New Community Opportunities Center at ILRU presents: Building an Effective, Comprehensive CIL Youth Program

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Introduction and Meaningful Inclusion of Youth in CILs

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>> DARRELL: Good morning everyone. Have you all had enough coffee yet? We shared a very interesting shuttle ride yesterday. My name is Darrell Jones. I'm with ILRU and that sounds like my phone ringing.

>> AUDIENCE MEMBER: We got it.

>> DARRELL: Okay, good planning. We are so delighted to see you here this morning and to have you join us for this very exciting program.

I'm just going to go through some housekeeping items first and then we're going to get started. Carol and I have been around to badger you about your pre-survey, but if you weren't around when we came around, just wanted to make sure that you get these filled out before we get started this morning.

We had a pre-survey and a post-survey because it helps us to evaluate the quality of our training programs. It helps us to know what information you arrived here with and what information you leave here with. So we can tell if we're actually doing something effective. So we deeply appreciate your taking care of that.

And a few other things that you might want to know about is that we are videotaping this. The camera will be on the presenters. So you need not worry about your hair or your makeup, but it is going to be critically important that you use the microphones when you speak. So make sure that you get that microphone, you might want to take it off the pedestal so it's easier so you're not having to, you know, try to pull it off there if you have a comment. Please, please raise your hand before you make a comment or ask a question. You do not have to turn on the microphones. They are being controlled by our capable A./V. person here in the back. This is Keith. He will raise the volume of your microphone if you raise your hand. He'll see which table and which microphone and that way we can make sure we're capturing everything.

One thing I wanted to remind you of is please don't wear fragrances, perfumes and colognes and those kinds of things for the safety and comfort of people with chemical sensitivities. The restrooms, if you didn't spot them, are right across the hall. How remarkable for a conference to have a rest room so close.

At lunchtime today, we are going to vacate the room as soon as the session ends for about 20 minutes. The staff here at the hotel are going to bring our lunches in and just set up our tables. So you're not going to have to go through a buffet line, but if you can leave the room for that period of time, it will just facilitate things for the staff.

Tonight we have a reception at 5:30. And we encourage you all to come and spend that time with your colleagues so you have a chance to get acquainted on a more social level and can do some networking.

And finally, I wanted to mention the website, our wiki, our wiki page that has resources that will be of assistance to you as you work on your youth programs. This url was sent out to you. Sharon Finney of our staff sent it out to you, but if you missed seeing it, it's also in your packet. It's on a little sticky label there. I really encourage you to spend some time with that website when you get back because if you haven't looked at it yet, I'll just tell you quickly what you will find there is all of the PowerPoint presentations that you will see over the next two and a half days, the video recordings will be posted there after we've had a chance to get them captioned and reviewed.

There are also some other resources that the three centers who are going to be presenting have shared with us. Things like some sample grant proposals that they have written, some brochures, descriptions of their programs, job descriptions, there are a number of resources that can just serve as templates that you can take a look at and possibly use for your own purposes. We also have links to a number of other websites that talk about developing out programs that we think you will find of interest.

So on that note I want to introduce Richard Petty. ILRU's program director who will kick us off with some background information for you. Thanks.

[APPLAUSE]

>> RICHARD: Okay, I'm continually microphone challenged, so if I don't get this right, let me know. Let me just continue with a little bit of housekeeping, if I may. When you do grab those microphones, bring them close to your mouth. That way we'll make sure that people can hear you and your message gets out to everyone in the room.

Also those of you who use the sign language interpreter or the C.A.R.T, we want to make sure that when we have break-out sessions that you are able to participate in your break-out and we'll help facilitate that if need be, but we also will just ask that you and the C.A.R.T. writer and you and the sign language interpreter just make sure that you're covered for those break-out sessions. We want to make sure. But if you need us to help, we're more than happy to do that. So we just want to make sure that everything we do here is fully accessible, and that also is a broader message for the rest of you and that is that if there is anything we can do to make this experience more accessible for you or just a better experience for you, don't hesitate to ask any of us from ILRU or the training team. We will be happy to see that we get you connected with the person who can help you and can do that. So that's very important to us. We think it's important for anyone who is doing training in this arena to do that and we want to be topnotch at it.

