You First Podcast Episode 27: 2021 Florida Legislative Wrap-Up

[background music]

Announcer: Welcome to "You First -- The Disability Rights Florida Podcast."

Keith Casebonne: Welcome to a new episode of You First. I'm your host, Keith Casebonne, and thank you for listening. I'd like to quickly remind you to subscribe to the You First podcast. You can find us on Apple Podcasts, Spotify, and most of the other places you regularly get your podcasts from. You could always listen at disabilityrightsflorida.org/podcast.

It's time for our annual Florida legislative wrap-up episode. That's not quite accurate. We did our first one in 2019 but missed last year due to the timing of session and the start of the COVID-19 pandemic. We're trying again for 2021 and hope to get back on track and make this an annual episode topic.

To fill us in on new 2021 legislation related to issues important for people with disabilities are Tony DePalma and Olivia Babis.

Tony is Disability Rights Florida's director of public policy, and Olivia is our senior public policy analyst. One note before we start. At the time of this recording, Florida Governor Ron DeSantis has not signed or vetoed some of the items we'll be discussing.

Please check our blog at disabilityrightsflorida.org/blog near the end of June or early July for a full and final breakdown of the legislation discussed here today. Hey, Tony and Olivia, thanks so much for being on my guest today.

Last time we did this was a couple of years ago, unfortunately, 2019. We had planned to do a Florida legislative wrap-up in 2020, but didn't unfortunately due to being a complex time with the COVID pandemic starting up and whatnot. Of course, the 2020 sessions still occurred. What's a major takeaway or two from that session to start things off?

Tony DePalma: Thanks, Keith. Thanks so much for inviting us back to talk. I was bummed out we didn't get a chance to talk at the end of the 2020 session, which so everyone can recall ended on Friday the 13th of 2020 with folks in hazmat suits scrubbing down the House of Representatives because there was a COVID outbreak. Way back then we didn't know what COVID was.

I'm still not sure that we fully understand what COVID is, but it definitely robbed us of a chance to get together and talk about the things that happened in 2020. At the risk of having a 12-part podcast series here, I wanted to mention a couple of the big takeaways from 2020 and then throw it over to Olivia to talk about how session '20 was different from session '21.

Folks might remember, during the 2020 Legislative Session, one of the big issues being considered was the iBudget redesign which was finally passed as Senate Bill 82.

This has been a process that had started way back in 2019 in a lot of regards to review how iBudget is structured, how service provisions are made, how efficiencies could be generated, how cost plans could be better embraced within the overall framework of things. This Senate Bill 82 was passed.

I would say from our perspective, the two biggest things that happened. One was in terms of changes to waiver support coordinator provisions, and how waiver support coordinators are contemplated to fit into the overall framework of the iBudget, which again, is Florida's Developmental Disabilities Medicaid Waiver program.

The other big thing that happened in Senate Bill 82 was the authorization 72, new beds for folks at intermediate care facilities. For folks who've been paying attention for a long time, there had been a cessation of new construction on ICS in the state and a certificate of need process had been put in place for new construction.

For the legislature to authorize 72 new ICF beds as like a cost-saving measure presumably are a way to direct folks with high-cost plans.

The attendant needs related to those high-cost plans into institutional settings rather than to provide those services in the home or community as Medicaid allows for and specifies was certainly something that caused us a lot of consternation and something we're still reviewing to understand whether this was a one-time service solution or a new trajectory to things again.

Our organization, Disability Rights Florida, exists to try to counsel against re-institutionalization efforts. There's been a whole three or four decades worth of progress made away from institutional living as an undeniable part of how disabilities were serviced eons ago.

We hope that Florida continues to try to invest in appropriate home and community-based services for folks on this waiver and otherwise in the state. As we're recording this podcast, there's a chance that the state is going to pass up receiving something between $300 and $450 million of one-time HCBS or Home and Community-Based Services from the federal government.

When you think about it in those terms, in terms of what passes one year and what happens another year, there's a tie together there. Definitely, one thing we were looking at a whole bunch in the 2020 session.

Right before throw it to Olivia, I wanted to mention there was guardianship reform Senate Bill 994 has to do with qualifications and disqualifications of guardians either at an appointment or during a guardianship. Also, this bill was passed in response to make sure that guardians have to appropriately authorize "do not resuscitate" orders in coordination with their "words."

