

ROUGHLY EDITED TRANSCRIPT

ASSOCIATION OF PROGRAMS FOR RURAL INDEPENDENT LIVING (APRIL)  
PARENTING WITH A DISABILITY WEBINAR  
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>> Hi, folks. Thanks for calling in. I will just open up your lines.

>> Kimberly, how are you?

>> Good, how are you, Kimberly?

>> Good! I'm tired today, but good.

>> For those of you just joining us, we are just getting set up here and we will get going in about ten minutes.

It always feels a little weird to me that there's no music when people start joining. We are here and we are just getting ready and hopefully those of you who are just joining us, we will start in about ten minutes.

>> Hi, it's Susan, just letting people know I'm here.

>> Great. Thank you, Susan for agreeing to speak with us today.

>> You're welcome. Now, do I leave my line unmuted for the entire time or do I go back

and forth? What should I do?

>> So, I'm going to leave you -- all the speakers unmuted on the line -- on the main end and if you can just unmute and mute from home.

>> SUSAN YUAN: Okay. I'm on a primitive phone. I'm not sure I can do that.

>> You should be able to. If you don't have a mute button, try star six.

>> SUSAN YUAN: Okay, I will try it now.

>> And then when you want to unmute, press star six again.

>> SUSAN YUAN: That works!

>> Great!

>> For those of us who are just joining us, we are getting our speakers all set up. Thank you again for joining us. If you need access to CART for today's call, you can get that link from the APRIL website at [www.April-rural.org](http://www.April-rural.org).

>> SARAH LAUNDERVILLE: Hi, Mary, I wanted to say it's Sarah on the call.

>> MARY OLSON: Hi, Sarah. Thank you.

>> SARAH LAUNDERVILLE: I will put myself back on mute for now.

>> MARY OLSON: Great.

For those of you who are just joining us, we are going to get started in just about five minutes here. Thanks again for joining us for the final IL conversation of the year. And I think I'm still looking for Kelly Buckland in our speaker notes. So if you are there, Kelly, if you could give me a star two, that would be great.

Hi, again, folks. For those of you who are just joining us, hang tight for just about four or five more minutes, while we wait for more folks to join us. Thanks again for joining the last IL Conversation.

Yes, hi, did you have a question?

>> KARA AYERS: This is Kara Ayers, I was joining as one of the speakers.

>> MARY OLSON: I apologize. I didn't have you in my list, but I'm glad -- thank you for star twoing. So we will make you a moderator and if you can mute and unmute from home, you can do that either with a mute button on your home phone or using star six.

>> KARA AYERS: Okay. Thank you.

>> MARY OLSON: Hello again, folks. I see lots of people starting to join us. Just so you know, we are going to hang tight here for just a few more minutes, until we get to the top of the hour, as folks join us, but thanks again for joining the IL Conversation on "Parenting with a Disability."

Hello, we are at the top of the hour and I will go ahead and give a little brief overview and stall a little while as more folks are joining us here.

But if you are dialing in, you are in the right spot if you are looking for the IL Conversation on "Parenting with a Disability."

We've got a few more folks chiming in right now. We'll get started in just about a minute.

All right! I'm going to go ahead and get started while folks are joining us. Good afternoon, and thank you all for joining us for today's IL Conversation "Parenting with a Disability."

I'm really excited about this one. It's going to be a great conversation, and it's the final one in this year's series. If you need access to CART for today's call, please go to the APRIL website at [www.April-rural.org](http://www.April-rural.org). And you can follow that link right on our IL Conversations tab. If you have trouble accessing it, you can always email me, and that's [Mary.Olson@mso.umt.edu](mailto:Mary.Olson@mso.umt.edu). And I can send you those links directly.

Today's call is going to be recorded, and the audio recording and the transcript will be available online at our website under that IL Conversations tab following the call.

We are also going to work with our speakers and hopefully get some resources up there for folks as well, that we talk about today. During today's conversation, if you want to add to the topic from your experiences, or if you have questions, please press star two on your phone to raise your hand, and then I can make your line live.

When I unmute your line, you are going to hear the moderator state your line has been unmuted. Go ahead and ask your question at that time.

Once your question has been answered, if you could go ahead and press that star two again, it just lowered your hand and cleans up our queue.

If you have any other questions, you can type them in our CART chat box as well and I will voice them for you.

Please remember to evaluate our conversation today, on our website, following the call,

under that IL Conversations tab. Your feedback is really important to us, and it only makes us stronger as an organization.

This IL Conversation is presented by the IL-net which is operated by the Independent Living Research Utilization program ILRU, in partnership with APRIL, NCIL and Utah State. The support for this IL Conversation is provided by the US Department of Health and human services Administration for Community Living. No official endorsements of the Department of the Health and Human Services should be inferred.

And without further ado, I will just briefly you an introduction of the presenters and then I'm hopefully going to let them introduce themselves a little bit as they are speaking.

So we have got a great panel today. We have Sarah Launderville, Kelly Buckland, Kimberly Tissot, Susan Yuan, and Kara Ayers and Nancy Brieden. I will let them talk about themselves and this great NCIL committee. Hope I pronounced your names correctly. I will go ahead and turn it over to Sarah.

>> SARAH LAUNDERVILLE: Hi, Mary, can you hear me okay?

>> MARY OLSON: I can.

>> SARAH LAUNDERVILLE: Okay. So, yeah, so thanks so much for having us on the call today. I want to just take a moment and thank Mary Olson who has been so helpful, not only for our call today, but all year long for these IL Conversations. I'm so excited to be able to participate today. And I appreciate you organizing these calls and your dedication to education within our movement.

So as Mary said, I'm Sarah Launderville, with the Vermont and the newly elected vice president of NCIL, and I also get to chair this NCIL Parenting Task Force. Personally, I'm a mother of three kiddos. I have twin daughters who are 9 and I have a son who is 7. And I have a psychiatric disability. I have lived the challenges around parenting but also some of the wonderful pieces around parenting and bringing forward how we talk and communicate around being parents with disabilities.

So we have some excellent contributors to our panel today, who I will ask to introduce themselves and they are going to share their personal experiences around parenting with a disability, as well as their experience within our CIL, SILC network. And we hope to cover a bunch of topics today, including the task force itself, how you can get involved in our work, parenting rights, reproductive assistance, guardianship issues, adoption, divorce and separation, equipment and then also just advocating for legislation and what work your CIL or SILC can be doing around working with parents with disabilities.

So obviously within 90 minutes we will only be scratching the surface of these topics but in hopes that you continue these dialogues within your state and where we should go next with these issues.

So I want to turn it over first to Kelly Buckland who is the executive director of the National Council on Independent Living. And Kelly, would you mind starting with a little bit about who you are and your personal experiences and give everyone a little history about the work that NCIL has been doing involved, which led to this task force?

>> KELLY BUCKLAND: Yes, absolutely. Well, I'm Kelly Buckland. I'm the executive director of the National Council On Independent Living. I have been here for a little over eight years. Prior to that, I was the state Independent Living Council director in Idaho for about 15 years. And then before, that I ran a Center for Independent Living in Boise, Idaho, for about six years. So I have ran a Center for Independent Living and I ran a SILC for a good amount of time. And I'm also a father of an 18-year-old son, who just moved away from home to go to college. And I'm going through parenthood withdrawals, I guess. Or maybe just a change in how my parenting is done, because it's done from afar now.