What I am really up here to do is to give you a little bit of context about this training, but I'd like to depart from that for a moment and just sort of take a moment of personal privilege if you'll indulge me, I hope you will. And I've been thinking about this for several days and especially last night and this morning as I was on the way over here. This is one of the most important trainings I believe that we have done in some time. And it comes from my personal background and a lot of us who were on the training team I think have had very similar experiences, but I grew up with a disability. I grew up as a kid with partial vision, and when it came time for me to transition to high school or even to really deal with a lot of issues that kids with disabilities deal with in junior high and high school, and then to make that transition, I really had no support system. And I believe it's true that a lot of people don't have support systems. And I think schools do a wonderful job with what they do, given that credit. I think rehabilitation does a very good job and we need to give them credit for that, but in terms of making sure that people have help and having a sense of personal power, that people have support in terms of their self-esteem, that people have the practical advice and guidance about making attrition from school into higher education or to work. I believe that's not being done. If it is being done, I think it's being done by you guys or could be done by you guys if you're not already doing it and centers for independent living around the country. It's just so important that there be an avenue, that there be a resource for kids, an avenue that really I don't believe exists, and that's important for them. That's important for them day in and day out. But it's also important for the movement and there is a reason that we are a movement and that's that the needs that we have as people with disabilities have often not been met by the larger society, we become advocates. We create a change and we don't want to leave a generation without the skills or the understanding of the importance of that, that they will have to continue to make change.

And we talked about this last night as we sat around the table preparing for this training. There are a lot of us who are going to be moving on. We'll be retiring. We'll be going into other careers and other things. And that will leave -- if we're not thoughtful about it, we'll leave a gap in the independent living arena, in the movement, it will leave a gap in the possibility of change and without really intending to, we could leave a generation adrift and not able to address the issues that they are going to need to address because we haven't fixed everything. We have not solved everything and we know that. We know it day in and day out as we continue to experience the challenges and the barriers that prevent us from having an open and accessible society.

So that is something that we have to impart, not only the understanding, but the skills and the tools to be advocates, the skills to be empowered as an individual, the skills to actually do things day in and day out. Many of us, as we grew up, made that transition by probably failing more than we succeeded because we didn't have those support systems. And such a crucial thing that centers can do.

So I just had to share that personal perspective with you. It is so important, and I believe that many of you already believe that and I hope those of you just consider that as up with of the most important reasons that we're doing this training. There is the practical information that we're going to be talking about. There is the empowerment and all of those things that centers can bring that almost no one else -- if just no one else at all -- can bring to the table.

Okay, the context: ILRU is an organization that provides training and technical assistance to a number of different groups here in the region, Region VI area, we operate the Disability Law Resource Project, our disability business project called the DBTAC or the Southwest ADA Center, nationally, we operate the IL NET and we do that in partnership with NCIL, the National Council on Independent Living and APRIL, and Utah State University of which there is a representative and others who will be here at this training. Again, those projects provide training, technical assistance, the IL NET provides training, technical assistance, publications and resources for centers to help them become effective organizations or to become even more effective.

We have the New Community Opportunity Center, and that's the project that operates and sponsors this training and that is a project that is specifically targeted to creating new programs within centers for independent living. And those are programs that serve needs that are not met. One of those is youth transition and the other is community transition from institutions to the community, from nursing homes to the community. And those are the two focuses of that project, the New Community Opportunity Center.

And not only are we interested and committed to seeing that this new -- these new programs exist and helping centers to create them, but also we recognize that there are potential funding streams for centers, potential opportunities for centers to grow and expand and that makes centers more powerful, that makes them more diverse. It makes it possible for centers to be not just dependent upon one single funding source, Title VII, or just a few funding sources. And that's so crucial because in this day of changing of -- of a changing funding environment, nothing is certain. So the more that we can diversify, the more that we can expand centers, the better off that all of us are and along with that we're providing services that need to be provided in the community.