That's in response to a lot of bad things that were happening in the state -- hopefully aren't happening any longer. Some of the other bills that passed in 2020 that I think have bearing even today post-COVID or COVID still happening include Senate Bill 400, which authorized elder abuse fatality review teams in judicial circuits statewide.

Also, House Bill 767 made changes to licensure inspection, resident rights, and staffing in assisted living facilities in the state.

The one other one I wrote down, and I appreciate the chance to go back and think about what the heck happened a year ago, was House Bill 945 which was a bill relating to children's mental health. This was requiring the state to develop a coordinated system of crisis stabilization care with mobile response teams and managing entities through a service and needs assessment.

Session 2020 was its own beast, so to speak, but none of it could have helped us understand what we were in store for Session 2021. Luckily, Olivia got to breathe, and live, and eat every bit of Session '21 as much as she was able. Olivia, would you let us know how the 2021 session kicked off and went?

Olivia Babis: Sure. In 2020, I was at the Capital when they had people on the hazmat team scrubbing everything down, so that was a little bit concerning to be there that day. I think I was one of the first staff people sent home after that when we closed our own offices. [laughs]

It was definitely a stark contrast from 2021, wherein 2020 I was able to be there. I was able to meet with our representatives, state senators, provide legislative education, attend meetings, attend committee meetings, whereas, in 2021, you couldn't do that. It really did make things a lot more challenging. We did have virtual meetings with some of our state senators and state representatives using Zoom.

We were, of course, overwhelmed with emails with people wanting to meet, and people wanting to send emails who weren't able to attend committee meetings, that otherwise would have provided public testimony there. Sometimes, they would be unresponsive just because of the influx of emails that they were getting. As I mentioned, we were unable to attend committee meetings.

There were two different processes on the senate and the house side, so it wasn't consistent. For the senate, you had to go to the civic center that was half a mile from the Capitol to provide public testimony. It was still in-person testimony, but it wasn't actually in the committee room.

Then, for the house, they were still allowing in-public testimony with appropriate measures with testing, social distancing, masks, but we did see, unfortunately, where some people were not wearing masks. We did see some of our state legislatures that were diagnosed with COVID throughout the session due to exposures.

Of course, that was a staff concern. We didn't want to jeopardize our staff going there and contracting COVID.

Keith: Sure. You had to go somewhere to virtually testify?

Olivia: Yeah.

Keith: You couldn't just virtually testify from your home via Zoom?

Olivia: No, we were permitted to submit written comments, however, those weren't read in committee meetings. It was not an equitable solution where you had people that can go to the meetings, provide public testimony, they're being heard, they're being heard by other members of the public, they're being heard by media.

But when you submit that written testimony, other than the people that you hope are reading it that are the committee members, it really doesn't get read by others, so you don't have as much influence and as much impact. That really made the 2021 session really challenging.

Keith: I can imagine. Regardless, bills were introduced and some even passed. Let's start breaking it down, some of the outcomes from the session. Let's start with some bills related to education.

Tony: Thanks, Keith. That's actually a very good place to start. There is a whole bunch happening in student education world related to students with disabilities. There's things that are happening front and center in headlines around the state. There is also legislation that passed that didn't get the same attention.

One thing that did get a whole bunch of attention was House Bill 7045 related to voucher programs. This is a continuation of the state's investment in school choice options and the notion of providing private placements and private education with public dollars through voucher programs, through charter school programs, and the like.

This legislation actually repeals the Gardiner Scholarship Program beginning this upcoming school year and repeals the McKay Scholarship Program the following year. It merges both of those programs into the Family Empowerment Scholarship program, the FES program.

Within FES, this legislation establishes the FES disability scholarship as an education loan savings account, allowing parents to choose from both public and private options.

One way to understand that development is in terms of how it generally impacts all students in the state. I know there's a lot of folks who believe that taking money out of public education to put into a private education placement system is an inappropriate use of public school funding dollars.

A lot of discussion this year related around...They're trying to increase accountability in the process, like if we're going to take public dollars to fund private placements, then there needs to be the same oversight and accountability that's created in the public school system.

At the heart of all of this is just one of those fundamental issues between free markets and government service provision. In a lot of regards, free markets certainly work. There are certainly the students with disabilities, their families who have benefited from school choice to receive a different/better education in a private setting.

