

>> Good day. You are listening to Ability Radio. I am one of your co-hosts, Amelia Headley LaMont, executive director of the Disability Rights Center, and today we are joined by a very special guest who has provided a lot of assistance, technical assistance some would like to say, with the work that we do, involving parents and youth with disabilities, Diana Autin, who is the co-director of Span, the Parent Advocacy Network. How are you? Good day.

>> Good day. It's wonderful to be here with you. Thanks so much for inviting me.

>> Well, thank you for helping us out during our time of need from time to time. Tell us a little bit, if you can, about the work of the Parent Advocacy Network. What does that involve?

>> So, the Span Parent Advocacy Network is an organization that is both led by and staffed by parents of children with disabilities and special healthcare needs. We help families and youth and young adults, as well as professionals who support families and youth and young adult, by providing information, training, advocacy, also leadership development and support around parent professional collaborations at the individual level, at the program level, and also at the systems level to make sure that the voice of families and of self-advocates is part of the decision-making process about all the policies and practices that affect children and families, not only in our state but also across the United States.

>> So, by your state, what do you mean? What state are we talking about?

>> So, we're housed in New Jersey. And in New Jersey we are the organization that is like the Disability Rights Center of the Virgin Islands. We are the Parent Training and Information Center. We are also the Family to Family Health Information Center. We also house a chapter of the Federation for Families and Children in Mental Health and Parent to Parent, we're the affiliate in New Jersey for Parent to Parent USA.

We also house some national projects and some regional projects that help other parent centers and other family-to-family health information centers be able do a more effective job reaching and serving diverse families and youth.

>> It sounds amorphous; okay? How does a parent access your services? What kinds of situations you might see in your experience?

>> So, most of the time, parents access us by giving us a call or by going to our website. And they may be trying to get help because their child has been suspended from school, or their child may be having difficulties in school and they want assistance in decided whether or not the needs to have an evaluation to identify a disability or to develop an individualized education program. Sometimes a parent will contact us because their health insurance has failed to cover needed medical expenses, and they want to appeal a denial of coverage. And sometimes a parent has just had a new child and wants information about what resources are out there, what services and supports can I get, are there other parents who have children like mine that I can learn from and talk to and get support from? So, calling, going to our website, and then we get a lot of referrals from professionals.

>> That's excellent.

>> It's very helpful.

>> So, I'm assuming if you aren't living in New Jersey, can an individual, say, from the Virgin Islands, access your website? And if so, where do nay need to go?

>> Anybody can access our website, and it's www.spanadvocacy.org. But if you're from the Virgin Islands, I would recommend two other things. I would recommend, first, that you go to parentcenterhub.org, because that is the website of the National Parent Technical Assistance Center, and so there are resources from all over the United States and the Territories that are available at

parentcenterhub.org. And then, secondly, check out that website for that amazing Parent Center and the Disabilities Rights Center of the Virgin Islands, which also links to Parent Center.

>> That's right. Which is drcvi.org. So, it's parentcenterhub.org. Okay.

>> And there are materials in multiple languages about every aspect of early intervention, special education, transition to adult life, anything, really, any kind of information a parent, or even a professional, might need to know to be able to understand those processes under the Individuals with Disabilities Education Act and Section 504 of the Vocational Rehabilitation Act.

>> Well, I have a confession to make, I first learned of Span by looking at your website, and one of the things I noticed, I just thought it was very creative, you had something, at one point, had to do with lunchtime coffee or something. I don't recall what the branding was, but it was very engaging.

>> We have lunchtime -- for a long time, we did lunchtime teleconferences, and then we did lunchtime webinars, and now we do lunchtime Facebook Live presentations.

>> Oh, lunchtime; okay.

>> So, the Facebook Live presentations are usually half an hour or so on kind of going onto a particular topic. Maybe it's about discipline or positive behavior supports, or perhaps it's about getting help in the general and classroom. Maybe it could be something around the IEP process or transition to adult life or early intervention. So, those Facebook Live presentations, you know, we get a decent amount of people watching them live.

>> Right.

>> But then we record them, so we get lots and lots of -- hundreds of people who watch them afterwards. We also have one of the things I really like, it's one of my favorite things on our website, is we have a webinar around the IEP process.

>> Now, IEP stands for?

