**CIL Strategies for Involving Parents**

**in the Transition Process**

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>> Hello and welcome to the CIL Strategies for Involving Parents in the Transition Process webinar presented by Jayne Chase, Aaron Baier and Stacey Milbern. Today's webinar is being offered by the New Community Opportunity Center at ILRU, a National Training and Technical Assistance Project of ILRU, the Independent Living Research Utilization program in Houston, Texas. This presentation is being funded by the U.S. Department of Education's Rehabilitation Services Administration and no official endorsement of the department should be inferred. Today's presentation is being recorded and will be archived on the ILRU web site for future use. We will break at specific times during today's presentation for the presenter to address your questions. For those of you joining us on the web today you can ask questions about using the text box under the yellow emoticon symbol which is on the right side of your screen. If you are using the captioning today you can ask questions via the captioning screen. Staff will then post your questions in the public chat on the webinar platform. Finally, for those of you on the phone we are periodically check with the operator throughout the presentation for questions. Our presenters will try to get to as many questions as we have time for but keep in mind we will also need to cover the material in the presentation in a timely manner. Any questions that we're not able to address on the webinar today will be responded to off line in a written format sent out to participants. The materials for today's call, including the Powerpoint presentation, was e‑mailed directly to you prior to today's presentation. So, again, if you're participating by telephone you may want to have those materials in hand during the presentation. If you're participating on the web, the Powerpoint slides will display on your monitor. Also, please take a minute to fill out the evaluation form that was included in your materials and which we will display again at the conclusion of today's webinar. It's very quick to complete and it's very important to us to get your feedback regarding this presentation. We really want to know what you think of our presentation today. Before I introduce today's presenters I would like to give you a brief overview how this webinar fits into the big picture of the New Communities National Project.

The purpose of this presentation is to provide specific content on transition issues. It's part of a larger set of activities provided to the IL field and it's designed to assist you in centers to develop self‑sustaining programs that support community alternatives to both institutionalization for individuals of any age and youth transition from school to post‑secondary education, employment and community living.

Some of the project partners include the Utah State University, Center for Persons with Disabilities, which is where I am located, and the National Youth Leadership Network, the presenters today represent them, and you can see a list of other project team members.

What we're hoping you'll learn today from this webinar are the important role and value of parental involvement at key points in the youth transition process, when and how centers can involve parents in a way that maintains consumer self‑determination and best practices and strategies to assist parents with challenging situations through real‑life examples of effective parent/child collaboration through the transition process.

Now I would like to welcome our presenters, Jayne Chase, Aaron Baier and Stacey Milbern and give you a brief bio for each.

Jayne Chase is the mother of three children, Christina, Todd and J. Paul. She became involved in disability issues when J. Paul received the label of autism. She has worked tirelessly for children with disabilities and adults with disabilities in creating welcoming, inclusive communities where everybody belongs. Jayne believes all means all and no one should be excluded from participating in full community life. Jayne has held various positions, including the director of Partners in Policymaking of Alabama, the Alabama Director of Projects Relating to Employment and Assistive Technology, as well as consulted on numerous projects. She collaborated with Auburn University creating a distance learning course for teachers to work with students with disabilities. She is a national advisory board member of Autism NOW as well as an Adult Ally consultant with Reap What You Sow.

Aaron Baier currently serves many roles within independent living and youth movements. He is president of the National Youth Leadership Network Governing Board and coordinates youth transition and work readiness services for Access to Independence of Cortland County Incorporated in New York. Aaron has more than four years of experience in independent living services and advocacy for people with disabilities. Aaron also brings his experience as vice‑chair for the New York State Commission for the Blind and Visually Handicapped, the CBVH, State Rehabilitation Council, YOUTH POWER!, which is NYLN's New York state partner, and other local boards in the specific areas of youth advocacy, policy oversight, peer mentoring counseling, transportation and housing. Aaron is a graduate of State University of New York College at Cortland with a bachelor of science in psychology.

Stacey Milbern, the National Youth Leadership Network's Community Outreach Director, is a powerchair‑roaring activist working in queer and women of color communities. Cofounder of the Disabled Young People's Collective, she has been a youth organizer since high school. She recently moved out of her parents' home in North Carolina to the San Francisco Bay Area. She has been documenting the journey of building an interdependent home in an epistolary BLOG titled To the Other Side of Dreaming. Through To the Other Side of Dreaming friends were able to raise $8,000 to help support Stacey with all the disability‑related cost of moving, attendants, assistive technology, et cetera. She served on the North Carolina Statewide Independent Living Council for years and is excited to get involved in the California disability community.

With that we'll now begin our presentation with Jayne.

>> J. CHASE: Thank you, Jeff. Hello, everybody. I'm happy to be here today talking with all of you. A year ago I didn't know how to pronounce webinar, now here I am participating in one. This is something new for me. But I'm glad to be participating.

I wanted to talk to you first of all about some common perceptions I believe of families in the transition process. These are some things I've heard personally myself, that families don't know and they don't care and they don't have the skills to do this, and really what made them become parents anyway, they're not qualified to be parents, especially parents who happen to have a disability themselves.

Of course, you know, we always know better than they do. These are some things that I personally have heard. I'm sure you all have heard it, too. Making judgments about parents. I was even told one time that my son needed a surrogate mother, and maybe if he had a surrogate mother could do better.

So those are some things that families hear.

Some reasons for these perceptions, ableism, a system of power that favors people marked as able‑bodied and polices those marked as having a disability. I see that a lot in my work.

Ageism, it says people of a certain age are no better, less valuable, less deserving of self‑determination.

Classism and racism.

Presumed incompetence.

And that old paternalism. We know best. We know what's best for you. We know what's best for your son or daughter. You've not gone to school to know what we know. We know best.