But thankfully, we have things like Facetime and we have Skype and texting and all that kind of stuff so I can stay in relatively good contact with him.

So one of the reasons I mentioned my past about being the SILC director in Idaho is because that's really kind of how this stuff started. We -- when we did our state independent living plans, we did a number of forums around the state in different cities, and we would get input from people with disabilities about what should go into the state plan. And when we did that, we got input from people with disabilities that they were losing custody of their children because they were parents who had disabilities. And so we put it -- we put in our state plan that we were going to do something around this. And so we started up what was called -- what we called in Idaho, the Committee on Family and we had a bunch of different members included on it.

We had parents with disabilities. We had centered. We had attorneys. We had the PNAs. We had state protection workers. We had the parent training centers and the DE councils, the university centers, and we had legislators on there as well. We had two of them that were prominent. We had the Chair of the House Health and Welfare Committee and the Chair of the Senate Health and Welfare Committee.

And what we did was we went through all of the current child custody laws in Idaho. We removed any discriminatory language that was in there -- and there was lots of it, believe me! And then we put language in that built protections around parents with disabilities against discrimination. And then we created or tried to create what we considered a fair evaluation system of parenting because just the whole way the system is set up when they evaluate you, with a parent with a disability, they can start from a deficit model as to how they can provide any supports that help you out as a parent. So we had meetings throughout 1999 and up to 2002, and we introduced legislation, child protection, adoption, divorce, separation and guardianship.

And the first year we introduced the legislation, in the Idaho Senate, it passed unanimously, but then it was killed in the House. So we tried to fix what we thought the problems we heard in the House were. We introduced -- we reintroduced the legislation again in the Senate in 2001. It passed the Senate unanimously again. And unfortunately died in the House. So, again, we went back to the committee. We tried to fix what we thought the problems were, addressed by the House. And this time instead of starting it in the Senate, we started it in the House, and we broke it up into two different bills -- actually, four different bills.

So the first year we introduced -- in 2002, we introduced two bills, one that dealt with guardianship and adoption, and then a second bill that dealt with marriage and separation. And I think this is kind of an important piece of the story, because what happened was the chairman of the House Health and Welfare Committee went to see "I Am Sam" which is about a parent with a disability. And he invited me and entire House Health and Welfare Committee to go with him and watch it.

And so we all did, and the movie fortunately, or unfortunately, moved the committee to where those two bills went out of committee unanimously. Went to the House floor, passed, and went over to the Senate and passed and were signed by the governor.

So it was interesting to me that the movie with Sean Penn in it, had more impact on the committee than real parents that we brought in and who testified in front of the committee. We had real parents who had their children taken away, come into the committee and the movie had more impact on them.

It was good in that it helped pass the bill, but it was bad in the way that Hollywood had more effect on them than real people.

But the following year, we introduced two more bills, one dealing with child protection and one dealing with termination of parental rights, and they, again, passed out of the House. And passed the Senate and were signed by the governor. So we had effectively addressed every child custody statute in the state. So we learned a number of things through those. One was you need to involve the courts. You need to involve the prosecutors, and you have to hold the line and be cross disability and hold the line that this is a civil rights thing. It's not -- it's not a child custody thing. It's a civil rights thing.

So anyone who is abusing or neglecting their children should lose them, but it shouldn't be because of stereotypes and misconceptions and outright discrimination against parents with disabilities.

So those were kind of lessons I learned. Then I moved to DC to go to work at NCIL and I'm about to come to a conclusion on my part here. And I had always thought it was unfair that we had been able to protect parents with disabilities in Idaho, but parents in the other 50 -- or the other 49 states and the territories, didn't have protection.

So I went over to the National Council on Disability, and I specifically requested that they do a report on parenting with a disability. They did -- they did do a report, and I specifically requested that they put my legislation in the report as well, and as a lot of you probably know, Robyn Powell did the report and she just did a fabulous job on it. It's called "Rocking the Cradle" and it's on their website, if you haven't seen it.

That started it into a national movement and NCIL then at that point started up the parenting task force that Sarah talked about, that's underneath the ADA civil rights subcommittee of the legislative committee. And NCIL has been doing some national work on this, really since then. And I'm just really happy that we have this opportunity to present that work to you all today.

So with that, I will turn it back to you, Sarah.

>> SARAH LAUNDERVILLE: Thank you Kelly. I appreciate how the laws start from the deficit model instead of supportive model. It's really amazing how "I Am Sam" pushed forward that legislation. And it shows how movies push forward things in our movement and something that we have to be mindful of. You are right, it is indeed a civil rights issue.

I want to turn next to Susan Yuan who knows a lot about attitudes and spent her career on parental rights. Susan, can you tell us about TASP and the organization that you work with and your personal experiences and the work that you have been doing, including your experiences around child protection and the assumption that you have seen that people make around folks who are parents with disabilities?

>> SUSAN YUAN: Thank you, Sarah, and thank you, Kelly.

I got into this field of disability because I'm the parent of a 43-year-old man with disabilities, who communicates by typing. And that got me in the general field of disability, and from there, I went into the family support field. I was just cooking along fine, looking only at families who were raising children with disabilities, until about 20 years ago when I got approached around a situation of a mother with mild intellectual disabilities who was losing the custody of her son. And I got called in kind of out of blue on that situation, and got to know the mother. I ended up, in the end, as guardian for her son for the next six years.

You know, the way we kind of stumble into things. And the reason that I ended up as guardian for her son, was that her parental rights were clearly going to be terminated, but she asked me if I would be guardian so that she wouldn't lose contact with him. And he's now in his mid-30s, and they still have contact together, but from that one small situation, I got connected to the disability lawyers in Vermont to the protection and advocacy and the Disability Law Project and started getting called in on more and more situations.

And I started being asked to do assessments and realized that I had to learn to do them right. And I will talk later, if we have time, about what a good assessment is of a parent with disabilities, in contrast to most of the things that are out there.

But along the way, I also discovered across the country, a small group of people scattered around the country who were trying to address the needs of parents with intellectual disabilities. And gradually, we began to meet each other at conferences, and then we began to have our own conferences. And the more that we talked with each other, the more we discovered that there was a need for an organization to begin to move things forward and we created the organization known as The Association for Successful parenting. And that group is focused primarily on parents with intellectual disabilities and learning difficulties, but we recognize that in order to do anything significant in advocacy, we really need to work cross disability.

And the more that I began to talk about what the issues that are parents with intellectual disabilities face, the more that other people chime to say, yes, but that's the same for all parents with disabilities. So we created this organization, and it's a very committed group of people that includes lawyers. It includes social workers. And the lawyers and the social workers often fight with each other. And it includes people who run programs, you know, little scattered programs across the country. It includes researchers that give us information on what the latest research is, which then informs the kind of testimony that we can give in court. It includes psychologists who do the assessments and we're working very hard to make sure those are good assessments.