>> Individualized Education Program. And every child who has a disability, who's identified in school is entitled to an IEP that sets forth the services that they're going to receive and how their progress will be assessed and reported to their parents. So, we have this webinar that's about the whole IEP process. But we also have divided that webinar into very short snippets, where we call them frequently-asked questions, or FAQs. So, there's a question about what's involved in and evaluation. And you just go to that FAQ, and you just hear the part of the webinar about the evaluation process. So, it's divided into --

>> Yeah, they break it up.

>> -- a bunch of small, easy to understand short clumps of information.

>> Right. >> And you can go just straight to the FAQs about the topic you're interested in and get the answer to your question.

>> That's a great idea. I mean, we might steal that. That's an excellent idea. Because it is overwhelming.

>> It can be very overwhelming. And I'm a parent myself. I'm an attorney. And I remember the first time I had to go to school to talk with the school personnel about my son.

>> Right.

>> And even though I was an attorney, I felt overwhelmed.

>> Of course.

>> I felt like I didn't know anything about the process, what was supposed to happen, what my role was. I really didn't know how much I could contribute to the conversation. So, even though I was an attorney, I pretty much sat there quietly, and it really wasn't until time evolved and I continued to be part of the process that I really began to understand how critical my voice was in the conversation. I knew my son at home, in the community with family and friends in a way that the people at the school didn't know him. And they knew him at school in a way that I didn't know him. Adding what I knew with what they knew, we were able to come up with the supports and services that he needed to succeed.

>> Well, tell us a little bit about yourself. You said you're a parent.

>> I'm a parent. I raised four adult children. I also have an amazing 13-year-old granddaughter who lives too far away, but I love her. So the reason I actually got into this field -- I was a civil rights attorney, and the reason I got into this field was dealing with -- trying to deal with schools around the struggles of particularly my older son, and an opportunity came to work at Advocates for Children, which is in New York City, and I felt that would be a wonderful opportunity for me to use my legal skills to help other children, but also for me to continue to learn more about my rights and my role as a parent in the, then, New York City School System.

So, I've been a lawyer a long time. I've been in the Parent Center movement. Parent Centers are funded by the U.S. Department of Education to help families of children with disabilities from birth to 26, and my experience at Advocates for Children, and for the last 25 years at Span in New Jersey really has been the most fulfilling work I've ever done in my life, and it's very empowering to me individually, but also to think of all the families that we help through our individual assistance, our training, our resources, our materials, our webinars, et cetera.

>> Well, your passion is certainly evident. I will attest to that, ladies and gentlemen. If you miss any part of this broadcast today, we will be posting this interview, as we post all of our shows, on our website at drcvi.org, and this interview will also be transcribed. We're going to take a short break, and we'll be right back.

>> We're back. You're listening to Ability Radio. I'm your co-host Amelia Headley LaMont at the Disability Rights Center of the Virgin Islands, and today we are joined by Diana Autin, the co-director of Span, the Parent Advocacy Network. And we were learning just a little bit, an overview of what this parent training and information center provides, and it sounds like a number of programs. You engage in person, online. You do training. You develop materials. What don't you do?

>> Well, one of the things we don't do is represent families in due process hearing.

>> Okay.

>> We're in great partnership with Disability Rights New Jersey.

>> That's good to know.

>> Which is the Protection and Advocacy Agency in New Jersey. We actually have a signed memorandum of understanding so that we collaborate. One of the most exciting things that we do together, along with our Council on Developmental Disabilities, is a project called SEVA, Special Ed Volunteer Advocates, where we train parents of children with disabilities to support other parents of children with disabilities in preparing for, attending, and following up after IEP or Individualized Education Program meetings, and one of the goals is to help families really be able to understand and articulate what their goals and their dreams are for their child, their expectations and the kinds of supports they think their child will need in order to achieve those goals and dreams, and also to be able to help the parent learn the skills and the content knowledge that they need to be able to advocate on their own in the future.

We also help the parent learn about parent professional collaboration skills, because if you're a parent with a child with disabilities, it's not going to just be early intervention providers or school systems that you're going to need to partner with.

>> Right.

>> But adult service providers and even community-based services that are available to all children and youth, you're going to have to use advocacy skills to be able to have your child included in a typical child care center or after-school care program, be able to participate in the Y, participate in the library programs, take the public transportation. So, all of those areas of life, parents of children with disabilities have to know how to partner with professionals and advocate on behalf of their children.

>> So, how did you set that up, because this is exciting, and I really would like to see if we can implement something like that here in the Virgin Islands?