These beliefs, I believe, are so pervasive throughout everywhere, and especially when we're transitioning. Part of this transition process.

Then really what is a parent? Or who is a parent? So many times I have seen this that youth ‑‑ kids really don't have a traditional model of a mama and add a daddy and a dog and a cat and all that, sometimes they're devalued or excluded. Now families are so different. There are all sorts of families. Some examples would be biological or adoptive parents or foster parents, so many grandparents are raising their grandchildren now, even great grandparents. Sometimes an older sibling takes this role. Of course, adult allies. So how can we move beyond definition of what is a parent into understanding of what a good support system looks like?

Parents are sometimes ‑‑ the one thing in a kid's life, you know, that we're always there, hopefully, and maybe sometimes that's not a good thing. But parents provide, among other things food and shelter and transportation, medical care. Parents have to learn educational laws. I have included this cite right ‑‑ site right here, Wrightslaw.com. Keeping track of appointments. I think parents always want to support their 81 child's dreams. What does this son or daughter want to do?

So these are changes when I've worked with agencies that I wished myself had happened in our lives, is to take time to know who your customer is. What does this support system look like? I've always thought it was very interesting how we think it's okay to a young man or a young woman with a disability: Where do you live? Or to ask parents: Where does your son live? And we would never, ever ask people such personal questions if there weren't that disability issue involved. We would never go up to someone and say, well, where does your son live? So, I don't know, I wish those things could change. And I wish we could familiarize ourselves with how people choose to live their lives and not be so much up into their personal business and know that in some generations families share one roof and what right do we have, really, to intrude on such personal decisions made by families? And what barriers are in place for families? I know that so many families who English is their second language. We don't have enough interpreters for them to be part of this process. This is a very complex, complicated process for anybody, and especially, most especially, if you're coming to this and you need and interpreter. Even the ideas are new. And do the parents work outside the home? And who are other people providing support? And how does the power play out between the adult and young person and others, and how can we figure out is there harm taking place? Is there abuse? I came up with this what parents wish you knew. Parents often feel, due to past experiences, that they're only asked to participate in meetings or even be present because it's required by law and they don't really feel that their contribution is valued nor listened to. And I wish that you would listen to me. I know better than anyone my son's unique gifts and talents. This is something I always tell parents when I'm working with parents, I can go to school to learn what you know, but there's nowhere for you to go to know what I know. And I know you do this every day, but these concepts are sometimes frightening, and please be patient with me and respect an recognize my feelings.

And independent living is not a place. When I first heard the term "independent living" years ago, it was a scary word because I thought it meant that my son was expected to be totally independent, and I'm not totally independent. You know, I don't do my taxes. I don't do lots of things for myself. I have someone else that does that since ‑‑ things I'm not good at, things I need support in doing. But the term "independent living" is sometimes viewed ‑‑ we say that there ‑‑ that that's where we need to be. It would be unobtainable to certain young people with disabilities and certain young people without disabilities, and their parents, due to the misconception of the word "independent." Talk to me about interdependence. And please know best practices. I have fought for years for my son to be in fully included schools. He has always been part of communities. So don't talk to me about segregated work or living arrangements. That would be almost disrespectful, or it would be disrespectful.

And transition is a rite of passage. Too often students with disabilities, transition is just another artificial word. We don't call it that when kids without disabilities are moving from school to community. We don't say John is transitioning to community. Or John ‑‑ if John does not have disability. I think that word for many people means separate and apart from everybody else. I wish that that transition process could be celebrated. It's a rite of passage. The things my son did when he exited high school, we had parties, we celebrated. Those were rite of passages for him, as they were for his brother and sister. And I'm not grieving because of my son's disability. People have told me, you need to get through the grieving process, and I wanted to ‑‑ well, as we say in the south, stomp their guts out. I love my son. I don't grieve because he has a disability. And I don't like people telling me that or suggesting that I would be.

Okay. This is the end of my part. I'll welcome any questions, and I will try to answer them to the best of my ability.

>> Thank you, Jane. We'll now break for our first question and answer segment. Let's start by addressing some of the questions posted by participants on the web. If again you want to post a question, go over below the yellow emoticon in that box and you can type in your question. While we're waiting for those, let's check with the operator, Ryan, to see if there are any questions from participants on the phone.

>> Again, if you have questions, please press star 1 at this time.

>> Okay.

>> Holding for questions.

>> Thank you, Ryan. If you'll interrupt me if there are questions that come in. I don't see any questions at this point on the web for Jayne. Are there any questions on the phone?

>> Currently not showing any questions.

>> Okay. Thank you. I think what we'll go ahead and do then is ‑‑ actually here's our first question, so let me read that for you, Jayne.

In your opinion, at what age do you think transition should begin?

>> J. CHASE: In my opinion, I believe transition should begin at a very early age, certainly no older than 14. Transition ‑‑ that word, again, could mean lots of different things, but as we work with kids who don't have disabilities and they're allowed to explore different things, you know, like possible career choices, we should be doing the same for kids who have disabilities. Some people that really helped me and my son when he was younger was we had a great vocational rehabilitation counselor. I know they get a bad rap sometimes, but she was very helpful to me, and my son wanted to attend college, and she was the one suggested he start with one class, and so many just really common‑sense type things like that that were very, very helpful. But I don't believe it's ever too late or ever too late to begin talking about being part of community.

>> Thank you, Jayne. The next question we have for you:

What would you suggest to motivate parents who are not as actively involved with their son or daughter?

>> J. CHASE: I'm not sure that some parents have ever been given permission to be actively involved with their sons and daughters. I know parents who ‑‑ it comes to mind of a story of one mother in particular. She had no, as we say, formal education, but she had so much wisdom and had a Ph.D. in life but she did not feel welcomed or she felt ‑‑ she felt like she was not quite good enough, that people knew more than she did because they had the degree behind their name, and all she was a mother. So I don't know how we can go about bringing and making environments more welcoming for parents so they do feel comfortable in participating in these things. That's an age‑old question. We have to go where they are, though, I know that. Whatever that might mean.