But the concerns that have always been true -- and some of this is played out in reporting from National Council on Disability in recent years, from the National Disability Rights Network in recent years -- is that there's not sufficient counseling for families at these moments of decision and consequence when they might take their students out of public education.

Move them into private placement regarding the loss of federal educational entitlements under the federal IDEA or Individuals with Disabilities Education Act, also other non-discrimination protections that apply in public schools that don't apply in private placement.

School choice, no matter which way you slice it, is certainly an issue of extreme relevance for students with disabilities and their opportunities. As the state continues to invest heavily in these types of voucher programs, it'll be something we continue to watch.

We continue to encourage families with both positive and negative experiences as this happens to get in touch with us and let us know how this is breaking out on an individual level for sure.

Keith: Without getting down a rabbit hole too much on this, is the reason they do this that it's cheaper to invest with the vouchers to the private schools than it is to actually improve the facilities and services within the public schools? I know that's a big point of contention and a subject of its own.

Tony: I would say that's one fair reading of all of this. Another reading of what's happening here, there's some folks who believe that students with disabilities who might otherwise negatively impact the school's overall performance on standardized testing or who's the public school system themselves are just of the opinion like, "We can't or we aren't doing a sufficient job of providing for the students."

You would hate to see a private school voucher scheme to be the funnel for those types of predicaments, but there's folks in the state who definitely think that might be the case.

Aside from school vouchers, there were definitely other things happening in education world under consideration by the legislature. Not least of all was House Bill 149, relating to restraint and seclusion. This was the legislature's first successful attempt to add standards, and definitions, and prohibitions into Chapter 1003 to govern the use of restraint and seclusion on students.

Back in 2010, the National Disability Rights Network published reporting that opened a whole bunch of eyes on the federal level regarding the prevalence and danger of using restraints and seclusions on students with disabilities in school. The trauma creates both a long-lasting psychological level as well as the physical injuries associated with the practice.

This legislation, for once and for all, outlaws the practice of seclusion on students with disabilities in public schools and provides a whole bunch of parameters for how restraints are to be utilized. The one concerning part of this legislation for DRF is that it relates to mechanical restraints.

In the 10 years since the standards that were put on place by Florida appeared in Chapter 1003, there have been a successful reduction in the use of mechanical restraints on students. At last report, there were less than 10 districts in the state that were using mechanical restraints.

This legislation doesn't really change how that looks. It actually adds some safety precautions to the use of mechanical restraints. Our problem however is that, in so doing, the language now contemplates the use of handcuffs, straitjackets, tie-downs, and zip ties.

Again, these are referenced in the bill as things that can't be used if they restrict breathing or blood flow. The natural negative inference of that means that they might be able to be used if they don't restrict breathing or blood flow.

That's a good example of stuff that we'll keep our eyes on as the state begins to implement these new provisions and to see if there's further legislative action needed in upcoming sessions.

Keith: Do you think it's going to cause any increase in the use of that? You said it's gone down for 10 years. Is that part of the fear that it may actually go up again?

Tony: Yeah, it's a little of the fear that districts might interpret this new law as permitting for the use of straitjackets, or handcuffs, or zip ties, or tie-downs in this manner. If you consider for a moment that roughly half of all restraints reported in this state are initiated upon very small students, third-grader below, that's a real, alarming thing to think about...

Keith: Scary, yeah.

Tony: ...of the notion that a kindergarten class might keep a straitjacket in the room as, again, rather than doubling down on what we would argue is the way forward which are de-escalation, positive behavioral interventions, and supports, person-centered planning.

There's definitely a lot to like in House Bill 149, and it's really encouraging that the legislature finished the job and got it across the finish line. Finally, I would say that there's definitely more to be done and something that will continue advocating around in upcoming sessions.

Real quick, just to jump into one other student issue that we were keeping tabs on this year, another bit of legislation that did pass is Senate Bill 590. Much like I was just talking previously, House Bill 945 passed in 2020, this year's bill Senate Bill 590, there's a lot to like in it as well.

We support just about every bit of the bill. We believe it's oriented correctly. If anything, I think it might just not go far enough. The legislation requires schools to make a reasonable attempt to notify parents of a minor student prior to him voluntarily committing or examining that student under what's known in the state as the Baker Act.

It mandates collection of data by districts in the state on the number and frequency of students who are Baker Acted out of schools. It requires all school safety officers to undergo crisis intervention training, definitely a good thing.

