly impact the disability community in Florida. That's why we wanted to give you an inside scoop into what we have on our radars for this year's session.

Keith: Today, on the podcast, we have our friend and coworker, DRF Public Policy Analyst Caitlyn Clibbon. She's one of our staff members who's closely watching what's happening with the Florida legislative session and considering the impact these laws will have on folks with disabilities. She offers some insight into what the topics we as an organization are focusing on and keeping a close watch on.

Maddie: Caitlyn talks to us about a variety of issues that span from mental health, students' rights, community integration, and much more.

Keith: It's a valuable conversation and gives us an idea about what is on the horizon for the Florida disability community. We hope you enjoy.

Maddie: Thank you so much, Caitlyn, for being on "You First Today." We're really intrigued and excited to learn a bit more from you about Disability Rights Florida's 2023 legislative session priorities. Could you tell us a bit about yourself and give us a background as to what legislative session is and what that looks like for DRF, what we do for legislative session?

Caitlyn Clibbon: Sure. I'm Caitlyn Clibbon. I'm a Public Policy Analyst at Disability Rights Florida on our policy team. We do legislative advocacy each legislative session in Florida. We have a 60-day session every year. Our session this year starts in March. We're gearing up for it now. We've already had some committee weeks leading up to that.

Leading up to it and throughout session, we will perhaps propose some of our own bills. We will definitely follow bills filed by others and that are related to anything that might impact people with disabilities.

The state analyzes bills to decide whether to support or oppose. We will go and speak at the legislature on behalf or in opposition to those bills, and generally, just try to guide any legal reforms that are going to be happening in such a way that they will benefit people with disabilities.

Maddie: Awesome, thanks for that background about what session is and our involvement in it. What I think we're hoping to do today is hear about what DRF's, Disability Rights Florida's legislative priorities are for this year.

Like you said, there's lots of bills and lots of action going on at our Capitol with legislative session. Certain things definitely impact the disability community that we want to keep an eye on. Could you talk a little bit about some of our priorities, primarily starting maybe with our focus on autonomy and self-determination, and rights protection?

Caitlyn: Sure, yeah. I'll just preface it by saying that when we're deciding what our legislative priorities are, we don't always know all the bills that are going to be filed.

We try to think about our principles, what we believe in, our goals and objectives of our organization, and list out the things that we think should be priorities in legislature, and we use that to guide us when we're deciding to support or oppose a bill.

Some of these are things that we may see during sessions and we may not actually say anything about, but this is what we hope for our state. In the vein of autonomy and self-determination, rights protection, I think that those principles are overarching principles that guide most of our priorities, but specifically in that category.

First, one of our main priorities is supported decision-making and advancing that cause in our state. There are people who have used supported decision-making in Florida but it's not currently codified in our statutes as an alternative to guardianship, which can make it difficult for people to utilize.

Some judges don't know about it, or attorneys don't know about it or understand how to use it, so we would like to see that codified in statute to make sure that people who don't truly need to be in a guardianship aren't unnecessarily placed in one losing their rights in the process.

Similar to that, we do have some indication that there may be bills filed this year that attempt to reform the guardianship system itself aside from supported decision-making.

Our priority would be with any bills filed to affect the guardianship system, would be to make sure any of those changes would be rights-protective. Making sure that the system is not abused, and for anyone who does abuse that system, they are held accountable for doing that and taking advantage of people.

Maddie: Just for folks who might be listening that may have never heard of supported decision-making or guardianship, could you just speak a little bit to the difference between those two, and our perspective of why supported decision-making is important?

Caitlyn: Yes, absolutely. In a traditional guardianship situation, this is something similar to what people might have seen with the #FreeBritney movement in California, with her conservatorships. In Florida, we don't use that term.

We use the term guardianship, but essentially, is a way that if a person has been declared incapacitated, which is a legal term and has some pretty specific meanings in the court system, person is declared incapacitated by a court, their rights can be removed from them and a guardian is appointed who exercises those rights for them.

We call that substitute decision-making because the guardian is substituting their own decision for that of the person in the guardianship. Alternatively, supported decision-making allows people to retain their rights and continue to make their own decision. Instead of substitute decision-making, it's they are making their own decisions with support.

It allows them to retain, hopefully, all or many of their rights. They can be used in conjunction with a guardianship, so maybe some rights are removed and others are retained and exercised with support under supported decision-making agreement.

Or ideally, for those who it's appropriate, the guardianship is avoided entirely and they retain all of their rights and are able to utilize the support they choose to help them make decisions if they feel like they need that.

Maddie: Great. Thank you so much for going over that and providing that background.