>> Thank you, Jayne. Just a quick comment from somebody else from down south, they like your "stomp their guts out."

>> J. CHASE: Well, my best one is, I don't know how many of you know Comcast but this is kind of an inside joke today, Comcast is my Internet provider, but ‑‑ to their office and disembowel them and drag their entrails up and down the street. That's my best thing we do in the south. But thank you very much.

>> Jayne, one more question, how did you get your son involved in the transition process and make sure his input was included?

>> J. CHASE: Well, I don't know, I didn't come out of the box like this, but I did try to include him or allow him to explore his interest when he was just a little boy, and then that progressed as it did with his brother and sister. He didn't like formal meetings, so we had to kind of figure out ‑‑ get information from him in an informal way. Again, he had a great counselor who would meet with him not sitting around a table but just walking or something like that. And then I also tried to always instill in him he had the right to have his voice heard, for safety reasons, among others. And he had a poster in his room that said "nothing about me without me.." I was hoping he would not want to learn to drive. I'm ashamed to say. But he did. And, I said, are you sure, you know, you really want to learn how to do this? And he pointed to the sign to remind me, that I need to be practicing what I've been preaching so long. So J. Paul has his driver's license. We've always try to support him in ways we did his brother and sister. But sometimes parents are not told these things, see. They're always told they need to be grieving and what their kid can't do, and so, I don't know, I think they just ‑‑ if they could just be around people who could be more positive. And I know I'm talking too much. I'm sorry.

>> That's okay, Jayne. We have just a few more questions. I have a come more questions have that come in.

How would you suggest we strike a balance between what youth want and what their parents want when those things are different? And how do we prevent one or both from checking out of the process in those types of circumstances?

>> J. CHASE: That's a difficult question. I know that comes up a lot. I do believe ‑‑ I've done this presentation before, being the passenger instead of the driver in this road we all take, and sometimes our sons and daughters don't even want us to be a passenger, they don't even want us in the car. So I do believe, though, it's got to start leaning over toward the person, the young person who has the disability. And that's a delicate dance, isn't it, to keep the parent involved where you're not alienating that parent or that parent feel like you're trying to form something to knock them out of the picture, and yet listen to the ‑‑ your customer, who is that young person with a disability.

And I really didn't give you an answer, did I? I know that's difficult. I know that's very difficult. But, again, I think we have to start modeling that where the parent learns by what we say and how we do that their son or daughter is our customer and that they're there in a role to support but not to lead.

>> Thank you, Jayne. I think what we would ask Aaron and Stacey to do is keep that question in mind as they do their remarks. I'm sure they will have thoughts as well as far as respecting the youth and parents in this process. Let wrap up with one final question. Oftentimes schools are under the gun with IEPs and force parents into meetings they're not ready for. How would you suggest we guide parents to coming to meetings prepared?

>> J. CHASE: Again, according to the school districts. Some are good, and some of them need their entrails dragged. Some don't want their parents involved. They say they want the parents prepared but that's the last thing they want. They don't want parents informed because they start asking too many questions. I don't know. I wish you had access to parents' names and addresses and you could send them good material where they will be prepared and know who you are, that you're there to support their son or daughter in this process. That good information is not given, and I stress the word "good" and I have a source at the end about alternatives to guardianship because when my son was becoming a young adult, it was just assumed that we would have guardianship, and it was horrible, and parent are not given good information. Again, I did not answer your question. I'm sorry. I'm thinking.

>> Thank you, Jayne. We're going to go ahead and turn the time over to Aaron who is going to continue with the next segment of the presentation. Aaron?

>> A. BAIER: Great, thank you. Again, welcome, everybody. So I would like to start talking about how do we involve parents a little bit better through Centers for Independent Living, and what I tell parents and what I tell other centers is that, first we need to consider what our existing youth programming is. Currently all centers provide very different youth programming or none at all, and so some examples are obviously peer counseling and mentoring programs where staff are providing support directly to young people. Advocacy services within schools or vocational rehabilitation services. So, again, you know, center staff who present or advocate for a young person through IEP meetings or special education meetings. I think those are important services. Peer support directly through other young people, youth support groups or youth speak‑outs are great programs to start getting that leadership and that empowerment to the young person. Tutoring and education services outside of school. So where the school is unable to maybe provide a full enough support system to young people, a lot of centers are able to use their peer mentoring services and others to provide direct educational support to young people. Job and life skills workshops and trainings, this could be career exploration, this could be workshops focused on vocational services. Just to help reinforce the things that may not be provided within schools. And also general education for young people and for young people with and without disabilities. Disability awareness, talking about the independent living movement. So these are some of the common services provided within centers right now, and so consider what you ‑‑ what you are doing within your centers and try to think how can we bring parents into those.

Often the center for independent living is going to be a liaison between not only the youth and the parent but also between the parent, the youth and other service providers in the community. As I spoke before, the CIL representative who is an advocate within a school system or within an IEP meeting can oftentimes be that barrier person, that person who brings down the barriers, or that young person who doesn't understand the meeting and for the parent who doesn't necessarily understand the meeting, you're there as an intermediary. It's up to the center ‑‑ because of this fact, it's up to the center to network and find the appropriate connections within a community that can support young people. And to build those youth programs we've talked about. Obviously, as Jayne spoke about, when a young person is in the driver's seat, just like with driver's ed, they need a support person, a teacher to go along with them, and that should be the person and that should also be the CIL and the programs they provide to guide them in appropriate direction.