>> The first thing that happened was our Council on Developmental Disabilities did a needs assessment, and many, many parents responded to that needs assessment, indicating that --particularly those parents who didn't have a college degree or had language barriers or perhaps the parents themselves had disabilities, were really struggling with the IEP process. They were finding that they were intimidated; that they didn't understand the process, they didn't understand their rights, or the contributions they could make.

>> Right.

>> They couldn't really express their expectations for their child and their hopes for their child and what they thought their child needed, and so they expressed that in the Council on Disabilities Needs Assessment. And so, the council saw this huge need for support for parents preparing for and attending IEP meetings, not advocating for them but helping them be able to advocate for themselves.

>> Why do you think parents felt that way?

>> Well, for one thing, in my experience, if you go into an IEP meeting yourself as one parent, or even if you have your partner, there are five people at the table across from you.

>> Right.

>> And so, you're there by yourself, or maybe with one person who feels just as intimidated as you do, with all these professionals who know so much that you don't know. You know, they were trained to be a social worker or a psychologist or a learning disabilities consultant, so they have some professional training that most of us don't have.

>> Right.

>> Even those of us who are attorneys, we don't have that training.

>> Exactly.

>> We may know the law, but, you know, what are good strategies for a child that has attentive disabilities or a child that can't learn to read.

>> Right.

>> So, that's one reason why parents are intimidated. Another reason is that the law is complicated. It has a lot of different components. That's why we could do a webinar but have, like, 30 FAQs --

>> Right. Right.

>> -- that are about specific aspects of the IEP project. And it's complicated.

>> Right.

>> And it can be very hard to remember all those components. But, third, you love your child so much. Your heart and soul you're pouring into that child.

>> Right.

>> And everything that you know can just fly out the window because you're so nervous that am I going to do the right thing; am I going to make the right decision; am I going to be able to get the school do what my child needs so that they can have a happy successful life.

>> Right.

>> So, there's a lot of reasons they feel intimidated, even if the people across the table aren't trying to make you feel intimidated. And I think another reason sometimes parents feel intimidated is that it is possible for professionals to try to make it easy on themselves to get decisions made that they would like to get made and not really ask the parent for their input and their feedback, not really consider that in a meaningful way. And so even though that's not even the majority of professionals, that is an experience that parents have reported to us. So, there are many reasons. Of course, the stakes are so high.

>> Oh, God, yes.

>> The stakes are so high, you know.

>> Right.

>> And sometimes we think that the stakes for this year are higher than they are. We think this year is going to determine the whole future of our child, which is not true, but, you know, it really can be very nerve-racking to think that I am going to make a mistake; am I going to not get them to really maximize my child's development, because we all love our children and want them do the best that they can.

>> Right. Understandable. Okay. So, you did a needs assessment.

>> And the Council issued an RFP, and we partnered with our Disability Rights organization, and submitted an application, which was funded. And so we developed a curriculum that builds on a Span resource parent training that we do, which is a six-part series training that we do for parent, so there's three extra sessions that really focus on how do you build capacity and skills of other parents, going deeper into two key issues, inclusion and transition to adult life, and also really teach people how to maximize an effective IEP meeting. So, we did those three additional trainings and we started recruiting parents for the very diverse array of racial, ethnic, socioeconomic language backgrounds in New Jersey, which is one of the most diverse states in the country, and we did training, and then we started matching the trained SEVA volunteers with parents who were seeking assistance for their IEP meeting. The priority is given to parents who are referred to us by the Disability Rights New Jersey or by our own staff through our warm line, parents who need that extra help that we can't provide through the warm line.

>> A warm line? What's a warm line?

>> So, it's not a hotline, because you can't call it on midnight on Thursday.

>> Okay.

>> A warm line, it just means that a human being answers the phone.

>> Okay. That's important.

>> So, we have our intake specialist who answers the phone, and then she collects the critical information, giving the parent some initial resources, and then one of our information specialists or family resource specialists will contact the parent again to answer their questions and connect them to additional supports and services. So, if it gets beyond what we can provide through those staff, then we can also connect those parents to a Save a Volunteer. And then the Save a Volunteer is provided with a stipend to meet three times with the parent, at least three times with the parent.

>> Okay.