Keith: I remember how important supported decision-making was even back in 2016. The fifth episode of this podcast was all about that, where we interviewed the first person in the state of Florida to be given a supported decision-making agreement. It was really fascinating. Go back and listen to that episode number five.

Again, we've also had another episode, I think it was 27, where we talked about the updates, what was going on in the state, the pursuit to have a actual law in the state of Florida to make SDM codified, as you mentioned. It's huge. It's a big deal. What are the chances of seeing this happening anytime soon? Does it look good? I know it has been an ongoing fight. How are things looking?

Caitlyn: Yes, it's been an ongoing fight and no one can make promises about what bills will pass or won't pass. We're going to keep trying to get this bill passed for as long as it takes.

I think that there are many people or many legislators in our state who have other priorities in this session. We've had some issues related to hurricanes and there's some hot-button cultural issues. My concern would be that this would just be taking a backseat in this session even if folks do support it.

That said, we are actively pushing for the bill to be sponsored and introduced, and we will work as hard as we can to get it passed.

If it doesn't happen this year, will be the same next year and keep working for it because we think it's vitally important to make sure that people can retain their rights as often as possible. Make their own decisions and live their own lives the way they want to live them regardless of how people feel about their disability.

Keith: Indeed. I hope at some point soon this becomes an actual law. It would be great. Let's shift gears a little bit and talk about healthcare. Obviously, the pursuit to make healthcare of high quality but also affordable and accessible to people with disabilities. What's on the plate in that topic area?

Caitlyn: One of the main things that we are hoping to see in this session is a Medicaid buy-in bill. That's something that's been filed in the past and it has some level of support. We think that it would be a great step forward for the state.

Medicaid buy-in, what that means is that the Medicaid program can be expanded to create a system where people with disabilities could buy into Medicaid even if they aren't in the poverty thresholds that are currently required. Right now, you have to be below a certain income to qualify for Medicaid.

In a situation where perhaps someone was receiving services like a personal care assistant, if you're on Medicaid, and if they got a job and they got private insurance through their job, that private insurance might not cover their personal care assistant, which would make it difficult for them to be able to accept the job. People want to work, people want to be autonomous.

Medicaid Buy-In program would allow someone like that in that situation to accept their job and pay into Medicaid like a private insurance program on a sliding scale. Pay a small premium every month and keep the Medicaid that does cover all of their necessary services.

Again, that's a really important priority for us because it really expands the opportunities that people with disabilities to work and be integrated into their communities in the way that they desire.

Keith: That's such an important thing. As you said it, having a good quality health care enables you to do other things like work, get an education, anything else, be there for others. That's definitely a huge, enables so much more quality out of life and so many other aspects.

Caitlyn: Another healthcare topic that recently we've been reached out to about it. One of our representatives is looking at filing a bill that would create a right-to-repair for power wheelchair which is an issue for many folks because people with power wheelchairs, there's only a few companies that will repair them and they have to get approval ahead of time and can only use certain parts.

It can take months over a year for some people to have their power wheelchair fixed when they need to be fixed. During that time, while they're waiting, they may not be able to use it at all. They might come to a point where they aren't able to leave their homes or aren't able to leave their bed or the place where they are because they don't have that mobility with their power wheelchair.

When that happens, it's really restrictive and can really impact their daily function, ability to work, ability to be in their community.

We want to work with anyone who is working on a right-to-repair bill and to try to make sure that it's going to be functional and actually help people and it's not going to get them crossways with any of their Medicaid or other benefits but allow them to have their wheelchairs repaired in a timely manner so they aren't getting stuck at home.

Maddie: Yeah, definitely. As someone who uses mobility aids, just having them being serviced and not having access to them for long periods of times, can drastically change how you're able to navigate the world around you. Your ability to leave where you live or navigate your school or employment location, anything like that.

It's really important that this is a priority for DRF to pursue. In that vein, maybe we can shift gears to talk a bit about education and how we can continue to protect students' rights and students with disabilities to ensure that they're able to access education they want.

Caitlyn: Our overarching goal again is education is going to be making sure that everyone's getting the services they need in an appropriate way, reducing the boundaries and hurdles to getting those services, making sure that all students are being educated in the least restrictive environment possible, mainstream classrooms if that's what they desire.

That's the overall goal for any bill that we would see. Does it do any of those things? If yes, we are going to support that generally.

Some of the specific things we're looking at is there's a bill that's been filed about transition services and making sure that when students with disabilities are approaching a team, that they can receive transition services appropriately, and that they're not being guided into guardianship such as something that often happens.