And more than anything else, we never do anything without parents themselves, that both on our board and in terms of presentations that we do, we believe that it's extremely important to have the voice of parent prominent. And we became a nonprofit organization in 2009. And have held five or six different international conferences. We have members right now from more than 30 states and three -- no, four countries. And we try to work as much as possible as I say, specifically for parents with intellectual disabilities, but when it comes to moving the agenda forward, we recognize we have got to be cross disability.

And I'm -- I'm honored to be a member of the SILC -- or the NCIL parenting task force, and I have also -- this is my sixth year as a member of our state's SILC in Vermont.

I think I will let other people talk and then talk a little more later about the myths that are out there around parents. The myths, particularly in the child welfare system.

>> SARAH LAUNDERVILLE: Thanks, Susan! And I really appreciate you connecting all of these groups together within our movement. And I'm just super lucky to live in a state where we can access Susan around assessments to help us support parents with disabilities within our center.



So next, I would like to invite Kimberly Tissot who is a champion on our task force and what have you been working on, around reproductive assistance and adoption.

>> KIMBERLY TISSOT: All right, great! Great! My name is Kimberly Tissot and I'm the executive director for ABLE, South Carolina, which is located in South Carolina, obviously, and we serve approximately half the state. We serve 23 counties.

Let me tell you a little bit about my personal story. I am a woman with a physical disability, and I had had some fertility issues due to the side effects of chemotherapy and radiation. So my journey to parenthood started trying to, first, try to do in vitro fertilization, through reproductive specialists and the fight during that process was unbelievable! Just being able to be examined and being able to really get a full assessment of my situation and how -- and how and if I could even get pregnant.

So that was -- that took probably about six different clinics and six different specialists to try to find somebody that would be able to see me and give me some answers. We ended up getting -- being very successful with that piece. Not through pregnancy, but tried to also use surrogacy, and that was a little bit of a complicated situation but we did have a very close friend who was willing to do it. So we had an egg donation, and went through it. Unfortunately that all failed. I was destined and wanted to be a mother. So I decided that we were going to adopt.

I went to the Department of Social Services. We did all the applications to adopt, and when my husband and I went to go sit down to finally adopt, they said, you are not allowed to adopt because you have a physical disability.

Well, at the time, I was actually working for Protection and Advocacy. So they told -- they said that to the right people. So I was able to obviously fight for my rights, but, you know, I always think about that story of what happened if I did not know my rights and just walked out? I would not be a mother because shortly after that whole situation, I think my advocacy efforts really contributed to getting a placement immediately to be able to adopt. We actually got our son through the foster care system at six weeks. And that's not -- that's not very common. But I now have a 7-year-old little boy, and we did adopt him through a lot of fight and struggle with the Department of Social Services, but at the end, it worked.

So as a Center for Independent Living, what we have done is we have really looked at some of the systems change around parenting and South Carolina and the "Rocking the Cradle" report, South Carolina was throughout as having issues. Our child welfare law actually said that a person with a mental deficiency, mental illness or extreme physical incapacity -- or had a physical incapacity could actually have their child removed and their rights terminated. And so that's just on the basis of disability.

So we definitely wanted to do something to change that law, and to just change the system overall in South Carolina. So what we ended up doing, our organization, our

Center for Independent Living, little old us, we ended up writing legislation and having it introduced. And we had it introduced in 2015, and we started in the House. And it passed all the way through. There were some questions about people with mental illness and that kept being the theme of the topic, when we were talking with legislators.

And -- and this -- in 2015, that piece of legislation, let me just go back a little bit, was very, very broad. It includes child welfare, foster care, reproductive health, it was very, very broad. What ended up happening with the legislation, it ended up dying with the Senate. We said, let's regroup and get with some partners to help write this legislation and making sure that we had allies when we were going to the hearings.

And so we ended up partnering with Protection Advocacy and Department of Social Services, believe it or not, to be able to craft a piece of legislation to call the persons with disabilities right to parent act to be able to get introduced. Well, of course, sitting down with Protection and Advocacy and the Department of Social Services, P&A was on our side, but the Department of Social Services, they thought that they really needed to continue keeping that language of mental deficiency and extreme physical incapacity in the legislation.

So we, at the end of the day, we could not agree on the piece of that we created together, but our organization ended up getting it introduced anyways with the Department of Social Services not agreeing.

So it got introduced into -- we had -- it actually introduced in the House and the Senate both at the same time. While it was in the House the Department of Social Services was supporting the bill, with the exception of TPR and removal, because they wanted to keep those disabilities in. During one of the hearing, of the legislator that introduced the bill pulled them aside and said you are violating the Americans with Disabilities Act and so we had to convince the Department of Social Services to get on our side. That -- later that afternoon, of that hearing, the Department of Social Services called my cell phone and said, Kimberly, we will go ahead and we are supporting this piece of legislation.

And so I ended up having the Department of Social Services lobbying for this bill as well. But luckily, the bill ended up passing in May of 2007, and it's called "The Persons with Disabilities Right to Parent Act" and it is a very progressive bill and especially for South Carolina. We removed all disability being a reason for termination of parental rights or removal, and it covers child welfare. So all aspects, including foster care and adoption. It covers the family court system, the removal process. So pretty much everything.

And my favorite part of the piece of legislation is we have something in all of the sections regarding child welfare of the department or any other covered entity must not terminate the rights or remove the rights of a parent or legal guardian with a disability solely on the basis of disability. So that really got us covered. We also have information about -- we also have something about that the department must comply with the ADA and Rehab Act. It's a very progressive law and we are very proud of it. And so now

our job is to make sure that it's being used and being enforced.

So we have been working very closely with the Department of Social Services and -- and with changing their actual policies and procedures and their training. So not only are we involved, so the Center for Independent Living is involved. Persons with disabilities are involved in creating with the Department of Social Services involved, but we are going and training their new staff members as they get them and their current ones to make sure that they are understanding how to work with parents with disabilities.

So I'm sure we will talk more about that in a little bit.

>> SARAH LAUNDERVILLE: Awesome. Thank you so much, Kimberly. Your story is -- I'm always so impressed with you. Your story is so impactful. What if you didn't know what your rights were? You already were an advocate and knew this. I think that's what drives the work of our task force, because so many people within our IL network still don't have this information and they do give up on this, either dream or goal or whatever of being a parent. So that's really impressive.

And I also love your connection to the Protection and Advocacy to help support you as you led the charge in this. I'm so proud that your center led the charge to change the law and you did it cross disability. As a woman with a psychiatric disability and a parent, I appreciate that because sometimes as we all know, through legislation, some disabilities kind of get thrown under the bus for the sort of this greater good, and I think you should be really proud that you stuck with it and did it in a way that was really representative of our IL movement. That's awesome.

Next, I would like to invite Kara Ayers and tell us about your adoption experiences that you have had.

>> KARA AYERS: I'm so professional, I'm the associate director at the University of Cincinnati Center for Excellence and Developmental Disabilities. And today I also, in the room with me as part of our lend program we have a seminar on evidence-based medicine this year, dedicated to the disabled parenting project to which I'm a cofounder and so we have our SCBM team. This time coincided with the time when we work on this project. So in addition to cofounding the disabled parenting project, I also sit with Susan and others I'm sure on this call on TASP, on the board. And just recently, I became a consultant for the national center for parents -- National Research Center for Parents with Disabilities.