It requires school districts to adopt procedures mandating attempts at de-escalation to be made prior to initiating a Baker Act out-of-a-school setting on a student and also something that didn't get much attention at all that I thought -- I was very pleased it appeared in the final draft -- is this legislation allows school districts to create policies to provide accommodations for drills conducted by exceptional education centers.

I myself am now in my 40s, so school is a distant memory to me. But I believe especially at the moment, there's a lot of drills, a lot of other procedures that schools engage in to try to reinforce safety precautions and help students understand what to do in the event of just the whole range of awful things that can and have happened in schools.

In that process, one thing that needs to be considered is how students with disabilities are included in that planning and that the planning itself is accessible to students, including providing accommodations that are necessary to have these processes be meaningful for those students.

That was another thing we saw this session in education world.

Keith: You mentioned the Baker Act in there. I know that might be a good segue to a bill that didn't pass, related to the Baker Act, but not specifically for schools, just more general mental health-related. Tell us a bit about that.

Tony: Absolutely. This is a good example. Mental health legislation isn't siloed. There's aspects of mental health considerations in housing legislation, in criminal justice reform, in correctional reform, in health care, in a whole bunch of regards.

Mental health is a very important aspect of student discussions at the moment. Again, this session, there was legislation filed that was pretty extensive legislation, and we're referring to Senate Bill 828 and House Bill 405 here. This was legislation to expand the scope and application of the Baker Act as well as the Marchman Act.

The Baker Act is housed in Chapter 394 in Florida law and the Marchman Act is housed in Chapter 397 in Florida law. Both of these procedures have been codified and grown in the state for decades now. There's lots of different opinions and feelings about how they function at the moment.

In a school setting for sure, which is something that at the moment there's 37,000 minors a year who are Baker-Acted, but also in general terms. Again, there was a lot to like in these bills as well.

One thing that caused us a whole bunch of opportunity for review and concern and coalition work was in the notion of unnecessarily expanding or broadening these provisions to include, for instance, a property damage component. The notion that if someone is engaging in property damage, that the correct avenue to remediate the situation is to have that individual Baker-Acted or Marchman-Acted.

There's also other aspects of definitional changes in this legislation that we believe might have allowed for the Baker Act or Marchman Act to be used on, for instance, populations of individuals experiencing homelessness in the state.

Other folks who were deemed not to be taking appropriate care of themselves one way or the other, which I would argue isn't a good, respectful gesture towards folks who live non-traditional lives or might be experiencing homelessness.

Again, there's folks in the state who think that the Baker Act and the Marchman Act are fantastic criminal diversion provisions that we would rather send someone to be reviewed or examined rather than sending them to jail. That is a little bit to account for why these provisions are being looked at in terms of how we might use them more often.

For a disability rights organization like ours, that's a scary proposition and something that we immediately got in touch with other stakeholders in the state and nationally to size up and to the extent that this is legislation we see reintroduced at some point in the future will be ready to provide a good facts, good information, good policy education around the implications as we see them.

To that point, Keith, I would say that just as there's a whole bunch of folks thinking about the ways that provisions like the Baker and Marchman Act to help keep folks out of criminal justice systems or out from the possibility of being arrested in those predicaments, there is a whole bunch of legislation that related to courts and different court procedures in the state.

A whole bunch that I know Olivia is real excited to talk about, but I wanted to highlight one real quick if I could before we throw it to Olivia. This was legislation that picked up steam after reporting came out in the "Miami Herald" this spring regarding the state's management of its Florida Birth-Related Neurological Compensation Plan.

This is a plan that's administered by an agency in the state or an entity in the state known as the Florida Birth-Related Neurological Injury Compensation Association frequently acronym and abbreviated as NICA, N-I-C-A.

NICA has been around for decades in the state. All hospitals in the state pay into this fund. This fund was created to provide a continuum of care, a lifetime of care for folks who are born with birth related-neurological injuries.

The reporting that came out in the Miami Herald laid bare some grisly facts about how this program's been operated and administered, and what the experiences of families who are participating in this program, as well as the participants themselves, what their lives were like.

The reporting indicated that there are billions of dollars in the state set aside to pay and reimburse services and help make sure that all of the costs of life are provided for individuals who have birth-related neurological injuries that they're upon participate in this program.

As a contingency of participating in this program, families basically sign away their right to sue the state or to sue the state for future damages, or anything like that.