So that's some of the context of how we got here. We brought together a team of trainers, Judith Holt from Utah State University is the lead. I'll introduce Judith in just a moment, but we also have people from several programs around the country we think are some of the best, and they are people who are being generous with their time and their knowledge. I think the fact that you have some grant proposals, some sample grant proposals in the packet is just one indication of how generous they are being. People don't usually share grant proposals. And that's -- that's generous. It's something that is valuable and I encourage you to look at those and to use them.

And not only are the folks from LIFE of Mississippi, the Toledo Center and the center from Minneapolis here to do training, I know that they will be very eager to talk with you informally and I know that they will be very happy to talk with you beyond this training outside of it if you have additional questions. They have a lot of knowledge and they are really energetic and passionate about this particular topic and they are some of the best people that do training.

So that having been said, let me introduce Judith Holt. Dr. Holt is someone that I've worked with for about 20 years or more.

>> JUDITH: A long time.

>> RICHARD: A long time. And that from the time I was director of the center in Little Rock, when Judith was at the university program and we have continued to work together and she has -- she and her team at Utah State University have helped us to create programming in several areas and this is one of the important areas, youth transition. So I commend her and her team to you. Judy...

[APPLAUSE]

>> JUDITH: Thanks, Richard. And Richard has a new dog, Twain, who is just a few weeks into the job and doing very nicely. This is Twain's first conference.

Typically, when we start a conference, we have people go around the room and introduce each other. I looked at the number of tables last night, counted the number of people and thought, well, that can go on until lunch. So I'm going to try and expedite this. I'm really glad that each individual, that each person is here, but I'm going to kind of introduce you a little bit differently. Texas, who do we have here from Texas? Oh, come on. Texas make some noise.

And then since I'm from Utah, who do we have here from Utah? Clear in the back. Remember where they are.

Oklahoma? Great. Welcome.

Wyoming? Has it quit snowing?

>> AUDIENCE MEMBER: Yes.

>> JUDITH: Good. Montana?

Missouri? Some of you want to adopt a state, that's fine, too. I thought about being adopted somewhere else myself.

Washington? Great.

Pennsylvania? There we go. Okay. All right.

Tennessee? Over there. Yes. Okay.

Nevada? Okay, great.

Ohio? I think they were practicing that.

New Mexico? Great. Welcome.

North Carolina?

Florida? Oh, okay. Florida and Utah tend to hang toward the back. I'll have to analyze that.

Colorado? Great. Lots of folks from Colorado.

Alabama? Roll tide.

>> AUDIENCE MEMBER: Roll tide!!

>> JUDITH: My good friend said every time I say Alabama I have to say roll tide and I try very hard to do that. And you did well this year. I lived in Louisiana for a long time. We'll get you next year.

Virginia?

>> AUDIENCE MEMBER: Right here.

>> JUDITH: California? Someone registered from California.

I see this list just goes on and on. Indiana? Great. Okay.

New Jersey?

Connecticut?

>> AUDIENCE MEMBER: Right here.

>> JUDITH: New York? Okay.

Georgia?

>> AUDIENCE MEMBER: Wooo.

>> JUDITH: Mississippi? And Minnesota?

>> AUDIENCE MEMBER: You betcha!

>> JUDITH: 25 states represented. That's remarkable. Just briefly because you came here to hear the presenters and not to hear me, I wanted to just briefly remind you why you're here besides being in warm sunny Houston which is nice. We want to learn how to better involve youth and young adults as an integral part of centers, not as an add-on piece or not as a by the way piece, but as a full part of centers. We want you to be able to learn about new promising practices that centers are doing. And when I say that, you'll certainly learn from the presenters, but I think all of you are involved in youth programs in some way. And I hope as we begin the presentations, when you have something to add or comment on, you'll do that. Because I think we're all in a learning process here. I'm not sure anyone has it entirely figured out. We want to help you think about what you need to do to expand and become more ready for your youth programs.