So that's kind of my professional stake in this, but personally, yes, I'm a parent of three. I have a 10-year-old son, Eli; a 7-year-old daughter Hannah; and a new 6-month-old Riley. And so Eli was adopted after my daughter Hannah. So we went a little bit out of order from China. And I have a physical disability. I have an osteogenesis imperfecta and I use a wheelchair full time, as does my husband. We knew that several -- we're connected to the community, little people of America and we knew of several couples

where both couples had different forms of dwarfism and had adopted but we were not aware of any couples where both parents were in wheelchairs that had adopted from China. Culturally, that's viewed as a different kind of severity of disability.

So we embarked on that process kind of knowing that we couldn't -- we knew how to fight for our rights through the American system but we knew it would take some cultural negotiations and patience to do that but we were able to figure out how to do that successfully. We adopted him. It took about a year which is average, or typical, and we brought him home in 2014 and since then, I have been able to kind of provide peer mentorship to some other parents with disabilities.

I haven't yet come across or been asked to support a couple like us, where both parents have disabilities and use wheelchairs but I definitely have been able to help other parents where one parent may use a wheelchair, everything from a travel aspect of going to China to actually adopt your child, but we found that before that, it was important to really emphasize the strength of what we can bring to the table as parents with disabilities, and that's also what I focus on as a researcher in terms of looking at it, from a strength-based approach and that there are specific aspects of the experience of having a disability that if we look at those, and we talk about those, that they bring a specific strength to the table as a parent. So that's kind of my experience and I'm excited about the call today.

>> SARAH LAUNDERVILLE: Thanks so much, Kara. Thank you so much. I was on mute. Thank you for giving us the perspective of adopting from another country.

I would like to ask Nancy Brieden to introduce herself and tell us about a situation that is going on within the Vermont Disability Law Project.

Nancy, are you with us? We can't hear you.

>> I will check on that at my end, Sarah. While we are looking at, that I wanted to remind folks that while we are going, please do press star two, if you have any questions and we can start to get you lined up, and then when we break for questions, we can know who is ready.

So I will let you go ahead and finish in and I will see how we can get Nancy patched in.

>> SARAH LAUNDERVILLE: Awesome. So we'll move on a little bit.

One of the issues we talked about at our task force meetings are issues around separation and divorce and what happens around parenting. And, I want to open it up to nip who is on our panel, but maybe Susan, if you want to start us off, that would be great.

>> SUSAN YUAN: Am I off mute?

>> SARAH LAUNDERVILLE: You are off mute.

>> SUSAN YUAN: Okay. Well, one of the issues around separation and divorce is that while when a parent has a child in custody through the child welfare system, there's automatically going to be legal representation provided. Now, the quality of that representation varies dramatically. Sort of with the lawyer that you end up with, but I have seen some incredible lawyers that were assigned to work with parents at no cost, who did beautiful jobs and I have seen others that didn't pay much attention to the case.

But when somebody is going through a divorce or separation, there's no lawyer provided for the parent with a disability, and most parents with disabilities, or I would say many parents with disabilities, don't have the assets to be able to go and hire lawyers to represent them. So for a start, one of the things that needs to be addressed is trying to get them connected to pro bono lawyers who will take this on. I was involved with a situation in Vermont, where a mother had a public guardian and usually, you know, we wrestle around guardianship issues but this was a wonderful public guardian and she scoured the state until she found a pro bono lawyer who would take on representing this mother in a custody battle with her ex-husband. And it ended up very successful, even though the mother did have a documented intellectual disability, and even had a guardian herself. But the pro bono lawyer was able to argue for her.

But very often, there's just the same assumption in the courts as there is with regard to custody issues with child protection, that the disability is going to get in the way of parenting. And that's, once again, where getting good parenting assessments is extremely important, and I know that Through The Looking Glass, which was the National Center for Parents with Disabilities, up until about a year ago, but they had a lot of assistance that they would offer around assessment of the needs of parents, particularly with physical disabilities, for accommodations.

And if you can begin to get a good assessment that says, look, if you have this, this, and this in place, the parent can be successful, that will begin to stand up in court.

So the issue of assessment, with parents with intellectual disabilities, it's even more difficult around issues of assessment, both in divorce court, and with child welfare, because people still throw around IQ measurements as something that's relevant to parenting. And we have been able to go in now -- we have enough research accumulated through TASP, that we're able to go in and basically testify that there's no reliable correlation between IQ and parenting skill, until the parenting skill is between -- the parenting IQ is between 50 and 60.

So a parent with any kind of an IQ can be a bad parent. You have an IQ of 160 and be a lousy parent, but there's no reliable correlation between IQ and parenting, until the IQ is a lot lower than most of the parents that are involved with intellectual disabilities. So just trying to find the research to back that up and trying to get good assessments.

And I want to say something about the power of assessments. There was a case in 2015 in Massachusetts, it was called the Sarah Gordon case and, of course, that's a pseudonym to try to hide people's identity and give a little privacy, but it was a case where a parent with an intellectual disability was denied the right to raise her daughter, even though she had a good support system in place.

And because we had been working on this issue of assessment for quite a long time, and we had good training from Maurice Feldman of Canada who has done a lot around parenting assessment, Dr. Nicole Brisson who is also from the lovely state of Vermont, was able to testify in that Massachusetts case, which was in the midst of a complaint with the office of civil rights, of Health and Human Services, and the Department of Justice.

And the Department of Justice and the Office of Civil Rights, through that case, found that discrimination had occurred. And it became a landmark case that really extended the power of the ADA much more over parenting than had it before. And following that decision, then TASP worked with the office of civil rights and the Department of Justice, to come up with guidelines for child welfare agencies that were also put out in 2015. And if you want to find these things, and you are willing to dig a little in a website that still needs work, the TASP -- the organization TASP has a website called [www.achancetoparent.net](http://www.achancetoparent.net), and we have those decisions and we have the guidance to child welfare agencies available on that website, as well as a lot of other information.

Do we toss it back to other people and then I'll come back on other situations?

>> SARAH LAUNDERVILLE: Yes thank you, Susan. You talked about the importance of assessments. Where can people throughout the country go to access services like assessments if they wanted to?

>> SUSAN YUAN: Well, I would say that parents with physical disabilities should still contact Through the Looking Glass. I believe it's [www.lookingglass.com](http://www.lookingglass.com), but you can find it easily by googling Through the Looking Glass.

And they have worked with many Independent Living Centers. So this should not be a new resource, because they were -- they have been there since the -- since the 1980s, and they have been accumulating that expertise in how to do appropriate accommodations and also how to do appropriate assessments.

If you are interested in finding out more about assessments for parents with intellectual disabilities -- and we are also doing some assessments around parents with mental health issues, as well as traumatic brain injury, you can contact me at [syuan@uvm.edu](mailto:syuan@uvm.edu), or through TASP, the Association for Successful Parenting, and we can link you to -- there only have been a handful of people really trained to do these accommodated parenting skills assessments, but we know who they are and we can try to link you with

them. I know Nicole Brisson is going all over the country doing assessments right now.