The next thing you need to look at are the young person's goals. The main goals obviously are college and post‑secondary even indication, employment, and moving on directly to a career, and sometimes a young person is not going to know exactly what those goals are going to be. So when you look closely at these goals and kind of break them down, you're going to come up with objectives, and we'll talk about those in just a second.

What does parent involvement look like? When a student is looking at a college or trade school or other post‑secondary options, they're going to need several things from a parent. The student is going to be dealing with financial aid, they're going to be dealing with looking for schools, they're going to need transportation. They're going to need a lot of support through that process. The number one thing with that, and with all of these goals, is encouragement. The parent, whoever that might be, whether it's biological or not, is going to need to be a positive support to that young person and, again, to move to the involvement with schools, a real high school education, high school diploma or general education diploma is needed, and some states don't offer full equality when it comes to graduation from school. In New York state, an example I use is the IEP diploma, which is essential lay certificate of attendance for students, and it doesn't allow for an equal opportunity post high school, and it's one of the biggest barriers that holding back both the understanding parents and the ability of students to move forward. So it's up to a CIL representative to encourage parents and youth to learn about the barriers that exist within your own communities, within your own states and within the country about graduation requirements and what are the opportunities going to be after high school. Seeking out appropriate colleges, again, we talk about transportation, the parent is oftentimes going to be that person that kind of helps take young people to a school or is able to help find the way for students to move outside of their comfort zone and look at new opportunities. The parent is going to need to be involved for financial aid purposes obviously because of financial reasons. Many parents have gone to college themselves and can give the young person some real‑life experience, share with the young person a real‑life experiences as how they made it through college or how they made it through life post high school.

Then we look at employment and career opportunities. Again, encouragement. It's the young person is in the driver's seat. As often as we would like to see all young people go to college and enhance that education, often a young person, the student, needs a break or they would like to go directly into a job or find a job, and it's up to us to encourage them to follow their dream, follow their passion, but also to keep them aware of what other opportunities are out there. So allow choice in the career. The CIL and the parent are able to provide job shadowing and career exploration opportunities whether it's through the parent's job or through a program at the center. Parents can provide support through applications, building up a resume, writing a cover letter. Positive attitude and appreciative behavior ‑‑ appropriate behavior can really be the turning point. Parents and extraneous figures in a student's life can often be very hard on what real life really is, and real life is difficult, and that's not to belittle that, but it's important that we put a positive spin on what life could be and what life can be for a young person who is passionate about what they want to do and, again, it all comes back to that encouragement. Money management and time management are extremely important for parents to impress upon their young people. As they move into a professional world, doesn't matter what the job is, that young person is going to need to learn these essential skills and in some curricula, through high school, they're not always getting those skills. So it's important that they come from somewhere, and that again is part of that transition from youth ‑‑ or from parent knowledge base to young person knowledge base, passing the torch, passing the driver's seat to that next phase of life.

Then we reach our most valuable young people in the world, the ones that are undecided, the ones that we all wish we could have been and said, I don't know what I want to do when I grow up, and most importantly, again, encouragement. We encourage them to take their time, to decide on something that they're happy about. What do they enjoy doing? And where this really comes into play is not at the end of the transition process but throughout it, from whenever it begins, at age 14 or age 13, or earlier, what does a young person really enjoy doing? And that's often where we get those careers that we want to do. We want to be the fireman. We want to be the space astronaut. And so what needs to happen in order to get there? Being transparent and open and honest with young people is one of the most important things. Showing those options and being realistic with young people as to what are going to be the expectations. Being positive and optimistic. It's easy to be encouraging, but it's not so easy to be optimistic about the outcomes. When little Billy wants to become a professional football player and during his senior year of high school and has not played any football or any athletics, it's very difficult to be optimistic with that, but at that same point, we need to, number one, help them understand the limitations and, again, those high expectations of a career path that they would be choosing. It doesn't necessarily single it out or nix the whole idea. What it does do is it creates an opportunity for them to be creative and thinking outside of the box to get to a point maybe where they're not that professional athlete but they're working within that realm or get to work with a professional athlete.

The next big thing for getting parents involved in the transition process is to provide support to the parent. As we've kind of covered so far, this transition is not just a transition for the young person from youth to adult or high school to college. It's a transition for the parent. Jayne mentioned all those things the parent provides, food, shelter, transportation. This transition period is a phase where the parent is taking their knowledge base and giving it to the young person to move on with their lives, and this is an extremely stressful thing for a parent to give up those roles and hand them over. So in any of these goals that a young person has, that's the time where the parent going to be moving over and they're going to need some support through the process. Parents might try for a hostile takeover. The young person is moving too fast for them to handle and so they decide to take that control back and tell little Jimmy he's not going to be a professional football player because he just can't do it, and you can just stay at home with mom, and we'll be happy, and you don't have to worry about it because of your disability. Sounds cold, but, unfortunately, sometimes those cold realities are what makes parents very uneasy and what hinders progress through the transition process. Parents will feel less in value as they give away these roles. They don't necessarily want to give them up. They're comfortable with these roles. And they don't feel confident in the young person's abilities to handle them. Again we look at that ageism concept. The other big issue I've noticed throughout the transition process is parents drop out too quickly. It's both ends of spectrum. Parents can, again, take that control really right back or they can just leave the youth out there for the world to eat up, chew up and spit out. That's not healthy, either, because then the youth is left to their own devices to find support systems that may not be readily in place, but that's a good role for the centers to help build, is to build that support system for the young person, and that support system should always include the parents as a passenger in that driver’s seat. Facilitating a mutual agreement with parents and the young person is an important step. This mutual agreement should include possibly a written agreement that the young person is going to take a leadership role in their own life. The parent will be a passenger in this process. And have them both sign it. It gives them some concrete steps to follow. Where does the young person have a role? Where does the parent have a role? And how is that going to play out over the next five, ten years? The center can be a gentle reminder to the parents and keep things positive with everyone. This can sometimes be a support group or it can be during meetings with young people when a parent decides to try their hand at a hostile takeover, that center representative, that youth transition specialist, can be that gentle reminder, that nudge in the right direction to turn to the youth and ask their opinion and not shutting the parent out but trying to take the attention away from them if they feel that the parent is trying to push too hard.