I would say that's complicated by the fact that we live in a state that has a sovereign immunity cap, and that requires families who are trying to seek damages to otherwise do so through a claim's build process, which in lean fiscal years like I feel we are in at the moment. It means that not a lot of claims are paid.

NICA is a program that's intention is to make sure that folks who participate, folks who surrender away their liability rights against the state are provided for and cared for. This is legislation this year, and it was amazing.

Reporting comes out in the middle of session. The next thing you know, the CFO in the state has signaled endorsement of doing improvements here, and then a bill comes out. It's a fantastic outcome.

Keith: What a system.

Tony: What a system it could be. This legislation increases the maximum reward to parents and legal guardians. It increases death benefits. It increases annual psychotherapeutic services for immediate family members who reside with the plan participant. It specifies increased benefits for transportation.

It authorizes housing assistance, including home construction and modification. It provides for the filing of petitions to dispute reimbursement matters, which is something that the reporting laid bare as not working very frequently when families have issues or conflicts.

It directs NICA to administer the plan in a manner that promotes and protects "the health and best interests of children with birth-related neurological injuries," and it creates a code of ethics for staff and specified board members of NICA.

Finally, it requires the state auditor general to conduct an operational audit of NICA once every three years while also specifying additional reporting requirements. We're looking for successes of the 2021 session. I would say this was a good bit of legislation and one that we hope for that the legislature will take back up to continue refining in future years.

I'd love to throw it over to Olivia and hear more about some of the other bits of legislation from this year.

Keith: Please take it away.

Olivia: Sure. I think a good segue from Tony, who was just talking about with NICA, is the civil liability for damages related to COVID-19. While we're talking about restricting people's ability to file lawsuits in relation to COVID-19, of course, when COVID hit, it was congregate care facilities that really suffered the brunt of this in the beginning.

We saw outbreaks in nursing homes and assisted living facilities, in group homes, and in care facilities. For a while there, these individuals made up the majority of cases. They were 50 percent of the deaths at one point. Now, they're down to 30 percent but still disproportionately affected by COVID.

The civil liability bill created protections for individuals, businesses, healthcare facilities so that they inevitably couldn't be sued for issues related and pertaining to COVID. If they were short-staffed because they had 15 staff members that were suddenly out because they had been diagnosed, and we're out due to COVID.

Unfortunately, a lot of the issues that led to such high rates were already in place. That's why our opposition to this bill is that we're afraid that facilities are going to use this as a cover for the fact that they were already short-staffed before COVID.

But they weren't previously complying with infection protection procedures and policies [inaudible 26:42] this led to COVID being spread versus not necessarily just being surprised by, "Oh my gosh, we're dealing with a pandemic." Of course, that contributed to it.

Don't get me wrong, absolutely. When half your staff is suddenly out, you've got a problem, you have to figure out how to continue that, but we just don't want that to be seen when there were circumstances of gross negligence when we did see people who died indirectly because of COVID.

They died because of dehydration. They died from malnutrition. They died from bedsores due to just environmental factors related to hygiene because staff weren't able to keep up with everyone and to provide the care that they needed.

Visitation bans, of course, were in place. They didn't have the supports that they normally would from other family members, guardians, and other caregivers that come in and supplement staff that may come in and help that individual with bathing a couple of times a week or to make sure that they're eating appropriately.

That also, of course, reduced the incidence of reporting of abuse and neglect in these situations. Most of the time, it's your visitors, it's your caregivers, it's your family members that are going to notice instances like this. They weren't available. They weren't able to go in and provide that care and look for things that weren't going right with their family members.

We were concerned about the implications that was going to have. Of course, on the flip side of this, facilities were concerned about, if you have 70 people in some facilities that died, those 70 families were suddenly going to file lawsuits and that was going to drive them out of business. These are needed facilities right now.

There's a national conversation now around this for Home and Community-Based Support to think about how...We think about long-term care. Should we be putting people still in institutional and congregate settings? We know that this is where infections can spread and some of the difficulties with that. Of course, there is also difficulties with providing home and community-based care.

We have wait-list for med waiver. There is a shortage of properly trained providers that can provide this care in the homes. It's a lot of complicated issues to deal with. A lot of these, like I said, existed pre-COVID, but COVID exacerbated these issues. The state was trying to walk a line of protecting facilities while not taking away rights from individuals.