>> SARAH LAUNDERVILLE: Great. Thanks so much, Susan.

Any of our panelists want to weigh in on divorce and separation stories and how you are working around those issues in your centers?

>> KIMBERLY TISSOT: This is Kimberly, with ABLE South Carolina again. So something that we have taken on is we are really making sure that there are no more horror stories, so there's no one being turned away. So that we are making sure that people -- all of our consumers are aware of not only their rights but also their parenting rights. I have think this is a topic that folks reason really used to hearing. They are not used to hearing about family planning or any of that. And so even with all of the five core services, parenting can be a huge piece of that. So just building up those skills so that, you know, discrimination isn't occurring, and that could happen with family planning and divorce and all of that.

So that's something that we have been just doing.

>> SARAH LAUNDERVILLE: Awesome. Thanks so much. Anybody else around divorce, separation, that they wanted to weigh in on our panel? Great.

I do see that Nancy is on the call. I just want to see if she's unmuted at this point.

>> NANCY BRIEDEN: Hi, can you hear me?

>> SARAH LAUNDERVILLE: I can! Thank you so much. Can you introduce yourself and tell us about the work that you are doing at the Vermont Disability Law protect?

>> NANCY BRIEDEN: Sure. My name is Nancy Brieden, I'm the director of the Disability Law Project which is a special project within Vermont legal aid. We are not protection and advocacy agency in Vermont, but we do subcontract with disability rights Vermont which is the designated protection and advocacy agency to do a good deal of the protection and advocacy work.

We have four attorneys statewide and we provide representation to people with disabilities in a variety of legal matters.

One the things we do do, we worked with Susan and Nicky Brisson. Sometimes we cocounsel with the attorneys who are assigned to represent parents and termination proceedings and work with that attorney to either get needed accommodations in the court or get an accommodated evaluation or just raise whatever disability-based discrimination issues we might see in the case.

We are currently involved in a case where Nicky Brisson did do the evaluation. The

case is going to hearing next Tuesday and involves a young woman with an intellectual disability who -- whose parents have unofficially taken custody of her 3-year-old daughter. And filed a petition to get guardianship over that daughter and our client does not want her parents to have guardianship over her daughter, and so we are representing her in trying to defeat that petition for guardianship so that she can maintain full guardianship of her child.

So Dr. Brisson did a great evaluation. We are going to hearing on Tuesday and hopefully, we get a good outcome.

Sarah asked me to speak about another case that we were involved in, in Vermont, and this case involved a state termination of parental rights, for a mother, of her two children, the case -- we did not get involved in the case at the trial level. We were asked to come in and submit a friend of the court brief in an appeal of the termination case in the Vermont Supreme Court. But to go back to the facts of the case, the mother was somebody with a significant hearing impairment, and one of the children also had a hearing impairment, and interestingly guardian ad litem who was representing the children in the child also had a hearing impairment.

So early on in the proceeding, the attorney for mother let the trial court judge know that mother had a significant hearing impairment, and that they would need to be using these assisted listening devices, which I think most courts have these days. And it appeared from the record that throughout the -- in the parental state termination proceeding, they go on for years and you think that this case -- I think it was maybe three years of different court hearings over the course of three years. And from the record, it was clear that the assistive listening devices were not consistently used.

And it appeared also that when it was drawn to the court's attention in the context of any particular hearing, that the listening device hadn't been employed or engaged, the judge would turn around and say to the parent, well, you know, what's your problem? Why don't you speak up? Say something. Be assertive if the device is not on or if it's not working. And -- which is not the way it should be. There's an extreme imbalance of power in the courtroom, and it's really putting a great deal of -- a great deal of burden on this mother, to speak up and interrupt a court proceeding and say, Your Honor, I can't hear anything.

Her attorney should have asserted that, and that's a problem that the attorney didn't do that.

At another point, the court instructed the attorney and her client, the woman who was hard of hearing to use the microphone at counsel table to be able to communicate for the attorney to talk with the parent or the mother, because somehow the other device wasn't working.

And the attorney pointed out, well, if she was using this microphone to communicate



with her client, what she -- the attorney was saying was being broadcast throughout the courtroom, and, in fact, recorded, and, that would be contrary to the guarantee of confidential communication between an attorney and a client.

And the judge at that point, just said, well, you can have your privilege to confidential information or you can hear what's being said. But you can't have both. Which was a pretty outrageous comment from the judge.

So these problems with the equipment not being engaged happened through the three years of hearings. I think there were 17 hearings in all.

At the end, the parent lost custody or lost her parental rights based on the fact that mother didn't show up on time for the final merits hearing on the case, the final trial on the case that was scheduled for a three-day hearing and apparently mother had been confused because she hadn't really been able to hear very well. She was confused about what day the hearing was going to start. She wasn't there. She wasn't there kind of half hour beyond the start time and the attorney asked the court hold off on proceeding. And the court said, well, try to get in touch with your client and the attorney was able to get in touch with the client and mother said, you know, I didn't know it was today. I'm on my way. I can be in the court in half an hour.

And the judge said, too bad. We're going to go ahead and held the hearing without mother and issued an order terminating mother's right. That's the case that went up to appeal at the Vermont Supreme Court. We filed a friend of the court brief outlining all the violation of the mother's right under the Americans with Disabilities Act and that she had not been provided with needed accommodations in the proceeding.

Interestingly enough, at the time of the oral argument in the case, right before the oral argument, the chief justice of the Supreme Court, sent out a memo to all the judges, that he has a hearing loss and he used the assistive listening device in court hearings and he wanted to make sure that it was okay with the attorneys that he would sit on the case.

The case proceeded and the day of the oral argument came, and one of the attorneys was starting her argument and a few minutes into the argument, the chief justice leaned forward and tapped on the microphone in front of him, up on this high, you know, bench where they are sitting and said, is this device working? I can't hear anything!

So it was somewhat ironic that he was being subject to the same situation that this parent had been subjected to.

The court ended up overturning the termination of parental rights not on the basis of the failure to accommodate. The court actually refused to hear arguments on that issue for a technical reason. But it did overturn the parental rights termination. And so mother retained custody of her children.

And while we had put a tremendous amount of work into this case, it's not all been lost. We are planning to meet with the court administrator's office to point out the problems that were happening in this case, and I'm sure happening in other cases with courts failing to accommodate whatever the disability a parent may have in a proceeding, especially in a termination of parental rights proceeding.

And we have also met with representatives from the United States Department of Justice on this issue, and we'll be following up with them so it's pretty amazing that this many years after the passage of the Americans with Disabilities Act we are still having to prod judges and courts, other court personnel to make accommodations for parents with disabilities in court proceedings.

So I would be happy to answer any questions that people have about this, but I think that that's all I was going to say.

>> SARAH LAUNDERVILLE: Great. Thank you! And.

>> MARY OLSON: And this is Mary again. I wanted to pop in here for just a couple of things. One is, that you know, we are so happy to have the panel of speakers today, and also, one of the beauties of formats of IL conversations is that we really want some audience participation. So I'm going to throw a couple of questions out there, and hopefully we'll get some folks raising their hand.