Perhaps one of the most difficult aspects of involving parents is parents who are not necessarily involved. Hopefully parents are seeking that involvement with their youth truth transition process, however, you know, many of them are not. A good example that I use is during model transition program grant that happened here we would run parent outreach groups, and out of 250 specialized students in a school, we had 12 to 15 parents any given month, sometimes less. So it's important to look at how we can reach out to those parents that aren't involved or how we can help provide supports to the young people where the parent decides they're not involved and don't want to be involved. First and foremost, maintain confidentiality. You are serving the young person through their transition. And white parent is their legal guardian, it's very important that the young person feel they have a safe place to talk, and it's specifically for these controlling parents and parents without the best interests of the young person in mind that we maintain confidentiality with that safe place. A young person will open up and allow you to develop their support system and provide you information how they can get their parent more involved. When parents are involved it's good to call them and keep them up to date on progress. Again, maintaining that confidentiality in talking to the youth as to what they would like shared with their parent. A young person is going to be proud of their accomplishment, and likewise, a parent is going to be proud of them for them.

Providing more support to the parents. We called this a parent mentoring group. We didn't really like the idea of a peer parent support group. Mostly for the reasons that we want parents to have a place to voice their concerns, a place for them to share their expectations of their young people, and a place for them to help each other through that stressful time of transition. While it's an open forum for parents, it is moderated by a CIL representative. The parent support group is an opportunity for them to voice those he can spec tastes, to voice those ‑‑ expectations, to voice those concerns, to get feedback from other parents who have successfully transitioned their youth and whose youth have made it to the interdependence or independence level they had expected. Again, it's peer, but the moderator is there to keep focus and to not turn it into what Jayne and I like to called a pity‑fest.

So some foreseeable barriers to this. Again, lack of parental involvement. This is just sort of a recap. Though outreach is important, maintaining contact with parents is important. Keeping them involved through contact and through participation in workshops and trainings important. Inaccessibility for parents like their work schedule. So making sure that your meetings with youth and parents are flexible, made at a time when all parties can either be present or kept up to date. Often IEP meetings are scheduled when the school needs them and not fitting within the realm for parents. So sometimes a CIL represent sieve going to be a liaison between the parent, youth and the school, and will need to kind of be there for the interest of a young person when a parent is inaccessible at the time. Past experiences, lack of trust, or disconnected parents. These are parent who have been burned by other programs, by the school, and have ‑‑ or perhaps when they were young people themselves had been burned by a similar system. So we have to be sensitive to those concepts and those ideas. If a parent does not trust the system, they're not going to utilize it to its fullest capacity and they're not going to be involved with it. Essentially it's you can to the young person to stay involved, but without that parental involvement, the likelihood of a young person staying involved and utilizing that program to its fullest is diminished greatly. So it's up to us to be, again, that positive and consistent outreach and piece of the puzzle that is transition. Bad power dynamics. Again, we go back to the controlling parent or the controlling systems within a community that are just there for the interests of the parent or the interests of the community, not necessarily the interests of the young person who, again, should be in the driver's seat. Dependence on SSA benefits. Parents, when young people with very specific disabilities receive benefits, often the parents can become dependent on those that are drawn in by the young person and when that young person is about to leave for college or leave for a career or move out, those benefits are lost to the parent and it, unfortunately, can become a conflict when the parent decides they want to hold the young person back simply to hang onto those benefits. So those are just some foreseeable barriers. And I'm sure throughout your experiences you'll come up with many others and hopefully we'll have a forum for you to share those in. All right.

>> Thank you, Aaron. We'll now go to our second question and answer segment, and I've been told we might have lost a question from some participants that are using the captioning system. So if you could resend in that question, we will try to address that.

Aaron, a question from Jenny. Your comment about the response of 12 to 15 parents out of 250 students struck me. We see that all the time. Parents say they want to participate in information gathering, workshops, et cetera, but when it comes down to it, they do not act. And we're right there with the 12 to 15 out of 250. Thoughts?

>> A. BAIER: I have a lot of thoughts for that. Disappointment is probably the first thought that comes to my mind. It's not an easy process. Again, there's no easy solution to get parents there. The method that I've found that really, really helps is a very personable a. When there's 250 students, each of them with parents who have very different family dynamics, you have to pander to the needs of those families a little bit. Communication is the first barrier. Are they accessible by phone, by e‑mail? How do you communicate with those parents? If you can communicate with them, then you can send them the message of hope. You can send them the message of moving forward for the young person and a positive role for the parent. When you can provide those sorts of messages to a parent, they're 6 more likely to be involved. Again, it comes down to persuasion. We are, we're persuading, we're selling a product, and while it is human interest and youth interest, that product can be sold to a parent if communication is there. If the communication is not there, it's going to be extremely difficult, and I've even known center representatives to do home visits to go out and visit parents in person where transportation may be a barrier, especially in some more rural areas.

>> Thank you, Aaron. A question from alliance youth. Do you think a person's hobbies have an impact on his or her career choices?

>> A. BAIER: I hope so. You know, I didn't go into human services because of the money. So I think that a person's hobbies, a person's interests should play a huge role in the career path that they choose. Number one, because hobbies what are we do every day. Hobbies are where our skills lie. While they may not be, we're not going to have a career in stamp collecting or collecting things necessarily, those sort of organizational skills we gain from certain hobbies are going to really transition into a possible career, and it's really great when parents, young people and a CIL representative can sit down and think outside the box and brainstorm possible careers where a certain skill set can play into a career.