Whether they got those right or not, it remains to be seen. We'll see if facilities are going to be trying to use this to provide cover for instances that already existed in these facilities. That was one of the bills obviously that we were watching early on in session. It moved through very quickly.

It was a priority for leadership in both the House and the Senate and the Governor that they considered a special session before session to consider a civil liability damage for COVID. I had the blessings of everyone that we knew that this was going to go through.

It was definitely something that we were watching and had some conversations to make sure that our views and I made sure that these considerations were taken to account as this moved through the process of committees. We are also watching one that is a repeat and that we've talked about before. Although, it changed its face a little bit.

We started off with orange alert, and now it changed color. It is now purple because some of the leadership in the Senate was afraid that people were going to get this confused with Homeland Security color coding for a state of emergency again, and we're showing orange to make sure that that wasn't getting confused with that.

Purple alert is a much-improved bill from where we started with it three years ago. When this started, you're walking this fine line with people with disabilities a lot of time between allowing for personal autonomy and rights protections and then doing, of course, protection making ensure people are safe.

The intent of the bill is targeted for those that are prone to elopement. Someone that may wander from a group home or their family home and to issue an alert if the circumstances of when they went missing can be identified. We can't have helicopter mom that their child missed their weekly call-in, and so they're in panic mode and calling the police. This has to be a justified concern.

They were in my living room. I went to do something. The front door was open. They walked out. They're in danger of stepping out into traffic or something awful happening to them. They're in immediate danger.

That was the balance that we were trying to strike with that bill to make sure that we were providing that needed protection, but not stepping on people's personal autonomy that we couldn't have group homes using police as security because somebody missed a curfew. We worked extensively with the bill's sponsor for the last two legislative sessions, and it did finally pass.

We'll see if the governor signs it, but there hasn't really been a whole lot of controversy around this. I'm assuming that we'll see this go into effect. We're also looking at elections became a big talking point [laughs] of the session.

Keith: Of course, they did.

Olivia: We've seen this across the country where Georgia and Texas and Florida too have implemented policies to restrict voting right. Florida carried off even in the midst of COVID, a great election this time, and normally you're the ones. Everyone's watching like, "How's Florida going to screw this up?"

We did not. It went off without a hitch. The argument is that will they want to continue to see our elections go flawlessly. These are preventative measures to prevent election fraud. However, no instances of election fraud were discovered even after an investigation to find incidents of that and not a single case was discovered.

This does dramatically restrict the voting rights of vulnerable populations, particularly disability communities. Some of the restrictions that are placed are particularly around vote by mail is where a lot of this is centered. A lot of people with disabilities do rely on vote by mail due to lack of transportation or an accessible polling locations.

They think of this as an easier method of voting. Particularly in COVID, they didn't want to go to the polling location especially if this is somebody that needs assistance, and that may be marginalized and have more than one disability. That exposure could be very problematic for them.

To place those restrictions at people, we'll have to request a vote by mail ballot annually now for that election every year, which is a problem for people with disabilities. Vote by mail ballots or request forms aren't necessarily easy for people to fill out.

If you have someone that is blind or visually impaired and if they receive this in the mail, they're not going to be able to fill it out independently. Where our Secretary of State, the Division of Elections website is accessible, a lot of the Supervisor of Elections websites aren't. That is where people have to go to complete the vote by mail ballot if they even have it on their website at all.

This may not be in an accessible format online, or they may have to request the paper form that is mailed to them, then they can't fill it out due to print disabilities. This creates that problem for them. For those that are older, they're used to the way things have always been, and so to have to do this every year, they're not thinking about that.

There's, of course, additional costs to the SOE's office to have to send out reminders to everyone, every year. In addition, it place restrictions on who can return vote by mail ballots for people. Someone can only return two other ballots for people and there is restrictions on the relationship that you can have with that person.

You may not be able to get your neighbor to drop off your ballot for you if they're doing three other family members. That can be problematic for people with disabilities that don't have transportation, that may not be able to return the ballot by mail. That's hampering their ability to vote. Other issues with the bill are drop boxes and the limitations on those are restrictions on the hours.

A lot of times this is more convenient for people with disabilities to use versus having to go into the polling location or to the SOE's office. It is constricting people that were already restricted with their voting rights anyway due to lack of accessibility, like a poll worker training. This is adding an additional burden.