And, again to raise your hand, just press star two, and you can join in. But I'm wondering what do folks in the audience want to hear about? So what are your big questions about parenting with a disability? As in, what are some things that you feel like you need to learn more about some what are some things that maybe you are trying at your center? And are having trouble with? And while we are waiting for folks to join the queue with those questions, I had a question for the presenter, just wondering, what are your favorite tools and resources to take home?

So if I'm somebody who wants to learn more about my rights as a parent with a disability or how to help others, what are your top two places? I have one question in the queue as you are thinking about your favorite resources.

Okay, go ahead, caller, your line is open.

>> CALLER: My name is Karla Walker. We collaborate with paraquad Independent Living Center. And as well as Through the Looking Glass and I'm wondering if you all have any new developments on assessment. I know the folks at Through the Looking Glass have been working on the baby care assessment and we have worked with them to help pilot it, but as far as any new measures that you feel are reliable and valid with parents with disabilities and would promote folks doing parenting assessments to utilize?

>> SUSAN YUAN: I will jump in if I can. This is Susan Yuan. I will talk more about parents with intellectual disabilities because I know Through the Looking Glass has the expertise around parents with physical disabilities, and sensory disabilities. But according to the researchers that are part of TASP, there are no parenting -- there's no assessments -- there are no tools that are normed on parents with intellectual disabilities.

So when we do our assessments, we look at -- we may look at some instruments that we use, like, for instance, if somebody has said that the parent is under great stress or they are worried that the parent handle stress. Then we might do the parent stress index. But recognize that in many cases, we are doing it with parents that don't have their children with them. So they are not really in the real situation where they are dealing with their kids on a day-to-day basis. So even the results that we find on that, even if they were valid, even if they had been normed on parents with intellectual disabilities, they still may not be valid.

But we will use things like that. There's a term -- there's another instrument, called the parenting awareness skills survey that actually focuses on knowledge about parenting. And that has a number of scenarios that cross the age range from infancy up through teenage years, and there are 18 scenarios and you tell the parent, for instance, one is your 5-year-old has a tantrum in the grocery store. What do you do?

What do you say?

You know, they are very typical scenarios. And we use that -- we don't score it, because, for instance, apartments with intellectual disabilities tend to give fairly short answers. And if the answer is short, it doesn't score well, according to the chart that we are supposed to use to score it.

But we use it to raise hypotheses in our minds. All right? Maybe that parent doesn't understand the different stages of development. That might be a hypothesis that we get. The largest part of our assessments are direct observation. That we spend at least four hours in the home and in the community with the parent and the children. Just observing what they do. It's not so much what they say, or what the instruments say about them, but it's what we actually observe in their parenting. And we try to look for things like problem-solving skills. We try to look at the way that the parents interact with the children and that's what we base most of our assessments on rather than tools. And we don't advocate the use of projective tests.

Because projective tests, things like Rorschach tests that are often used in assessments, they are not measuring parenting skill. We want to look for something that measures parenting ability. We might look at the home inventory which does look at the environment. So we might look at something like that.

We stay away from personally tests and we focus on what we can observe of parenting.

>> KIMBERLY TISSOT: This is Kimberly. We like to focus too -- I was just going back to the Americans with Disabilities Act, the basic requirement is that any covered entity, evaluates a person with a disability on an individualized basis. So sometimes those tools are not going to capture some of the -- some of the needs from an individual. So, I mean, it definitely needs to be individualized and observation and just like Susan said, just observing and seeing what works and what doesn't, and really brainstorming and coming up with solutions.

>> KELLY BUCKLAND: This is Kelly too. In the legislation that we did in Idaho and I think that's in the report too, really recommend that these -- whenever -- if a study is done or the observation or whatever, is done on parenting it needs to be done by someone who has experience, and knowledge on parenting with a disability.

>> SARAH LAUNDERVILLE: Kelly were you done?

>> KELLY BUCKLAND: Yes.

>> SARAH LAUNDERVILLE: Sorry, it just kind of cut out. I wanted to make sure we didn't lose you.

>> MARY OLSON: Does anybody else have any thoughts on that question? Before we move on to the next one?

>> SUSAN YUAN: Yeah, this is Susan again. For parents with intellectual disabilities, there's a book out by Dr. Maurice Feldman, from Canada, and I think his coauthor is Marjorie Aunos, and it's called "Competency Based Parenting Skills Assessment."

And it really laid out the entire philosophy of how you appropriately assess someone with a disability, and the fact that you have to have knowledge of disability to start with. And that's in the APA guidelines too. That parenting assessments should be done by somebody with disability experience. But it's very rare that that's the case.

>> MARY OLSON: Thank you. We do have -- if you don't mind, we might move along.

>> We have some thoughts from our captioning audience. I have one that says I'm a wheelchair user, and I had an accident with when I was 17. I'm a father to be with my fiancée, but I keep thinking about how I will be able to be a good father for the child, especially when it will be an infant. I have limited use of my hands, but I would not like to miss the care for my child, because of that.

My fiancée is very supportive and tries to figure out ways to make it and find creative solutions. I'm wondering if you know of any organizations or other resources that you can provide that can help in order to find out how to safely help raising the child.

>> KARA AYERS: I can chime in related to the disabled parenting project. We found that the most knowledge was within our disability community. And so the disabled parenting project is that disabledparenting.com, and this' a Facebook page, where people like to most more specific questions, to how there's some great threads about carrying the infants and the carrying methods, they change. I know this as a mom to a 6-month-old. The way that I carried her in my chair as a newborn has changed in the last six months. And now that she has head control, we have different options with carriers and things like that. You will find some videos that actually have parents with disabilities demonstrating certain -- not only products but certain ways that people have found to use products that almost all of them are just typical parenting gear that people have adapted for their own needs and uses.

And I think parents with disabilities have really benefited from the fact that the parenting market in general has exploded. So there are many more kind of gadgets and tools and different carriers and things like that. We would love to have -- I think we are especially in need to hear more fathers with disabilities. We hope this individual will hop on.

>> KELLY BUCKLAND: Yes, this is Kelly too. I'm a quadriplegic and I just think that what she just said is exactly right. Like, you really do need to talk to other people and peers and I think if you surf the web and go to parenting project, you will find a lot of resources of other people parenting. I would start off, really, congratulations. Your entire life is going to change. Everything you do is going to be different from now on. I think every parent on the phone can relate to that.

But the amount of time that you are -- that your children are in the infant stage, it goes by way too fast. So really appreciate it, and be as involved as you can be, and really enjoy the time while you can. Because it goes by too quickly. Before you know it, they will be crawling up in your lap, and they are the ones that will be taking control over when -- when they are with you and that kind of stuff.

So really enjoy the time they are an infant.

>> KIMBERLY TISSOT: And this is Kimberly. I want to make a note that it's so easy to adapt to parenting. And I think any parent with or without a disability, there's always those concerns about being a good parent or not. And so it's no different in the disability community. We just -- you know, it's just all about adapting and figuring out what's really going to work for you and trying out things. And, you know, babies are scary, but you can -- you can figure out the best way to hold a child or to bond with a child, and it's just -- it's through trial and error a lot of times. And that's okay. I think that's every parent. Every parent goes through that.