>> Great. Thank you. The next question for you, Aaron: Have youth transition coordinators been involved in IEP meetings as supports for students?

>> A. BAIER: I have. Anybody can be an advocate in an IEP meeting. There are trainings out there. Wrightslaw is one we mentioned, where parents become trained in special education law. You don't have to be. A lot of times there are parent‑to‑parent groups that are available. But, really, it's all about educating yourselves as transition coordinators, transition specialists, and getting to a point where you feel comfortable going into an IEP meeting and talking about the laws and helping parents to understand those legalities, things like that a parent doesn't need to sign an IEP if they're not happy with it, and even though that IEP is not signed by them, the school still needs to implement the accommodations provided on it until the parent is fully satisfied with the amount of accommodations that are there. So it's these little tricks, these little loopholes, I guess, or bullets within a law that really are there for the parent's benefit, but no parent is going to go sit down and read a law book. Wrightslaw is one of the resources they can go to online. We as CIL representatives can do the same thing. We cannot just go to the school and say when are CSE meetings? We have to be there at the request of a meeting. But during our outreach and during our program, advertising we put out there that we are parent advocates, we are youth advocates. Therefore, whatever needs, whether it's going to an IEP meeting or just being there within other state systems, vocational rehab is another one. So it's really just knowing what programs you want to offer and educating ourselves to get to that point.

>> Thank you, Aaron. We had a question come in. We just wanted to clarify what the name of that training was again. I believe you're referring to the Wrightslaw with web site located in the slights earlier in the presentation. Is there a specific name.

>> A. BAIER: I believe it's just called the Wrights law, and that's W‑R‑‑I‑G‑H‑T‑L‑A‑W. It's a gentleman named Peter Wright. They generally have a schedule of the trainings done throughout the country on the web site. Not facilitated by this one person but a whole host of trainers that go around country and do these, usually at different colleges.

>> Also from my own experience, I'm also aware a lot of the parent training centers will have IEP rights curriculum or trainings to help folks understand the rights of an IEP meeting. So check with them as well.

Next question for you, Aaron, and then we'll check with the folks on the phone, do you have any networking ideas for outreach to the parents? Sit only through PTO, which I believe is parent training organization. Please make other suggestions.

>> A. BAIER: Go where the parents are. PTO is one great organization that you can always check out. But my recommendation in any community is go where the parents are going to be. General outreach is local community, festivals and setting up tables wherever possible and just bringing information like the Wrights Law information or the services your center provides and just talking to people. Parents are everywhere. And the parents within a community have students within those school districts, and more often than not if you go to, like in arc ‑‑ like an ARC open house or a school open house and set up a table, the administrations of those schools are very willing to let you come in and talk to the young people and the parents, and basically it's just getting out there that your center provides these services in any way, shape or form. Like I said, there's all kinds of festivals and activities going on in a community and just having a presence within that community, number one, raises awareness for your center, number two, raises awareness for whatever you bring to those outreaches.

>> Thank you, Aaron. Let me check with Ryan. Are there any questions from the folks on the phone?

>> Again, if you have questions, please press star 1 at this time.

>> Then let me check with those using the CART system. I don't know for sure if we've answered those questions. If not, please submit those again. I'll just give it a minute. I think we'll go ahead and get ready to transition over to Stacey, and so we'll conclude this question and answer session. If you have questions and answers that you didn't post quite yet, we'll try to get to those at the end, but by like to thank Aaron and we'll now turn the time over to Stacey for the last part of the presentation.

>> S. MILBERN: Thank you, Jeff. The last part ‑‑ trying to give you an example of best practices people can reflect on and go about your day thinking about how am I going to play out [ INAUDIBLE ] the first example we wanted to give was about an organization called Detroit summer and Detroit summer is not a disability organization but a youth organization based in Detroit, and we wanted it lists as a model because they have done, like on Facebook, their organization is on relationship building, specifically intergenerational relationship building. So when you start thinking about that, when you talk about youth transition, it's not something that is being done for the first time. We're not creating a new wheel. Disabled people have been working with their families to live on their own forever, and if we can think about what model, it kind of works that we're not just doing the same mistakes over and over again. So Detroit Summer is promoting intergenerational dialogue, which means like talking to young people and working together and they do a lot of that like around sharing food and creating like oral history projects together and focusing on even ideas like skill‑shares, thinking about a skill as something that belongs to the community and not the individual, and thinking about like, okay, what are the ways I can transfer the skills I have to another person. If you start thinking about that in terms of youth transition, then you can think about like, okay, what are all the skills that an adult with a disability can pass onto a young person with a disability or a parent to another parent or adult with a disability to a parent and so on and so on. So it's helpful to think of that in terms of youth transition.

The second model we give is actually NYLN and it's called Reap What You Sow. So the Reap What You Sow crick slum a curriculum that looks at how young people and families can work together to build a support system that maximizes self‑determination, and why it's innovative and I wanted to include that is kind of actually relevant to the question that was asked earlier to Jayne about how youth workers can balance parents' worries and anxieties for safety and the young person's desire to live their life how they want to live it. A big issue when we're talking about youth transition is often like there's a power dynamic where the young person isn't really being heard and it's frustrating and really like disempowering and not very great for talking about having a conversation together. So the Reap What You Sow curriculum really actively tries to bring parents and young people together in the same space and setting values, what does self‑determination mean, what is ableism, and all factors that are shaping this person's self‑determination in a community, and how can we work to like build support within that environment.

So when we talk about kind of examining what power dynamic is between the parents and a young person, it can be ‑‑ kind of ask first what are values and kind of like disrupt [ INAUDIBLE ] space where people are engaging with each other and really listening and not just acting out of fear or shutting down and all these different things.