>> The first time is to help them really hone in on what they want to accomplish at the IEP meeting, what their goals are, the issues that they have, and help them prepare to advocate and communicate with a professional. The second is going to the IEP with the parent. They don't speak on behalf of the parent. They're really there to provide support to the parent. And then the third meeting is following up after the IEP meeting, kind of debriefing what happened, what went well, what could have been done differently, is there anything else you want to follow up with, you know, anything else that you want to work on; so those three meetings. And then each of the SEVA volunteers has to help two parents in the year following their volunteer training. Some have done more than two parents. And we're now in the third year of this project.

One of the most exciting ideas that's come out is we've had a few young adults, self-advocates, that went through the SEVA training, and they're interested in us trying to get funding to set up a program where we would have a young adult self-advocate be the volunteer advocate with a youth or young adult with a disability. So, we're investigating trying to get funding for that, because we think that's a wonderful idea.

>> That would be exciting. Particularly, I know here for example, the transition is very, very, very important. Regrettably, we have a lot of young people who are not in a place where they can work.

>> Right.

>> And are spending their young lives, you know, either at home or leave the Territory because there is not much opportunity for them. So, I could see that as another thing that we can hopefully look at and implement, you know, youth representing youth or supporting youth. Not representing. That's not a good word. But providing support.

>> Yeah.

>> Yeah, that would be.

>> And the transition is probably the least implemented component of the Individuals with Disabilities Education Act everywhere, in the United States and the Territories. The outcomes for youth and young adults with disabilities are very, very poor. There's been some improvement. We know the kinds of things that make for improved outcomes, having jobs, you know, as part of your IEP when you're still eligible for education services, the job sampling, having support from vocation rehabilitation is something that really helps. But one of the things that is the most powerful is having high parent expectation. There is a very significant correlation between parents expecting their child to work and to be able to be independent and have a full life in the community and young adults with disabilities who actually are employed and are independent and have a full life in the community. So, parents, you know, we often don't understand that the things we do, what we say, our expectations for our young people, how we support their development of their self-advocacy skills, that's one of the most effective ways in which we can ensure that our children with disabilities have good outcomes.

>> I like that. That is so critical. We need to, you know, expect more from our children, and not make assumptions because he or she has a disability that he or she can't.

>> That's right. And I guess one of the examples that we give in our Transition Workshop is, we say, imagine that you just had a child who's learning thousand walk, and the first time that they fall, you pick them up and I say I'm never going to put you down until I'm sure you can walk without falling. That child would never learn to walk.

>> Right.

>> And we do the same thing to our youth with disabilities, our children with disabilities. We protect them to an extent we don't want them to fail. But learning from failure is probably the thing that leads to the greatest success for all people, with or without disabilities. So, we can't just pick up our children with disabilities and say, I'm not going to let you fail, I'm not going to let you fall down, until I'm positive you're going to be able to succeed, because the way you learn to succeed is by learning from your failure.

>> Right. That's how you remember.

>> Yes.

>> You know?

>> As an adult, I've made a lot of mistakes.

>> Me too.

>> To learn from those mistakes has been so invaluable.

>> Absolutely.

>> We can't be over protective of our children, especially our children with disabilities, because we don't give them the opportunity to make mistakes and learn from those mistakes, to take a chance and then succeed.

>> Right.

>> Or learn from not succeeding.

>> Right. There is an excellent YouTube video that our local Department of Education had shown, and it featured a young man -- his name I don't recall -- with autism. And the title is call "The Dignity of Risk."

>> The Dignity of Risk, that's exactly what I'm talking about.

>> Yeah. It was excellent. It was Excellent. Okay. Well, we are really, really learning a lot today, and, again, if you miss any part of this broadcast, it will be posted on drcvi.org. We're going to take another break to pay our sponsors. We'll be right back. You're listening to Ability Radio.

>> We're back. You're listening to Ability Radio. I'm one of your co-hosted, Amelia Headley LaMont, Executive director of the Disabilities Rights Center of the Virgin Islands, and today our guest, our very special guest, is Diana Autin, co-director of Span, Parent Advocacy Network. Based out of New Jersey, but provides, quite honestly -- I shouldn't say "but" -- and provides a wealth of information to parents, families of children with disabilities. What is the acronym? You said something about S-A-V?

>> It's S-E-V-A, Special Education Volunteer Advocates.

>> Okay.

>> One of the reasons we call it "SEVA is because SEVA is a Sanskrit word for service, and so all of our SEVA volunteers are parents themselves who have learned to how to advocate for their own children successfully, and now who want to give back to the community and help other parents. And we think that parents teaching parents, parents helping parents, parents supporting parents is the most effective way to be able to help another parent learn how navigate a system, learn how to advocate on their own. For one thing, it's great to see another parent as a role model, and to say, "You know, if you could do it, I could do it too."