Keith: Making things worse.

Olivia: Absolutely. We obviously were watching that. There's challenges to these bills across the country, and Florida is no exception to that as well. It's definitely something that we're watching and waiting and seeing how this is all going to play out in the courts at this point.

There is a controversial bill that we were watching this session regarding disability abortions. Abortion is a complex issue for the disability community. Of course, people with disabilities were victims of genocide of the eugenics movement.

They were the first people to be killed through the German T4 Program up to concentration camps and hundreds of thousands of people with disabilities were murdered.

Obviously, there's a lot of concern that we're doing selective abortions based on disability, and we're not taking into account the actual quality of life for people with disabilities. Just because you have a fetal diagnosis of Down syndrome, not everyone's Down syndrome looks the same.

We've had people with Down syndrome that go to college. They're professors at universities. They've run for local offices. They've done amazing things. Then you do have some that do need more care and more lifetime care. You never know where on that spectrum someone is going to fall.

The perspective we're taking from this is that there needs to be education as to what life with Down syndrome can look like so parents can make an informed decision. The issue that we had with the bill was the language that was used in it.

It almost felt stigmatizing in itself. The way that disability was described, it was very much the medical model of disability where we're looking at this as something that needs to be cured or needs to be treated or needs to be eliminated and not the social model of what services and supports can we offer to people with disabilities to make their life successful.

That was the point that we were making that here we are in Florida. We have one of the longest, largest waitlist for med waiver in the country. We're only second to Texas. We have 22,000 people on the iBudget waitlist. We have even more on the long-term care waitlist. People wait decades, and that's not hyperbole.

People literally wait decades to receive services. Parents are applying for services for their children when they're in school, hoping that they will receive them when they're in transition age. That doesn't happen. Sometimes they're still waiting when you're 30 or 40.

Our argument was that if we're making this claim, that we value the lives of people with disabilities, and that's a statement that we all agree on, absolutely, we should value the lives of people with disabilities.

If the state is going to come out and say that, then they need to make sure that people have the services and supports that they need to value the lives with disabilities, to make sure that they're not ending up in congregate care facilities when it's not their choice, when it's not their decision.

That they do have choice and options on where they want to live, employment options, that they have adequate healthcare coverage, that they're receiving equitable education. If this is an issue we want to going to address, then those are the means by which we should be talking about. Disability, and quality of life, and the way under which we value the lives of people with disabilities.

Keith: There's one other bill I want to talk about. In March, we did a podcast talking about this. It's related to supported decision-making. There was a lot of push to get this bill passed, but unfortunately, things didn't turn out like we had hoped. Tell us a little about the path that took.

Olivia: Absolutely. DRF worked within a coalition of other organizations, and stakeholders, and self-advocates, parents, and other organizations, have been pushing for supported decision makings for decades now. We worked together. We drafted a bill. We got those sponsors.

Representative Allison Tant was our bill sponsor on the House side. Senator Joe Gruters was our sponsor on the Senate side.

The fact that we got as far as we did, we are happy with that. We had bill sponsors. We had a couple of the committee who had hold meetings with us to discuss the bill. We met with those that unfortunately do oppose components of it to see where we can compromise and discuss those issues that they have within and how we can come to terms and come to agreement on it.

Even though it didn't move this year, we are hopeful that it will next year. We're hoping that we'll get through some committees and hopefully get it passed. Rome wasn't built in a day. Legislation, it can go slowly. As Tony mentioned, restraint and seclusion took 10 years to get through.

I'm hoping that [laughs] we don't take 10 years to get through, but the trend has been towards supported decision-making. There have been several other states that have passed it. There's been recommendations that have come down nationally recommending supported decision-making as a lesser restrictive alternative to guardianship. We're seeing this on a global scale.

This is where the movement is going. This is the momentum that we're seeing behind it. Hopefully, we're able to use that as to our advantage and be able to get this passed for next year.

Keith: Speaking of next year, perfect segue to wrap things up. Let's talk a little bit about what do you see on the horizon in addition to supported decision-making for the 2022 Legislative Session?

Olivia: I think the Disability Abortion Bill will definitely be back. That's something that we will be contending with again. My purple alert passed, so as far as it posted, I'm talking about, I don't know, other than SDM and disability abortions. What else will be on my plate for next year? Probably, we're going to see some election's bills again.