Sometimes, parents are told that their student, in order to remain involved in their student's education after they turn 18, they have to put that student into a guardianship. There are other ways to do that.

We've seen a bill that's trained to lay that out and make sure parents are informed of these other options and make sure students are informed about their options of how to if they want their parents to continue to be involved in their education, how they can make that happen. We're going to be supporting anything that will help in that process and get into that school-to-guardianship pipeline.

We're always also looking at data privacy, making sure that federal laws that keep students with disabilities' information private, that things are being respected, and that students aren't being unnecessarily stigmatized by being labeled in one certain way or another in school.

One other educational issue that we always watch are issues involving restraint and seclusion. The state made really good progress over the last few years in improving our laws surrounding restraint and seclusion. No one of the status in at schools is supposed to be using any seclusion anymore, and the restraint was really reduced.

We continue to watch those issues too and make sure those new laws are being implemented properly. If there's any additional ways to strengthen them, we would support that as well.

Maddie: These are huge and really create an educational space that's just more inviting and respectful and inclusive for folks with disabilities to be able to feel like they have a say in what their future looks like and have more opportunity and control and autonomy over their future and what they learn and how they navigate that.

I know going to different events across the state, parents will say that they've never heard that you can not do transition services or they've heard that they have to do guardianship in order to stay connected to their child.

I'm excited to hear that we're putting some investment into some of that education and ensuring that people have the tools they need to be able to navigate their next steps after middle school and high school, whether that's employment, whether that's additional schooling, whether at some training, or whatever that looks like.

It's really exciting to hear that we're really pushing for more knowledge about what people's options are, so we are getting autonomy back to folks with disabilities.

Caitlyn: Right.

Keith: Let's talk a little bit about services that are related to community integration. Someone with a disability should not have to be in an institution to receive services. Around the offices here, we hear things like HCBS and iBudget. What are those things, and how are they related to all this?

Caitlyn: That's a really big question, and I will do my best to answer it. In Florida, we have the iBudget Waiver, which is a program where people with disabilities can enroll for this waiver. It's supposed to provide them home and community-based services to help prevent the need for them to be institutionalized and taken out of their communities.

These are things that allow a person to remain in their home on a whole like a personal care attendant who can come and help with activities of daily living or whatever it may be that they need to remain in their homes and not feel like they are forced into going into some residential setting.

Our iBudget Waiver in Florida, there are a lot of people on a waiting list to receive these waiver services, thousands and thousands. Probably, it was over 22,000 the last time I looked people waiting on this list to receive these services.

Any legislative effort that would increase funding for that waiver so that more people could come off the waitlist and start receiving the services, we're here to support any of that. Anything that will help people remain in their communities where they want to be, making their own choices.

Related to that, as far as community integration goes, we definitely would love to see some improvements in transportation services, especially in rural areas. Florida is a very large state. We have a lot of rural areas that aren't served well by our transportation systems.

As far as people being able to get to a job, or get to a party, or wherever it is they want to go. We absolutely support anything that's going to improve the transportation option for people.

Any sort of assistive technology that people may need, we'd want to support anything that would make it easier for people to obtain that technology, and reduce the cost of obtaining it, and the hoops that people have to jump through, just making it easier for people to get the screen reader, or the wheelchair, or whatever it may be that they need.

Keith: Speaking of cost too, I know that the cost to provide these services to keep people in the community end up being cheaper than the cost to institutionalize. It's always boggled my mind that the priority, often, by government is the reverse. If you're looking to save money and be more efficient, I've never understood why community integration has not been a bigger priority.

Glad to see how much emphasis we're putting on this and trying to make sure that these waivers are fully funded and things like transportation, etc. are in place to help people with disabilities live full lives in the community and never need to be in an institution.

Caitlyn: You're absolutely right. It's so much more expensive to institutionalize someone. It is a little bit baffling as to why, when people want to remain in their community, the state isn't wanting to do that. It would save money. It would allow more people to come off the waiver.

That's one of the reasons it's a big goal of ours, is because reducing expenditures on institutionalization should make more money available for these other sorts of things, like transportation and technology.

Maddie: I wanted to backtrack just for a second because I heard a pretty astonishing number as you were beginning the conversation of community integration, saying that there's likely 22,000 people on this iBudget waitlist waiting for services.

Could you talk a little bit about what that reality is like and really the importance of fully funding home and community-based services provided through the iBudget waiver? What is it like if you are still on that waitlist and you're not getting those services?

Caitlyn: Sure. I just looked it up. It's 22,372 people, as of January 2023, that are on the waitlist. Maddie, what you're asking, those 22-plus thousand people are on waitlist because they have already been approved for these services. It's already been determined that they qualify for them and that they need them.