>> Absolutely.

>> That's one of the reasons why it's really important for us to have SEVA volunteers that really represent the full diversity of New Jersey, because we want a Haitian American parent who feels intimidated by the system to be able to see another Haitian American parent who has learned how to navigate the system, or, you know, Spanish speaking parent or South Asian parent, because often people will say, when someone who's from a different racial or cultural background or more privileged background, when they see that person doing something, they'll say, "Well, you know, you can do it because, you know, you have the education."

>> Right.

>> Or they respect you; right?

>> Right.

>> Which, of course, as we know, there is less respect, often, you know, for underserved families. But when they see another parent who looks and sounds like them, who has been able to be successful, that really, then, gives them the first glimmer of hope that it might be possible. It also sends a pretty powerful message to the school teams when another, you know, Spanish speaking parent, South Asian parent coming to the table as a support and, you know, brings that wealth of knowledge and experience to the table, and that really helps change the minds and hearts of school staff who may have some prejudices or stereotypes about the capacity of parents who perhaps don't speak English or don't have a college degree. So, that kind of modeling for the parent, and also the lesson, I think, that it teaches about busting, you know, myths and stereotypes about professionals is very powerful.

>> Have you had much interaction with these intimidating professionals, as we like to call them, from time to time?

>> Yes. Yes, we have had that. And one of the things that we know is that sometimes people who enter the field of education with the best of intentions, really wanting to do good and have a positive impact on children and families, they can get tired, they can get frustrated about the difficulties of making good things happen, the barriers that they face in their professional life, and so one of the things that we try do when we work with those professionals, whether it's working with them, our staff or working with SEVA volunteers to work with them, is to help them get back to why they came into the field in the first place, get to those underlying shared interests. Forget the positions that we're fighting over, this position, that position, I demand this, we don't do that.

>> Right.

>> Let's look and see, we all share a commitment to this child, so let's start there, and then let's build on that and create agreement on that based on that shared interest. And it's amazing how often that tough IEP team member can change their perspective when they're helped to go back to those underlying shared interests, why they came into this field in the first place.

>> So, in what form does this even come about? Not in an IEP meeting, for sure.

>> So, one of the things we do is we actually have a workshop that we do called "Creating Agreement," and we often are asked to do that workshop by parent groups or by school districts for their staff. Sometimes school districts that have a lot of tension between parents and professionals will have us come and do that for both families and professionals at that same time. That's what we like to do the best. We like it when we can have both the parents and the professionals there at the same time. They learn at the same time. They do role plays together.

>> Oh, my goodness.

>> It's great. But even at the IEP meetings, there's questions that you can ask at the IEP meeting to get back to those underlying interests, just helping to shape the flow of the IEP meeting. So, just even saying if a professional is taking a certain position that the parent is not happy with or doesn't agree with, having the parent ask the professional, "Why is that so important to you?" And sometimes, it just stops the professional right in their tracks trying to think about why that is so important. What do they say? "Well, that's all we offer." No, you're not going to say that. So just really asking, not just saying, "Why is that so important?"

>> Right. Right.

>> Really saying, "Why is that so important to you?" What would be accomplished if that happened? Really trying to help understand. And, you know, there's a saying about listening and trying to get to the other person, that somebody has to go first; right? Somebody has to go first to try to understand where the other person is coming from. And so we try to teach parents to model that real active listening and that curiosity, really trying to understand the other person, and then, hopefully, the professionals will then pay it back and try to understand where the parent is coming from, and from that, they can build a relationship that then leads to building a plan for the student that both the family and the professionals think has a good chance of succeeding.

We also really encourage parents to, if there's any kind of research or information that they want to share with the professionals to do that in advance of the meeting. Don't put the professionals on the spot and make them feel bad that they don't understand or they're not aware of the latest research. Send it in advance. Jot a little handwritten note, I came across this, thought it looked interesting. Might be, you know, useful for my child, can we talk about it at the IEP. It gives them the opportunity to look at it, see whether they think it's relevant, and then to come to the IEP meeting feeling they are competent and knowledgeable and up to date.

>> Right.

>> So, we have different kinds of tips about building the relationship that help with it getting to be a relationship. And, you know, it's going to be a long time, probably, that this parent and these professionals are going to work together, so let's get off on the right foot. Let's build a relationship that's built on trust and understanding these shared interests that we have about this child who everybody wants it is best for, even though we might disagree how we get there.