As a last piece about this, it's something that's intergenerational. The young people that lead kind of gather all curriculum tools we have and writing the curriculum and we worked with mentors and adult allies, plus Jayne who is on the forum, to kind of like test it out and get input and see what ‑‑ if this has been done 20 years ago, all that kind of stuff. The next thing we wanted to talk about was what would it mean to put young people at the centers because even when we talk about parent involvement in transition, we strongly believe young people have to be the one leading the process. The young people need to be the decision‑makers. And parents like Jayne said earlier need to be taking a passenger seat and being support person rather than the driver. So when we think about putting young people at the center, we can even think about that within our own organizations and our own CILs. So like what ‑‑ CILs. So what would it mean to hire a person with a disability to be a youth transition specialist instead of using someone without a disability or an adult who might not be as able to connect with folks. And then if we're talking about creating a program that's actually staffed by youth with disabilities, then what are the things that are needed in that organization to support that young person in succeeding, and again that means like mentorship, having space to kind of learn, learning comes from mistakes [ INAUDIBLE ] then we also wanted to talk about what parents can really do to support youth [ INAUDIBLE ] and understand the importance of youth with disabilities having self‑determination. We live in a world where people with disabilities systemically do not have a lot of self‑determination. What do we need to challenge that ableism, and not only ableism, but like talked about earlier is ageism and all the other things that come into play. So when we think about like authentic youth leadership or supporting youth with disabilities having self‑determination, then we get into conversations about like, okay, is our program youth ‑‑ which means youth are you mocking the determinations. Is it youth run? That it's for youth with disabilities kind of thing. Then when we think about, yeah, even challenging what folks think inside of themselves around what youth with disabilities are able to do. So at a lot of CILs, we talk to loft them, our youth transition program is ‑‑ what that means is maybe like young people came together and said we want to talk about this, but did young people actually do any of the designing the stage, inviting people to come, getting the interpreters, finding speakers, facilitating the meeting? Probably not. So what could we support young people having that kind of decision‑making power and having that space to do all those kind of learning and skill developments. We also wanted to do a CIL case study, and this is with Christine. So Christine is a young person who identifies maybe not totally as having a disability, and her parents have put a lot of fear like around identifying her as somebody who has like a psychiatric impairment with all the things that come with that. So Christine is a young person, she's not that excited, feeling like really disempowered, but is having a lot of pressure toward getting a IEP diploma and nobody really asked her what she wants to do with her life. It's more she's kind of being like shuffled around and pushed between different systems. So Christine goes to the CIL, and in the ideal situation, the CIL provided peer counseling. So Christine met one on one with somebody who could like talk about what her goals might be, what area she needed support in. Obviously, goal development, which Christine and the youth worker figured out, mapping out a plan for Christine. IEP advocacy, which might mean ‑‑ with Christine what kind of skills she might need to speak up for herself at an IEP meeting or going with her to an IEP meeting and speaking pup career exploration, talking to Christine about what things she might be interested in doing and then finding ways to support her given her goals. We know internship programs or after‑school programs are not always available to people with disabilities. Study assistance. Participation in a peer youth group. Christine is with other young people with disabilities. That is a part of her process. And the CIL youth worker to include Christine's parents and continue to make them feel active.

So as a recap, all in all today we wanted folks to leave with a message that it takes a village. So when we say parent involvement in ‑‑ we're not just talking about biological parenting. But what does it mean to frame the support system? And who are the people in a person's life that we can identify as support people and continue to build relationships with them and do it in a way that's really clear and ‑‑ and then this thinking about what does it look like to include parents and support people and what does access mean on a lot of different levels? So like Jayne said earlier and Aaron did, too, what does access mean for parent of a child with a disability and that parent has a disability themselves? A parent who English is not their first language? Or a working mom? Or a single you parent? How can we make it like so they are able to come to the meeting. Maybe that means coming to the meeting at night. Maybe that means having interpreters. Maybe that means doing different meetings instead of one on one face to face. That can mean like a whole bunch of different represent things. The second thing we wanted to point out again or recap is how can we incorporate young people building support systems that involve ‑‑ again go beyond that nuclear family model and thinking about who are all the people that can support that parent and that young person? And then how can we grow into generational mentorship ‑‑ how can we grow intergenerational mentorship? How can we support people who have been through the transitioning process mentoring young people and their parents. Also the peer mentorship and peer support. So, Jeff, I think we are at the question and answer stage again.

>> Great. Thank you, Stacey. Let's go ahead and check with Ryan first for the phones.

>> If you have questions, please press star 1 at this time.

>> And others, if you are participating on the web, go ahead and post your questions here onto the yell ‑‑ under the yellow emoticon in that box. While we're waiting for additional questions, a question came in at the tail end of Aaron's presentation from alliance youth and they wanted to ask why do people say we can't do things when we can?

>> A. BAIER: This is Aaron. You know, that's a really good question, and I think it really comes to the idea of ageism and that scared feeling of parents to let go of what they're used to doing. I'm legally blind, and when I was 16, it was very difficult for my parents to allow me to go outside of the home and be independent within the community, walk places that I wanted to go on my own, that sort of thing, and so it really came down to my ability to voice my ‑‑ voice my ability, make it known to my parents, and then at times go beyond their control to show them, force them to see my ability. I'm not encouraging young people to go out and put themselves in dangerous situations, but if you know that a situation is comfortable, it's really important to make that fact known to the parent, to your parent, and I guess kind of prove it or to ask how you can ‑‑ ask how you can show that you're able to do something, and that's where the other support systems come in, like a CIL representative, to look for new opportunities to talk to your friends at school, to talk to your supportive teachers and to your guidance counselors about how you can do the things you want to do and have an opportunity to try.