What it's like to be on the waitlist is you are a person who will need services, who have been determined eligible, and you just have to sit and wait and wait until your name comes up on that list. Not very many people come onto the waiting list each year.

I believe last year, a large chunk of funding was sent to the agency that oversees the waitlist to try to get people off the waitlist, and it didn't even put a dent in the numbers. It was 22,000 back then, and it's still 22,000 now. It's something that the [inaudible 21:16] really should prioritize at some point. I would like to see it done today, but...

To Keith's point, it would be a money saver in the long run, but it can be hard to write that big fat check right in the beginning. It must be incredibly frustrating to be approved, determined eligible until you have to wait.

Maddie: Yeah, and like you're saying, you have to wait and maybe not get off the waitlist for a very long time if ever which is...These are services that folks need in order to navigate through disability and daily living and things like that. To just not have the services available to folks is incredibly frustrating and disappointing.

Caitlyn: The result of not receiving these services, if you can't find a way around it or find a family member who will handle things or if you need a personal care attendant and you just don't have anyone you can rely on, that might lead to institutionalization for a person who doesn't really need it and doesn't really want it.

Maddie: Right. This segues well into one of the next priorities which is talking about mental health and folks experiencing a mental health crisis and the forced hospitalization and involuntary examination each year that happens with thousands of Floridians. Could you talk a little bit as to what DRF's priorities are regarding mental health and those with substance use disorders?

Caitlyn: In Florida, we have a system of mental healthcare and substance use care. Part of that system is a set of laws that we call the Baker Act, that allow people to be forced into a hospital, involuntarily committed to a mental health hospital if they've been determined to be a danger to themselves or others. There are some additional criteria there, but we don't want to get too legalese.

That system is meant to address immediate, serious mental health crises. Every year in Florida, this happens to around 200,000 people. That's a lot of people. When you speak to folks who've been through this, it can be very traumatic or difficult.

This is something that happens to people of all ages, all socio-economic statuses, but we do see it more among some groups and others. One of those groups of concern is students at schools.

We do see students being taken from schools and sent to these mental health hospitals without their parent's consent, and being kept there three days, five days, until someone has determined that they either never met criteria, or they no longer meet criteria, and they can go home.

That can be incredibly damaging for especially young people who might not be able to contextualize what's happening to them. Especially for some very young people, they might feel like they've been taken to jail for a mental health issue, or possibly something that wasn't truly a mental health issue, which is even more of concern.

Our mental health law, our Baker Act, says that people with developmental disabilities, people with autism, and some other conditions can't be Baker Acted. They cannot be sent to a hospital for this involuntary examination if their behavior is caused by their disability and not by a mental illness.

Whenever that happens, and it does happen, it's illegal. It's a completely unnecessary trauma. We work very hard to try to support any measures that would reduce the amount of times that people are being put into the system and also to reduce the trauma experienced when people are put into the system, kids and adults. [inaudible 25:09] for everyone. It can be very difficult.

Part of that prevention in part of trying to bring down those numbers, those 200,000 Floridians who are involuntarily examined every year is beefing up our community-based services. Making sure that we have mental health services and substance use services readily available in the community that are comprehensive, they're adequate, they're fully funded.

That they're available in all parts of the state, including our very rural areas, so that people can access services if they feel like they're having a mental health issue or a substance use issue. They can access the services before they reach the crisis point.

Maddie: Definitely. I just keep hearing this overarching theme in your priorities and the intent behind a lot of your work in session is just to reinstate and give agency back to folks with disabilities.

Whether that's ensuring that they have something like supported decision-making as an option, or just being able to access community-based services and not services in an institution, or being institutionalized in order to finally get seen for care of some kind, if you want to call it care of some kind.

I think I'm continuing to hear a theme of just prioritizing. Putting money, energy, and resources back into the community to ensure that folks have these resources and access to these things just all by themselves without having to be exacerbated by these other issues.

Caitlyn: Puts exactly right. I'm glad that came across because that is our number one priority, regardless of whether we're talking about health care or mental health, or criminal justice. That people with disabilities -- people, in general -- people with disabilities should be able to make their own choices and live their own lives and have their preferences honored.

Anything that helps further that mission is something that we're most likely going to get behind in. We just want to help people in Florida be able to enjoy the same kind of freedom and autonomy that anyone who without a disability expects to be able to enjoy.

Keith: Yes, indeed. One more subject area we'd like to talk about, and that's involving criminal and juvenile justice. Obviously, people with disabilities have always been disproportionately represented in that arena. I know that's also a legislative priority. Tell us a little bit about what you're seeking from session on that subject.