>> In our jurisdiction, granted, if there is a change in administration, it means a changing of staff, and it means you pretty much have to start from scratch.

>> Yes.

>> You know, meet and greet, and, you know, maybe a previous way of doing things has changed, because there are different individuals, hats have changed and whatnot. I'm wondering if you have that same experience where you live and work.

>> Yes. So, in New Jersey, every time there is a new governor, there's a whole new set of commissioners and a whole new set of assistant commissioners.

>> Okay.

>> That includes the assistant commissioner who oversees education, the assistant commissioner who oversees early intervention, the assistance commissioner who oversees vocational rehabilitation.

>> Okay.

>> So, in every agency, we have that. There's less turnover at the kind of ground level.

>> Okay.

>> The service delivery level in those systems, so the kind of changes in roles, people who are assigned to different roles stop pretty much at the assistant commissioner level. So, you do have people whose approaches change and whose manner of doing business changes. We always do try to get into meet with those commissioners and assistant commissioners as soon as possible after new people are named, because we want them to know who we are, and we want them to know that we are friends. Sometimes we may have to be critical friend, because we're going to advocate for what we think is right. But we know that their job is to make sure, if it's education, that children with disabilities and all children get the education that they're entitled to and that their parents are part of that process, because everybody knows the research says that things are better when parents are involved.

>> Absolutely.

>> So, you know, we have those shared interests, those underlying interest, even though positions we take on different issues may be different. We also want them to know that we will be critical when we think that we need to be, and that it's not because we don't support them being successful in achieving their goals. It's just that we have to support what we think is right and what we know from research and our own experience is right. So, it's the same way at a parent at an IEP meeting; the parent tries to get to those underlying shared interests. You know, it doesn't mean you always agree with everything. At the end of the day, you can still disagree. But you can disagree and still have a positive relationship if you take the time to build that relationship at the beginning.

>> Just briefly, if you can inform the public, what do we mean by an IEP meeting, an Individual Education Plan meeting? Why do we even have those things?

>> Well, parents are the reason we have an Individuals with Disabilities Education Act. There wouldn't be a law if it wasn't for parents who were advocating for the children with disabilities. And one of the things that parents of children with disabilities knew was that parents know a lot about our children with disabilities, and that knowledge and expertise have got to be part of the process of deciding what services and supports a child with disabilities is going to receive. So, they wrote right into the law that, at least annually, there had to be this meeting to develop the Individualized Education Program or Plan for every child with a disability; that the parents had the right to be a part of that meeting, to have discussions and be part of the decision-making process. Parents have the right to approve or reject the first IEP. So, that first plan that has the services and supports can't be implemented without parental consent. And then after that, parents have a right to participate in the planning, and if they disagree, they have a right to challenge it through mediation or a due process hearing or state complaint. So, parents made sure that parents were written in as equal partners in developing this plan of supports and services for every child with a disability.

>> And that plan is developed or should be developed every year.

>> Every year. It has to be annually developed.

>> Now, if you thought that there needs to be a change, you can go back in, can't you?

>> That's right. In fact, a parent can ask for an IEP meeting at any time. You don't have to wait until the annual IEP meeting if things have changed. If, thank goodness, the child has achieved all their annual goals before the end of the year, perfect reason, or if, as the parent is being informed of their child's progress, that it finds out it's a welcome progress, the parent has a right to say, "Let's have an IEP because the things we thought were going to work, aren't working, and we need to revisit this."

>> What have been some of the best challenges and successes that you've seen over your period of time with New Jersey Span?

>> So, one of the greatest successes is that Span is listed in every parent handbook for every agency in New Jersey. Whether it's a special ed, early intention, transition, child welfare, juvenile justice, we are listed as a resource for parents so that we are getting contacted by parents from every system. And we're getting referrals from professionals in those systems. So, think, you know, knowing that parents being able to know who we are and how to find us and how to access our services.

Another great success is we have a lot of volunteer parents. At any given time, we have 200 or more volunteer parents who have been trained and kind of are our ambassadors throughout the state, spreading the word about Span, sharing information, helping us at workshops, setting up community resource centers at libraries or health clinics. So, that's also really great.

And then I'd say the last success that I'm most proud of is that we really are seen as a key partner with all those state agencies, and so we're part of all those advisory groups and we are able to get parents on the advisory groups. So, you know, not only helping all those parents at the individual level, but taking all that knowledge and expertise and experience and bringing it to the systems level.