>> S. MILBERN: Aaron, can I answer that, too? Yeah, I am going through the transition process right now. I just moved out of my family's house. I'm 24 years old. I moved across the country. I'm really, I think, right now going through a lot eve motional process of feeling like angry that I ‑‑ that they didn't believe I would be able to live on my own and like how much of that wasn't about me but how much of that was about like ‑‑ yeah, that my mother had [ INAUDIBLE ] what safety means and there's obviously a bunch of conversations to be had about how safety can limit people's self‑determination but I think a lot of it wasn't even about me and also recognizing that I think a lot of parents are used to middle‑class backgrounds, that being a parent of a child with disability becomes like a primary identity, and so when we talk about transitioning, like we spoke of earlier, it's like talking about becoming almost a whole new person for them, and I think that gets scary for folks, and then all these different things come out in the wash. That's all I was going to add.

>> Thank you, Aaron and Stacey. Before we go to the next question I have been asked to just make a note about the audio quality on some of this. The joy of a webinar is we're actually located all over country right now, and sometimes that does affect a little bit of the audio quality. We do apologize is anybody is having a difficult time with some of the audio, and with that I would like to go onto another question for you, Stacey, and Aaron and Jayne if you want to chime in, since the transition process involves both students and the parents, what suggestions ‑‑ I think, Aaron, you talked a little bit to this, but what suggestions do you have to help the parent transition in this process?

>> J. CHASE: This is Jayne, Jeff. May I go ahead?

>> Please do.

>> J. CHASE: I was thinking about all this as we were all talking and sharing this information, and once parents learn that their son or daughter has a label, then their son or daughter becomes that medical model, you know, where you're always told what's wrong with your kid, what you can't do, and then to suddenly be in this position where we're talking about completely changing everything, it's very scary.

I think parents are the most judged people on the planet, frankly. We're either too ‑‑ we're helicopter parents or we're parents that are not involved, and it's hard for parents to know what their role should be, especially in this time. And parents of kids, especially with autism, they're all lumped together if that your kid has autism they should be doing this or they should not be doing that, and that's why I urge all of you who work in this field, and who do such wonderful work, and I know you're on this call today because you really care, is to know best practices and not get caught up in that medical model about what people can't do. I know you don't do that because you're a center for independent living, but I just had to say.

And, two, parents having to learn laws, having to learn what IDEA means and what Section 504 means, what the ADA means. I've had parents say to me, why do I have to learn that, why can't I pair up my son or daughter and people at school do what they're supposed to do? So there you have that element in there as well.

We worry about all of our children moving from the safety we feel of our home out there. I worried about all three of my children. So it's not anything extraordinary to worry about your son or daughter who has a disability. So I really don't think we should be penalized for that. So I'll add that and that's my take.

>> Thank you. Aaron or Stacey, do you have a comment about how to help the parents in the transition process?

>> A. BAIER: I'm just going to throw one quick thing into that, and that is that there's no prescribed picture as to what parental involvement looks like, and when I mentioned considering both current programming and the young person's goals, that's where the discussion really begins, and that's where between the CIL, the youth and the parent you come up with your own sort of agreement or ideal situation for how the parent can and should be involved, taking into account all the different factors that we've discussed. It's really a matter of what needs does that young person have, what are the insecurities or oversecurities of the parent or the youth, and how does the parent see themselves playing into it and how can we either limit that to help the young person grow or expand that involvement so that it doesn't hold the young person back?

>> Thank you. Stacey, do you have any thoughts on that?

>> S. MILBERN: Jeff, could you repeat the question so I get it right.

>> Since the transition process involves both students and the parents, what suggestions do you have to help the parent transition in the process?

>> S. MILBERN: I guess I'm thinking back to what Jayne was saying about worry things like that. So I think on a practical level supporting the parent might be just kind of doing it by experience, and I think a big piece of parents kind of letting go of the grip is a young person even making mistakes and like not dying and not all these things, not ‑‑ [ INAUDIBLE ] I mean surviving that and kind of growing from it. So that's a big piece like even the process to make mistakes and coming out on the other side. I feel like the other piece of it, too, is just ‑‑ I think this is where the support system comes into play. You're not alone. You have a community of people to support you. And the CIL is here to support you. And like what are the things ‑‑ asking what are the things that they need to be supported. So maybe something is ‑‑ a parent my say ‑‑ might say, one area of support I meet need is I need to know my teenager is safe. And so ‑‑ so safe for me when I moved out to California just meant that I took pictures of all the food I ate so my mom knew I wasn't eating hotdogs or things like that. All these different things of kind of easing into things. Yeah, so that's my answer.

>> Great. Thank you. This is the last call for questions. On your screen you have some contact information for today's presenters. Ryan, one final call for questions from the phone.

>> Not showing any right now, but if you have a question, please press star 1 at this time.

>> With that I would like to thank Jayne, Aaron and Stacey for this great presentation. I would again ask our audience members to please complete the evaluation form that's provided in the information packet that was e‑mailed to you, or by clicking on the link that's posted on the current screen.

Also, we would like to invite all of you to continue the discussions on youth transition issues by participating in the new CIL youth transition BLOG. The link to the BLOG will be on the second to the last slide of the presentation. I know Aaron has been a guest BLOGer on that, and I have the opportunity to coordinate that BLOG, and we would love to have more comments and participation in the BLOG so that we can continue some of these important discussions about what folks in the CILs are doing well and what barriers they're coming against. Chances are you have colleagues somewhere in the country that might have a solution for you in some of those issues, or could learn from your experience.

So, again, we would encourage you to participate in that.

With that I would like to thank everybody for participating and joining us today. Thanks again to our presenters. And if the presenters will hold the line we'll wrap things up. Everyone else, please have a fantastic day. Thank you.