And certainly we want you to be able to support youth as they transition from school to work or post-secondary to independent living and have the kind of health care they need. So it's a pretty ambitious agenda. I'm not sure anyone has it totally figured out, but within expertise in this room, I can see a lot of things coming together.

A couple of things I would like to remind you again, my role, my first role is to say use the mic. Okay? So you may hear me say that. Remember when you do, you need to -- this is a complicated series, but you have to raise your hand so they can see where you are. Then when you have the mic, you need to say your name and maybe the state or the CIL you're from, because frequently there are people in the audience who will say I want to talk to that person more at the break because they said something that sounds a lot like an issue that I'm dealing with or they have a problem that sounds a lot like mine or that's a good solution. I want to learn more about it. So its very important to say your name and where you're from.

I will remind you again about lunch. I know that's hours away, but we'll get to that again, okay? I would ask all of you -- I'm seeing, excuse me, ma'am, you have this little blue survey here. See, she's putting it in the center of the table which I love. Okay? So I'd like to come around and get the surveys at the first break. They really are important. You know, if I had a little something I could embed in your skin and track you around until I get the survey, I would be good, but Richard says I can't.

Anyway, we expect the sessions to be interactive. The presenters will let you know whether they want questions during the session or after, but we expect a lot of discussion. This isn't just passive sitting here for two and a half days and getting a lot of food. It's going to be fun. Although you will be sitting and you will be getting food, but -- so I think we're actually right on time. We wanted to start this morning out the way we think everything should start. You all know the mantra, nothing about us without us. Well, we believe that applies to youth too and those young adult leaders who are moving us forward and helping us see things differently.

I think I was selected to facilitate because everybody else is probably younger than I am. But Richard mentioned it nicely, I'll mention it more bluntly. The older generation is going to move on, retiring. There has to be a group of young, enthusiastic people to step in. We made a lot of progress. We didn't get everything fixed. We made a lot of gains. There is still more gains, there is still a need for a strong independent living movement. And maybe it will look a little bit differently than the older movement did. That's okay because we're facing different times; but we need new people, young people who are committed to this and so part of what we're here today is to help think about the ways that the CILs can move and support people into this new kind of -- further into this new Millenia.

I would like to introduce two of our stars here, Stacey Milbern and Cindy Singletary. Would y'all come up?

[APPLAUSE]

>> JUDITH: Let me guess, the clapping was for more them than me. And if I could ask each of you perhaps to just give a little introduction.

>> CINDY: Can everybody hear me? Hi, welcome. My name is Cindy Singletary. And I'm with NYLN and LIFE. But this is Stacey Milbern, and she is our community outreach director of NYLN which is the National Youth Leadership Network.

So we're going to talk about why you can't have nothing about us without us. We know that motto so well and now we're going to apply it to you.

I was going to tell you what NYLN is talking about. We love letters in this arena -- ILRU, NYLN, LIFE -- NYLN is National Youth Leadership Network. And what it is, it's a national nonprofit that is run by youth and it's for youth with disabilities. And that is very, very important. We work to build -- excuse me -- we work to build power and community with disabilities -- with youth with disabilities. We also work to build the capacity of our allies. And what does that mean? That means a lot of stuff. What that means is we want to work with everybody. We are a youth organization, but allies -- everybody needs friends. And we're not good by ourselves. Why would we sit by ourselves. We have youth and we want to teach other adults to help teach youth.

>> STACEY: So how many here today identify as young people? How many people here today are under the age of 28? Okay, great.

How many people are like 28 to 32? Okay, cool.

And then how many people identify as adult allies? Awesome.

So as we continue throughout the week, it's great if you can remember that here when we're talking about youth programming, young people have experts and a lot to say that we can all encourage each other to kind of step up and step back. Step up step back is a phrase that's oftentimes used in youth groups where it's designed to -- when you're in a big room to say -- oftentimes there are people that tend to take up more space, to talk a lot, to kind of control the dialogue. And so we want to encourage those people to step back and then we want to encourage people that are maybe shy or don't want to talk in groups to step up in any way they can, whether that's in the big group or one on one with folks. So let's practice that this week.