One of the worst areas, and this is one of my highest priorities in this organization, is inclusion or LRE. And despite litigation and trainings and projects and advocacy and policy changes, New Jersey still has one of the most segregated special education systems in the country. I think the only place that's worse than us is Washington, D.C. in terms of the rate of students in out-of-district settings. It's three time it is national average. So, that, I would say it is probably my greatest sense of failure. And the second, I would say, is that one of the last things our outgoing governor did was sign legislation that goes against what's happening all over the rest of the country, where people are ending the use of restraints and seclusion. But in our state, our governor signed into law, a bill that explicitly authorizes the use of restraints and seclusion and really limits the information that parent have a right to know about that or what they can do about it. So, it was literally the last act of our outgoing governor, and we're trying to get traction now to undo that legislation.

>> Now, explain that to our community. I mean, it's not a practice that I'm particularly aware of here, but it's important, I think, for parents to know. What do we mean by restraint and seclusion?

>> So, seclusion, in New Jersey, we have, I'm sorry to say, padded rooms in some districts, where children who are acting out whether be put in a padded room, or they will be put in a closet, locked in a closet with nobody with them because they are having behavior outbursts, instead of using what we know is effective, which is positive behavior support. So, you know, seclusion is putting child -- secluding them away. It's like solitary confinement in prison.

>> Right.

>> And we are moving away from solitary confinement in juvenile justice in New Jersey at the same time that we are allowing children with disabilities who have committed no crime to be put in closets and padded rooms.

In terms of restraints, you have maybe a child who uses a wheelchair who has restraints put all over their body, so they can't do anything because they're acting out. Or you might have a security guard who

jumps on top of a six-year-old because they're acting out and restrains them physically that way. We actually have had some deaths, as well as some serious physical harm that's been caused.

>> In school?

>> In schools. Yes, in schools. Which is one of the reasons why we're very active in national advocacy around eliminating the use of seclusion and restraints, because it's behavior on the part of adults that never should be used, and that doesn't stop challenging behavior, but, in fact, makes it worse. So, it's not evidence-based, it's anti-evidence-based. It's not effective, and it's traumatizing and can be, also, physically harmful to children and youth. So, we're working hard to try to limit the use, while it's still legal in New Jersey, but also to get that law to be changed by the legislature with support of the governor.

>> Okay, you used the phrase "LRE," which stand for least restrictive environment; right? So, what I'm hearing is that, in a number of jurisdictions -- and I regret to say that we're probably not an exception -- it's still an ongoing struggle to create a more inclusive educational environment.

>> Yeah. And that's, unfortunately, in places like New Jersey, that's even more true for children of color. So, in our state for example, an African American boy, the first time he's placed in special education, his likely placement is a self-contained class, which is a class just for children just with disabilities. Often, you're not learn thing same thing as the other children. A lot of times in New Jersey, they're in the basement, those classrooms, or, you know, that part of the building.

>> Over there.

>> Yes, over there. So, it's true of African American boys, Latino boys, and then African American girls and Latino girls. On the other hand, if you are a white boy or a white girl, your first special ed placement is likely to be that inclusion, that general in classroom with the supports and services. The law is very clear, regardless of your race or your ethnicity, the first placement should always be considered for a child with a disability in an IEP is the general ed classroom with their non-disabled peers, with the supports and services brought into the classroom and not making the child go where the services and supports are. So, the law is clear. Our state code is clear. Our state Department of Education has done a lot of training and technical assistance around this.

Unfortunately, in New Jersey, like New York State, we are one of the states that provided services to children with disabilities before there was a federal law, and the way we did that was through a network of segregated placements. So, once the law came into effect in a state that children with disabilities had been completely excluded, it was easier to start all with inclusion, because they didn't have this set of separate settings. But in New York and New Jersey, we had this both public and private separate setting.

Now, New York has been able to do a much more effective job of reducing their segregation. They're still higher than the national average, but not even twice as high, whereas we in New Jersey are still three times as high. Our rate has gone down, at the same time the rate of segregation has gone down, but at the same time, the rate of segregation nationally has gone down. So, we're not doing better than that rate. A lot of it has to do with racism and discrimination.