There's going to be some attempts to repeal what was passed this session. We may see further restrictions coming down. It's going to be this battle of the wills with election reform particularly as we're heading into the 2022 election.

Tony: From my perspective, Keith, some of the legislation we were talking about. We discussed presumptive next steps, and how we'll continue to review these things, and how here's restraint and seclusion is a good example of that. Some of the student Baker Act legislation also a good example of this.

When you look at and participate in disability policy discussions, you realize that they go on forever. There is wholesale of sea-change moment. There's also refinement efforts all the time.

Against all of that, there needs to be an understanding by the legislature and by others who do policy work that the health and safety, the integration opportunities, the rights of people with disabilities are what has to lead and govern these conversations. I would make the plug once again.

The only way to ensure that is to invite folks with disabilities to the policy table themselves ahead of time before we're in week eight of session, and people are like, "Is this a good thing or a bad thing? We don't know." There's a lot that can be said about inviting folks with disabilities into these policy discussions at a state level, also at a county, and city, and municipal level.

I would make the pitch again for every city and locality and county in the state to have a citizens with disabilities advisory board to help evaluate decisions and policies that affect the interests and opportunities of folks with disabilities. That, from my mind, isn't a hard ask, isn't rocket science.

It's a basic human consideration to make that if we're passing legislation, having policy discussions, about people with disabilities that we need to find ways to bring people with disabilities into those discussions as much and as often and as fully as we're ever able to.

That's something that DRF will remain plugged in on from now and into the future. It's not all about the things that we think or anyone on our staff thinks. It's about trying to create a seat at the table for folks with experience, for folks who are their own self-advocates to help the state and everyplace get this stuff right more often.

Olivia: We also need to keep in mind that every issue is a disability rights issue. People pigeonhole disability into social security or healthcare and don't think about it beyond that. When we did this two years ago, we were talking about an environmental bill because of straw bans.

People looking at this going, "What does an environmental bill have to do with disability?" We talked about the Disability Abortion Bill. What does abortion have to do with a disability? A lot between conversations about personal autonomy and valuing the lives of people with disabilities. These are complex issues that absolutely the disability community should be involved with.

I wouldn't be surprised if we see some bills on the accessibility of the legislative process. That was one of the things that we took issue with this session when a lot of individuals did was the lack of access to the legislative process. People with disabilities weren't having their voices heard.

I know I personally have been using video conferencing programs for 10 years of my work to meet with people that are across the state or in different regions, and this is an accommodation that people with disabilities have been requesting for years, that were often denied.

We saw in COVID that yes, this can be done where you can have your entire office of 100 or 1000 people working from home successfully using these platforms. People with disabilities don't necessarily want the world to return to normal. They want to see that some of those accommodations stay in place so they can participate in these processes.

Now that we've done that, there's going to be a stronger fight to keep that from being rolled back and to allow these types of accommodations to provide access to legislative process, but also to employment and other avenues of life to integrate people with disabilities into their communities more.

Keith: That's a great closing observation. Thanks again to both of you for having this discussion. I'm looking forward to doing it again next year. Hopefully, there'll be no pandemics in the way or anything like that.

Tony: That's definitely our hope too, Keith. Just so everyone who made it this far in the podcast knows, Disability Rights Florida, our public policy team is always open for communication.

It's not hard to find our email addresses and get in touch and let us know what matters to you either when legislation is filed and you might have thoughts on it, or if you're interested in trying to see other legislation get filed. There's lots of coalition-based activities we're a part of. Lots of planning that we're commencing on the inside of things.

Our shop's growing, and we want to be a place where folks with disabilities and other advocates and self-advocates, and folks with experience in the state can come and have discussions. Thank you for the podcast. I fall asleep every night listening to true crime podcasts and this is something totally different. I appreciated the chance to come and talk. Thanks to Olivia too.

Keith: Absolutely. Thanks to both of you. I appreciate it.

Thanks again to both Olivia Babis and Tony DePalma for being our guests today. I look forward to speaking to them again next year. Don't forget to check our blog for updates related to the Florida Legislative Session, as we're still waiting on Governor DeSantis to act on some of the bills that passed.

Thank you for listening to the You First podcast or reading the transcript online. Please email any feedback, questions, or ideas about the show to podcast@disabilityrightsflorida.org.

[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, the Disability Rights Florida podcast.

Transcription by CastingWords