A little bit about -- a little bit more about NYLN. So one thing NYLN has been working on in the past two years has been the reap what you sow curriculum and we believe that youth programming takes work and planning. And part of that planning is developing curricula. So you don't want to just organize a youth group, bring everybody together and go what do we talk about now?

NYLN has been figuring out what we think young people need to know in the world and we designed this curriculum that focuses on how to build support systems that really maximize self-determination. So the curriculum is actually designed for intergenerational groups, which means groups of many ages and so in inter-generational groups, a big thing is power dynamics. So we often see youth with disabilities coming in with their parents and maybe their parents say that they know everything about that young person and that young person doesn't really get to speak. So this curriculum really challenges that as well as talks about like what is self-determination. So not just believing you can do something or having the power to do something, but what is community self-determination. So what are people with disabilities allowed to do or able to do in this world? And it's really interactive, like all work should be, and so there is a lot of role playing and video and all kinds of stuff. So we just wanted to give a quick plug for that. So if you want to find out more about the reap what you sow curriculum you can visit our website at www.nyln.org.

>> CINDY: A little bit about Judith asked, again, I'm Cindy, an independent living specialist at LIFE which is an awesome CIL in Mississippi. I work on the Gulf Coast with the youth from 0 to 21 with our youth programs called healthy opportunities. Also known as [Inaudible] but you you'll hear more about that later.

I was the president last year of the governing board. I am now the chair of the outreach committee and then I am also the chair of the community partnership advisory council who are the institute for disability studies which is Mississippi's (inaudible) and then I also serve as -- now I got elected as the vice chair of the (inaudible).

>> STACEY: So my name is Stacey and I got involved with the independent living movement and the civil rights community when I was in high school. And it was a situation where I grew up really wanting to like not have people notice my disability. So I did everything I could to not be around people with disabilities. And then I kind of fell into the disability community through youth leadership work and from there I got involved with NYLN and I also -- (inaudible) and I created (inaudible). So basically it was a group of people mostly with developmental disabilities trying to really figure out how to build an organization where everybody had equal power and also equal responsibility. And do the work that we wanted to do.

And like I said I really, really identify as kind of like an independent living baby because I feel like very much like a product of all the work that people have been doing for the last 10, 20, 30, 40 years. And even in this last year, you know, being 24 years -- 23 years old and not, you know, doing all this amazing youth leadership work where people are talking about having self-determination, but still living at home with my parents and not really able to imagine living on my own and now I live across the country in California with my own apartment and all that kind of stuff. So I'm definitely thankful for the independent living movement.

So let's talk. On the screen there is a picture of a big brain and out of the brain there is all these electric -- what are those called -- lightning rods. So what we want to do is we want to do a pair share. So a pair share is a fancy word in youth work for talking to the person next to you. So everybody turns to the person next to you and it will be great if you guys aren't from the same CIL. So turn to the person next to you and the questions you guys are going to talk about is why are you here? And why is it important? What is inclusion? What do you see as the barriers? What needs to be in place so youth leadership can happen at your CIL? So let's talk for about five minutes and then we'll come back and we'll do a popcorn which is another fancy youth word for just saying people are going to give their ideas. Okay, cool. Thanks, guys.

>> STACEY: Okay, guys, let's wrap things up in another minute. Okay, great. Great.

So let's popcorn. Why are people here? Feel free to just raise your hand or shout out. Why are people here? But we have to use the mics.

>> CINDY: Don't make us call on you. I see a hand.

>> AUDIENCE MEMBER: Hello. In our discussions with -- we actually three'd up, we didn't pair up.

>> STACEY: So in youth work that's a triad.

>> AUDIENCE MEMBER: We were all here because of the diversified funding opportunities, but also because we see that gap in wanting adults to be aware of our services and all the opportunities that are out there, but then missing that opportunity whenever there are youth and expecting them to just kind of miraculously know that we're there. Thank you.