I don't know if you're familiar, there was a study that was done of teachers who, they would see how long a teacher would wait for a student to answer a question after the teacher asked the question. And they found that for black boys, the teachers would wait almost no time before either they would answer it or ask another student. But for white students, especially white girls, they would give a lot more time. They would wait a lot more time, because they -- this is probably why -- because they believed that the white student could answer the question, and they didn't believe the black student could answer the question. And, sadly, this was true even of black teachers. And when the researchers told the teachers that this was the case, they, vehemently denied it.

>> Of course.

>> Then they would see themselves on tape, and they couldn't believe it. It was so unconscious.

>> Right. Right.

>> You know, that kind of unconscious bias that everybody, you know, in our world carries around with us. So, that same kind of feeling that a black student, especially a black boy, probably needs that self-contained class, can do it in a general ed, that unconscious bias probably is one of the contributing factors. But, also, you know, having educated parents who say, wait, I'm not having my kid in that segregated class in the basement, are you kidding me? But that comes with a sense of privilege and expectation; right?

>> Right.

>> So that's one of the reasons we work really hard to build those high expectations of parents of color and parents who don't speak English and immigrant parents, so they also believe that their child can achieve and doesn't have to be in the basement.

>> I know in our conversations with you yesterday, was there any prerequisites as to what groups your office would help? For example, we had a conversation about whether an individual was documented or undocumented? Was there any restrictions there?

>> No. In fact, as a parent training information center and also as a family-to-family health information center, we're required to help every parent of a child with a disability or special healthcare need in our geographic area, regardless of documentation status, and, in fact, we are part of the New Jersey Alliance for Immigrant Justice, so we've been very active in activities to try to expand the rights of immigrants in our state, including access to drivers licenses, which just happened a couple weeks ago. So, it doesn't matter where you're from, what language you speak. Our staff speak 11 languages, and we use the Language Line for any other language we don't have, or we partner with community partners like community-based organizations or immigrant agencies. But it doesn't matter how old you are or where you're from or what your race, ethnicity, or language is, or your socioeconomic status, or what your political affiliation is, if any, your religion, if any, marital status, none of that matters. If you need our help, you can access our resources on our website, and you can call us up and you can come to our free workshops that are held all over the state, because we believe every child in New Jersey has the right to have a full and productive life, and we know that their parents are key to making that happen.

>> Absolutely. Now, even though we're not in New Jersey, what is your phone number, just so we can have that?

>> My phone number, the Span phone number is (973) 642-8100, and also our website is www.spanadvocacy.org. You can ask for help on our website, we have a place where you can request assistance on our website, as well as calling us. And, also, you can find a wealth of resources on our website, webinars and teleconferences and Facebook live presentations and YouTube presentations and materials in seven or eight languages, including Spanish, among others. And so, you know, we're very welcoming of anybody accessing our resources and using them.

And, of course, as the technical assistance center to all the parent centers like Disabilities Rights Center of the Virgin Islands, we'll also do our best to connect you to your local resources or your local PTI, but also your local family to family information center, which is right now, it's housed at the Council to the Disabilities of the Virgin Islands, and so we'll connect you to the resources that we're aware of. But feel free to reach out to us at any time.

>> Great. Well, we're going to take another short break, and then we're going to conclude this broadcast. You're listening to Ability Radio.

>> We're back. You're listening to Ability Radio. I'm one of your co-hosts, Amelia Headley LaMont, of the Disability Rights Center of the Virgin Islands. And, again, if you've missed any part of today's show, we

are going to post this on our website at drcvi.org. It will also be transcribed. Our guest is Diana Autin, co-director of Span, Parent Advocacy Network. What do you see for 2020 for Span?

>> Well, our motto is empowered parents educated, engaged, effective, and that's what I see for 2020. I see the opportunity for more and more parents to join together and to raise our voices to not only improve parent professional collaboration at the local level with the professionals that work with our own children but also at the systems level, at the policy level. There will be many opportunities to impact what's happening in Washington, coming out of the U.S. Department of Education and the U.S. Department of Labor. And all of those things that happen, whether it's funding or new rules or regulations, impact each and every one of us at the local level wherever we are, anywhere in the United States, Continental U.S. or the Territories, and so there are going to be many opportunities for empowered parents to get more educated, to get more engaged, and to be effective in making sure that we have the services and supports our children need to be effective and productive members of our communities and our society and our nation as a whole.

>> Wow. I want to thank you so much for taking the time to speak to us, to encourage our community, welcome, and we hope to have you back at some point soon. Thank you so much for listening. We'll talk to you again next week. Bye-bye.