>> SARAH LAUNDERVILLE: This is Sarah.

>> KELLY BUCKLAND: I really would echo that and, you know, when I first became a

parent, my sister told me -- gave me some of the best advice, I think I ever got, and that was, you just spend a lot of time with your children, and the rest of it comes kind of naturally.

>> SARAH LAUNDERVILLE: Great. This is Sarah. I have think the other thing is, first of all, congratulations. And to broaden this a little bit to what centers can do, at our Center for Independent Living, we have a grant program where folks can access up to \$1,500 for assistive technology. Yet, at the top of the list always is assistive technology for folks who are becoming parents and -- or parents. Because we found, that you know, back years and years ago, when people's parental rights were being term, we wanted to come up with a solution. Some people's parental rights were terminated and case managers were saying they couldn't do parenting because they didn't have baby cry signals. We think it's important for people to get the equipment that they might need. I would encourage centers if you don't do programs like that or connect with other places that can help people get access to that type of equipment, so they can continue to parent.

>> MARY OLSON: I do have one more question from the chatroom. Earlier we were talking about some different bills and legislation, and they were wondering if you could give us more information on the bill numbers or names so they could read them on their own. And before you answer, I want to mention that -- gosh, I'm not going to say your name right. The person who asked the question, Kyriakos, says thank you very much for all the helpful information. And I will make sure I make good use of it.

So, yeah, if you don't mind -- Kelly, or whoever was speaking about the bills. If you could tell us a little bit more about the bill numbers and names, so folks could look them up, or we could make -- promise to have those up on the archives.

>> KELLY BUCKLAND: Yeah. Give me just a minute, I will pull mine up.

>> MARY OLSON: Perfect! And, again, if you have any questions from the phone lines, you can press star two and that raises your hand and we can make them live.

But while Kelly is looking that up, that's all the questions that I have for right now. I will turn it back over to you, Sarah.

>> SARAH LAUNDERVILLE: Thank you so much. So, yeah, one of the issues that comes up in our task force and it kind of goes hand in hand with what centers can do, what SILCs can do around these issues. But before I get to that, maybe Kimberly, if you could talk and anyone else on the panel around guardianship issues that you see within the centers for independent living. That's something that we talked about on our committee.

>> KIMBERLY TISSOT: Yes, yes. We see this as far as guardianship with a person with an intellectual disability. We see this a lot that assumptions for intellectual

disabilities can't make decisions or care for themselves. That's the exactly opposite for what a Centers for Independent Living believe. They should be very much against any type of guardianship situations as that is not consumer control at all.

And so we have actually seen this some in parenting as well. We have worked with a young woman in our state, that has Down's Syndrome, and unfortunately, due to rape, she did become a mother. And her rights were very much violated in the very beginning, as her child was removed from her without even -- she was not even given an opportunity to parent.

But one of the situations that did come up was that she did have guardianship. So that was something that we actually worked with her on, and were making sure we are going back and reversing that because it's very difficult to be a parent and have guardianship.

So that's -- and I will leave you -- if you are going to the APRIL conference too, there will be a conference about supportive decision making, versus guardianship at that conference. And that's going to be really important for all centers to start learning that language of supported decision making and discouraging any type of guardianship because that strips somebody's rights away.

>> SUSAN YUAN: And this is Susan speaking up, just with -- you know when you have been battling around this field long enough, you really hear some stories that just make you cringe.

A situation with a woman who had an intellectual disability, whose parents were her guardians. She wanted very much to get married and she wanted very much to become a parent. And her parents finally said that the only way they would give her permission to marry was if her fiance would have a vasectomy. So once again, the rights of people to reproduction just aren't compatible with someone else making the decisions.

And there are so many other alternatives to guardianship out there that should be explored when people are at a point that they want to become parents.

>> SARAH LAUNDERVILLE: Thank you, Susan.

>> KELLY BUCKLAND: This is Kelly, I have the bills up. So if you look at the Idaho legislative web page, the two first bills passed in 2002. So you would go to the 2002 session of the Idaho legislature, and they are House bill 577 and House bill 579.

And then the following year, 2003 legislative session, was House Bill 160 and House Bill 167. If you look 'em up -- I have actually gone and done this. It's easy to go to the web page and find those sessions and the bills and you can pull them right up, and read all of the legislative language that's in there.

I'm not sure -- I don't remember if "Rocking the Cradle" report included the Idaho bills themselves but they certainly represented the Idaho laws a lot, kind of held them up as the gold standard.

And remember, at the beginning when I gave my presentation about the NCD, I requested that they put model legislation in it, and they did do that, and so there's model legislation in that report too. I would really highly encourage you to look at that because it -- addresses some of the issues that we didn't think about in the Idaho legislation, like Kimberly was talking about, reproductive technologies. That's not something in the child custody legislation, but it's definitely something that advocates should be thinking about, because before you have children, the first thing is you have to get pregnant.

So -- well, unless you adopt or something, but that's the same -- but we did cover that in the legislation, but the reproductive technology stuff is really important. So look at that too.

And then Mary, your question -- if it's not too early, your question about somebody who is not aware of their rights and the best resource to go to, I really do think that the -- there was a joint letter published by the Department of Justice and the Department of Health and Human Services that talk about states obligations under the Americans with Disabilities Act. And I think that's really a good letter and really does bring into focus that even if your state legislation says awful stuff, like Idaho's did and like South Carolina's did, there is federal law that requires that courts not discriminate against people, judges not discriminate against people with disabilities and the social services system can't discriminate against people with disabilities under 504, under the ADA. And so there are federal laws out there to protect us and I think the letter does a good job of bringing that into focus. I think it could have been better but I think it does a good job. So I would throw that out as my favorite resource.

>> KIMBERLY TISSOT: And this is Kimberly. Our bill is House Bill 3538 and it's called "The Persons with Disabilities Right to Parent Act" and just going off of Kelly too, we -- I mean, the -- the HHS and the Department of Justice technical assistance was key to passing this legislation, as well as the "Rocking the Cradle" report and the American Bar Association's resolution that they did.

We actually contacted the American Bar Association shortly after they sent out their resolution and they were able to not only write a letter of support for our piece of legislation, but was also able to send somebody to testify on behalf of the American Bar Association in support of parents with disabilities. So they were very much key to also passing our legislation, and just working with all of these -- you know, your colleagues in the field that are pushing disability rights, just start working with everyone to make systems change.

>> SUSAN YUAN: And this is Susan. Once again, the resources that have just been mentioned, the letter from the American Bar Association, and the guidance from the



Office of Civil Rights and the Department of Justice, as well as that decision in Massachusetts that really started the -- this strengthening of the ADA, that's all available, as I said before, on our website, [www.achancetoparent.net](http://www.achancetoparent.net). And it's not the world's greatest website. We want to improve it, but if you dig, you can find the stuff on there.