So filling in that gap and also maintaining programs that we already have and getting that attendance and then we also talked about really understanding how to incorporate youth-lead programs.

>> STACEY: Fantastic. That sounds like a great mission.

Anyone else? This side?

>> CINDY: Come on, youth. Some of y'all youth -- those of y'all who raised your hand.

>> AUDIENCE MEMBER: Hello. My name is Laura. I'm with East Texas Center for Independent Living in Tyler. And we're here partly because when I reviewed the agenda on the promotional materials, I was just very impressed with the content and, frankly, everything that was in there was of interest to us at the center. We have had a little bit of youth programming going on, but not near where we would love it to be, including having enough inclusion of youth themselves directing it which as we know CILs are all about that. So that's why we're here today.

>> STACEY: Thank you. That's awesome. Glad you came. Anybody else before I move on?

So we talked a little bit about nothing about us without us and for those that don't know, that's really like a disability rights independent living philosophy or a way of thinking that says people who you're talking about should be at the table. People that you're talking about should actually be the ones doing the work and making the decisions and having the power. And so we know nothing about us without us is an idea that has really changed, you know, communities. And I want to encourage people -- something that's important in youth work is the idea of accessible language. So we talked a little bit about not using -- well, you can use acronyms, but also kind of saying what they are. And so as I speak and as Cindy speaks, we're going to do our best to break things down in words that everyone can understand and it would be great if we can encourage everyone to do that for the next three days and also really encourage everybody to kind of collaboratively create an environment where people are allowed to ask questions and people are allowed to not know the whole 40 year history. As people we are often -- it's great to welcome people in.

So in terms of just the future of the independent living movement, you really believe that there is enough work to go around. Youth -- and part of bringing young people into leadership at CILs and in the independent living movement in general is really kind of letting go and being open to what the next generation of leadership is going to move forward.

So that agenda or what young people might want to do with the movement could look totally different. And honestly, I feel like this is rule I different and it's really important to support people moving in a step forward, even if you don't always agree with what those steps are. And then also youth just bring a new authentic view and energy. Things have really, really shifted over the last 10, 20 years. The conditions of growing up as a youth with disabilities is different. So a lot of times we talked about how -- yeah, just about how oftentimes the struggle -- the struggle has changed and so in the past, and there still definitely is an issue where people with disabilities are segregated and separated and it's about gaining access, but now we deal with people who are mainstreamed and grew up being the only person with a disability in their classroom. And how does that change what they want from a CIL? Maybe they want more community or maybe they want more like belonging and thinking about those kind of things.

And just really thinking about honestly where will the movement be without bringing in new leadership. Where will your CIL be without bringing in new leadership? And how can we talk about -- not to use the word as we do on the side or things that we do for you, but honestly as organizational sustainability as what's going to keep the independent living movement alive.

>> CINDY: So how can youth move the disability rights movement? We've talked about how you can be -- how we can learn -- we can also mentor our peers, our older peers. We can teach y'all some things. I know it's scary. I know it is, but we can. We can teach you -- I mean, I have been in the movement for awhile and y'all have been hard at work. Well, we can give a fresh new look to it and let you know, hey, guess what, this is the result of what y'all have been doing. This is how fabulous it is, but this is how much further we need to go. So we can take off some of that weight from y'all.

We can motivate you, again, like I said, to let you know we are the result. Us being mainstreamed, the older population that has been in this movement, y'all are why we are able to mainstream. We hope to be able to give you some moat taigs and also let you know, yeah, we feel the same passion you do. You are giving us your passion; but also in giving it to us, you need you to help us use it, help us know how to use it. And we learn from you. That is what we do, we learn from our peers because together if we're doing this together, we're going to change the course of the disability rights movement even further.

>> STACEY: So four things we want adult allies to know. We'll go into detail with these things. No. 1, prioritize youth serving in the primary leadership roles. So what this means is not only bringing in people as an advisory board members or volunteers, but actually as interns, as staff as board directors, how can we support young people in getting to those roles or how can you hire young people to helping you support and fostering mentor SHIP.