Caitlyn: Statistically, we know from studies across the nation that people with disabilities are far more likely to come into contact with the criminal justice system than people without disabilities. Once they've made that first contact, they're more likely to actually be charged with a crime. Then when charged with the crime, they are more likely to be convicted of that crime.

Then once they're convicted, they're more likely to get a longer sentence than a person without a disability. It's a compounding harm there. We do want to do anything to mitigate against that disproportionate representation.

There are lots of ways I think that can be attacked, but some of the ones that we've seen previously in Florida, seen efforts on and that we hope to see again, our first diversion programs.

If someone is maybe charged with a crime due to something that was actually caused by mental illness, we hope that we can have one day across Florida a good, comprehensive, evidence-based, law-funded diversion program to divert these folks and keep them from having a criminal record, which can be incredibly damaging for an entire future in job prospects, etc.

We also want to try to divert kids from the adult criminal system. In Florida, children can be charged as adults for many crimes at very young ages and they can be put in the adult prison system. That adult prison system is just not designed to meet the needs of kids, especially kids with disabilities, kids with IEPs who are still entitled to an education.

We want to try to prevent kids from going into that system in the first place. I'm not saying the juvenile system is perfect, but it is at least designed more with their needs in mind.

Another thing we look at is law enforcement. They're part of this system too. We want to make sure that law enforcement officers are receiving good robust training to help them understand working with people with disabilities in a nuanced way. Not overly simplistic and stereotyped. Some good robust training would be great.

Then especially in school settings, we have a armed school resource officer or security card in every school in Florida. We want to make sure those officers are also well-trained on working with kids and working with students with disabilities. Making sure that their interactions are positive and not leading to over-criminalization of behavior that may be related to their disability.

We also want to see an end to the use of solitary confinement, which is incredibly detrimental to people's mental health. People who already have mental illness, that mental illness will be exacerbated greatly by a solitary confinement. People without mental illness can gain a mental illness because of being placed in solitary confinement. It's well documented that that is very harmful to people.

Then, on that note, we also would love to see a law that would eliminate the death penalty for people with mental illness. Right now, some people may believe that this is already the law but it's not. That people who were mentally ill at the time of their crime aren't going to be executed for that crime, but they are. They can be, in Florida.

We would love to see an end to that too just because of the level of culpability in, what goals are we achieving with a death penalty for people who are mentally ill? That's what caused their crime. It seems like the goals are less clear there. That's something we would also like to see happen here.

Keith: It shocks me still to think that in 2023, things like solitary confinement and the death penalty are still options for, I'd say anyone, but especially people with disabilities. It's shocking just hearing it as a priority of something to change still at this time. It's so much going on in all of these arenas.

Caitlin, I want to thank you so much for being our guest today and talking through all of these things. There's so much that you and other members of our public policy team are working on for this session.

We appreciate all that you guys do to try to help steer the Florida legislature the right way and keep these issues on the top of minds as much as possible. Thanks for all that. Also, thanks for being our guest today and explaining all this to us. We really appreciate it.

Caitlyn: Thanks for having me. Thanks for being interested in what we're doing over in our policy arm. If I may, I would encourage folks who are interested and have opinions to reach out and let Disability Rights Florida know what they think our priority should be. We develop our priorities.

It's not supposed to be Caitlin's priorities. It's Disability Rights Florida. We're tasked with representing people with disabilities across the state. If we're missing something, let us know and let us know all about it.

Keith: That's huge, definitely. Thanks for that note, and we really appreciate your time.

Caitlyn: Thank you.

Keith: Thank you, Caitlin, for being on today's episode and for sharing so much vital information as we approach this year's legislative session.

Maddie: Definitely. We hope you enjoyed the episode and were able to learn something. We'll be back later this month to talk with Kenyan disability journalist, Alan Herbert, about international disability advocacy and disability in the media.

Keith: Be sure to subscribe to the "You First" podcast to be alerted when new episodes drop. We're on Apple Podcasts, Spotify, YouTube, and almost anywhere you get podcasts.

Maddie: For more information and transcripts for each episode, visit disabilityrightsflorida.org/podcast.

[background music]

Announcer: The You First 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. If you or a family member has a disability and feel that your rights have been violated in any way, please contact Disability Rights Florida.

You can learn more about the services we provide, explore a vast array of resources on a variety of disability-related topics, and complete an online intake on our website at

disabilityrightsflorida.org. You can also call us at 1-800-342-0823. Thank you for listening to You First, a Disability Rights Florida podcast.

[music]

Transcription by CastingWords