And also, I wanted to say that just in the last week or so, the new National Center for Parents with Disabilities, which is located in Massachusetts, just opened up their new website and I know that you can find -- I was trying to look for the website and I can't find it, but you can find it out by emailing Robyn Powell and her email is [rpowell@brandeis.edu](mailto:rpowell@brandeis.edu). And she has an entire document on there that looks at every single state's legislation. So it would have the numbers of all of the states that have passed bills and it would have a description of the characteristics and it also has information on which states have restrictive legislation.

So it's a brand new resource and I haven't had time to explore that website thoroughly but I can tell you it's good. So I know Robyn would give you the website if you can just email her.

>> SARAH LAUNDERVILLE: And Susan, that website is under Brandeis' website right now. So if people go to the Brandeis' website, it's the National Research Center for Parents with Disabilities. And if you click on parents, it will take you to the table of state legislation.

>> SUSAN YUAN: Great. Great.

>> MARY OLSON: Thank you for sending that. We have added that link that you sent to that table. It's in the chat CART right now.

And we will that to the archives too. So folks can access that.

>> SARAH LAUNDERVILLE: I know we are getting closer to closing, Mary, but I would love to hear just some final thoughts on how CILs and SILCs can be involved around this topic. One thing I would like to highlight, we know when we are working on these issues that people of color and people of same-sex couple this intersectionality around disability but oftentimes are more pressed and having a harder time accessing services or parental rights are being terminated because of that intersectionality. I think it's helpful when you look around how this CIL or SILC can be helpful, to put that in your thoughts around your policies and procedures and how you will really rise up our entire community around these issues.

I wanted to open it up to our panel around final thoughts on how people can be helpful around this topic and -- yeah.

>> SUSAN YUAN: I will jump in very quickly. It's Susan. I would say, try to be as

inclusive as possible in your discussions and go cross disability, because I kind of cringe when I see bills that are very, very narrow that really look at only the needs of one population when you know that the needs cross all the disability populations and there's strength in advocacy together. So that would just be my plea.

>> KELLY BUCKLAND: This is Kelly, I will second that.

>> KIMBERLY TISSOT: And this is Kimberly. Just as far as a center goes, just incorporating the parenting rights in everything that you do, having that, you know -- having that engrained throughout all the core services and also doing a lot of cross training with your staff. We have 33 staff members and that's something that we are work towards to make sure that everyone is an expert in this area so that they can provide more support. Because there's a lot of people out there that -- they want to have children. They may be facing barriers and we want to be that resource for them in our state.

>> MARY OLSON: Sarah, do you I have in final thoughts for us?

>> SARAH LAUNDERVILLE: I do. Just talking about what folks at home can do. I would just say also educate, educate, educate. So, you know, I -- I'm so glad that Sarah came to us with this topic, because it's one that has been tear to me. Well, I'm a relatively new mom. My child is two now, but I also worked in home visiting for the Public Health Department. I wanted to say there are lots of programs out there that are not focused on disability, but everybody supporting parents because parents is hard, like Kimberly said.

But one thing that I really tried to do was go in and educate all the public health nurses and all the public health social workers and really just talking from that social model that, you know, people with disabilities can do everything that all the other parents can. They just need to do it a little bit differently and here's some resources on how you can help, you know, referrals and such. That's the big place to start. Finding some agencies that are already working with parents and go ahead and bring the disability voice to them.

>> KARA AYERS: I would ask that nothing about us without us, and remembering that it's so important to incorporate with disabilities whether it be from research around this topic, to actually our program planning and implementation. Because, you know, we just have so much value that can be mined from the community and so peer support, I think, it can't be emphasized enough, the power that that has. But it's something that people don't realize. You know, we often feel like we are the only ones out there and so youth with disabilities are not necessarily given the same assumption. Sometimes in our society, it comes across that this American dream, which, you know, everybody has their own unique version of the American dream. But if yours include parenting, it can still include that if you are a youth with a disability. So I think from -- from youth all the way through adulthood, that it's important to remember to incorporate the value of our

disability community in every aspect of this.

Thanks.

>> SARAH LAUNDERVILLE: Thanks. I love that! And I actually made a mic live. We have an audience member with some closing comments. Do you have any thought.

>> I'm Shelley Houser. I'm a listener and I'm a parent with a congenital disability. I was born without my hip or right leg and I went on to having three children via C section with my own infertility issues in the beginning. But I just wanted to reach out to all of you, in case you ever have a need. For the last four years I have been honored and blessed to work with Villanova university here on the main line out of Philly where they wrote the first national and now international OB simulation where I teach their nursing students and staff how to transfer me as if I'm a 30-year-old with a newborn, after a C section and we go through this role modeling of how to work with somebody. You know, I carried my children, on my crutches until I could fit the prosthetic that fit around my waist. It was the first of its kind in the nation. And they found it to be useful. If anybody ever has that need, that they want me to talk to other physicians across the country and do a Skype, working here at the CIL, it is completely what we do, you know, to educate the staff.

When I had my first child in '98, nobody knew what to do. When I got pregnant in '97, nobody knew what to do with me. I emailed and Googled and emailed people from all over the world and I pretty much had to be a pioneer and a guinea pig to the whole process and I'm so honored to be able to help other mommies that want to be parents. No matter what their level of amputation or disability is. So if anybody, please feel free to reach out to me if that would help anybody that you work with in your little circles of this wonderful program. So thank you.

>> SARAH LAUNDERVILLE: Thank you so much. That's so wonderful. Is there a way that we can get her contact information through the network?

>> MARY OLSON: I can put it on the little chat bar.

>> SARAH LAUNDERVILLE: Thank you. Perfect!

>> MARY OLSON: And then just one more. I know we are at the end but I want to squeeze it in. Did you have a thought or a comment?

Hello?

Maybe not.

>> Oh.

>> MARY OLSON: Oh, go ahead.

>> I'm sorry. Can you hear me?

>> MARY OLSON: I can.

>> Yes.

>> I was just wondering if there was any, you know, parting words about how to get more involved in the NCIL parenting task force.

>> SARAH LAUNDERVILLE: Sure thing. Thank you for asking that.

(Laughter).

Yes.

>> KELLY BUCKLAND: That was almost like planned it sounded like, wasn't it?

>> SARAH LAUNDERVILLE: I know and it wasn't. That's awesome! So our task force meets the last Monday of every month, at 11:30 eastern standard time. And to join that work, you can contact me, it's at my email address and we will put this out through the contact. It's slaunderville@vcil.org or call me at 800-639-1522 and I'll get you connected with how to join that particular task force.

So we do have a meeting this coming Monday. If you are jazzed up about this please join us. We would love to you have.

>> Great. Thanks!

>> MARY OLSON: Great. Thank you again to all of our presenters and for all of you joining us out there. Please evaluate our conversations on the APRIL website. We will be reaching out to the presenters to gather all the resources they talked about and those will be available along with the transcript and the audio recording on the archive.

And without further ado, I say we're closing out for the last IL Conversation of the year. Thank you all again.

>> KELLY BUCKLAND: Bye everybody.

>> SUSAN YUAN: Bye, thank you.

>> SARAH LAUNDERVILLE: Thank you.

(End of meeting 4:32 p.m. Eastern Time)