>> CINDY: Myself, I came in -- (inaudible) has a nursing home transition program through AmeriCorps. They got me fresh out of high school and like Stacey I was not in the disability world so much. I kind of shied away from it, not meaning to, but just that wasn't my focus. But being in that, I learned so much, but they were also able to teach me about the disability rights movement more and able to mold me to where I was able to become an independent living specialist who works with youth. And I can't tell you how often I've heard from parents who have told me, you know, it's so fabulous that you are a youth because my child listens to you. So that is something -- that is doable. It's happening in Mississippi. So I just wanted to say that.

>> STACEY: We're going to go more in depth with that, too. So No. 2, be strategic and make plans. So we're saying that maybe treat youth programming as like a fifth core service, like what would you do to make that happen at your CIL. And No. 3, be political. So we're saying like a lot of times youth want community, so how can we bring young people in, but not just say with ice cream socials and the parties, but do like some political trapping. How can we foster the growth of the next generation?

And No. 4, create space for youth to be whole. And the anecdote I like to give, I used it as the last ILRU training of talking on a panel as another youth organizer and she was really encouraging adult allies to pick up the language of youth and to be really cool and someone that -- yeah, the youth feel like they can identify with, and I appreciated that, but I also wanted people to remember that actually youth space at a CIL can be the first time where young people don't have to be cool. And that young people can actually be themselves and can have a disability and cannot like -- try to hide everything and hold it in. And an amazing way to model that is for an adult ally to do that. So if we can create youth spaces where we're not like replicating the outside world, that is amazing. So we're going to go into that a little bit more.

>> CINDY: So youth in leadership roles. As I mentioned, I have some leadership roles. Stacey has leadership roles. Leadership provides youth the ability to have a position, to have a responsibility. It's a great way of learning. And it's common to see adults in the coordination program, planning and people in unpaid advisory roles. And Stacey said, that's fabulous but we also need to be able to have jobs. Young people with disabilities need to know they can work.

So they need to be able know -- and what better place than a CIL is for them to have the job. Because then they are able to continue the movement and also be themselves and such.

Assess what organizational power is and put youth there. Again, youth, we have the energy amongst us. Not always, but you give us some coffee and we're good to go. And so first give us positions. Mold us. Don't put a brand new youth that has never been in anything out front, but have somebody with them mentoring them, but let them speak. Let them explain, hey, I need transportation, I can't get to school. I can't get to my job.

Also you help them out and get them out there and they'll get comfortable with that. so when you're not there, they already know what to do, but if we're not mentoring them as a youth, they are going to be adults that don't know how to present what their needs are and present -- help the movement and therefore they're going to be either stuck in institutions or they're going to be one of those that's considered just loud and not able to actually put their energies in the right efforts.

Create a plan for supporting youth to leadership roles. So don't be whimsical, we have a position. Think about your organizational chart and think about where can we use a youth? Where would a youth be best? And don't limit the youth to that, but I'm just saying think about -- like, again, the person working with the youth, it's great if you have an older youth in that position. Because teenagers, they are going to be more likely to speak to another young adult than they will be to speak to an older adult. They are not going to tell an older adult about their personal issues. It's hard enough to get them to speak to the young adult about that, but the young adult say I can understand. I they can talk about their likes together. I like this music, and once you get that bridge then you can start that mentoring.

And then again the best motivators, like I said, they understand what youth are going through. They probably are going through some of those things or have just gone through them. The best thing to learn from is a person who has gone through it.

So again, if you have a youth working in your CIL, you can -- that young person that's being served is going to learn from that, but also if you have that youth working in that CIL, that older person that's working also, they're going to be able to teach that youth, that young adult what's going on. What's happened, like -- I'm trying to think -- Medicaid issues or some type of issue is going on or has just gone on, then they'll be able to understand and also if you have that relationship that youth is comfortable with that older adult, they are going to start talking to them. So you are mentoring them -- mentoring doesn't have to be we want to sit down and mentor from one o'clock to three o'clock. This is our mentorship program. Mentorship has to be natural. Like we do peer activities in my office, in my arena area and I have tried formal (inaudible). We may get a few people there, but if I do activities like recreational, something like that, I get a lot more people to come and then if you just kind of step back, you see peers working, you see mentorship happening. And you're like, I didn't plan that. Ha ha, that's what happened. So (inaudible) so if you say we're going to have a peer support program or a mentorship program, no.

And then parents and guardians -- parents and guardians, (inaudible). They are very protective of their youth and their young adults, and that's understandably so. They have been the caretaker, they have been the one that their youth has cried to when stuff is going on. They know firsthand what's going on with their child physically and such. But they don't quite understand what's going on in the growing up aspect with the disability. And so when they can see the youth being more independent and seeing them with other adults with disabilities that are independent, that are driving, that are working in a CIL, it's mind blowing to the parent. The parents are like, oh, my goodness, maybe Sally can do that. Maybe Sally will one day be independent. And so they're able to see that and that is a comfort to them. So that's one of the best things I love seeing is the parents having their eyes opened to the possibilities.

>> STACEY: So let's pause for a minute. I'm curious -- and let's just take a minute to quietly brainstorm and for adult allies the question for you is what would you needed when you were 21 years old to do this work, to work in a CIL, in youth programming? Or for young people in the room, the question is what kind of support do you wish you had at the CIL? So let's just take a minute.

>> STACEY: Are there any people that want to share? What would you have needed when you were 21 years old? In the back. Please use the mic.

>> AUDIENCE MEMBER: What I would have needed when I was 21 in order to put myself forward would be to realize that -- which I finally did realize -- that by avoiding other people of disabilities didn't make me any less disabled or any less visible and that staying in the back part of the room just made me not only disabled, but not friendly. That's what I would have needed.

>> STACEY: So maybe at a CIL that looked like creating a positive culture where disability is okay. Or really challenging the idea of assimilation. Assimilation means like when people or community really try to fit into a more larger community and oftentimes then that causes them to lose pieces of themselves. So do we have other folks?

>> AUDIENCE MEMBER: Over here. My name is (inaudible). I'm with the Disability Resource Center in North Carolina. Actually our center has only been opened since 2008. I'm actually 34 years old and so I actually went through the school system and everything pretty much just kind of learning as I went.

I would have liked to have had the support of a CIL just growing up as a youth, but there wasn't one available in our area which I've been privileged now as an older person with a disability that they've been a great support to me because going through the system, I was discouraged a lot because they would look at me and see my disability and they would question my intelligence. I mean, I even had that question and I'd be put in classrooms and they would think something was more wrong with me, but I didn't really have the support system that I think the CILs provide for individuals with disabilities and I'm glad that they are out there and continue to do the good work that we're doing and I just -- I'm privileged to have the opportunity to help the youth that are coming up now and that I can learn some great things from this conference that I can take back home with me.

>> STACEY: Thank you much and I think that really speaks to what we were saying earlier about the need to outreach to young people.

Any final person? What would you have needed at 21? Or what do you wish you had if you're a young person?

>> AUDIENCE MEMBER: I have something.

>> STACEY: Two more people. Go ahead.

>> AUDIENCE MEMBER: My name is --

>> AUDIENCE MEMBER: I'm Kelsey from the Disability Resource Center. Growing up I went through the school system in a regular ed class, everything was fine, but I wish that there was a program where, you know, that it taught other kids about people with disabilities. You know, I did fine. I eventually made friends and succeeded or whatever, but when you had -- my teacher was called an itinerant teacher, not really like an aide, but people looked at you like you were nuts and this person would be in the back of the classroom to kind of observe your classroom success or whatever and they would ask you, is that your dad or who is that person that's in the classroom? Obviously they are for you, so I wish that there was something that kind of made that transition more normal. You know, to have a disabled person in your classroom.

>> STACEY: Definitely. And I think a lot of what we've been talking about today focuses on the importance of bringing youth with disabilities together, but as they do that or as you choose what kind of youth programming you want to do, it's really, really important to remember -- and the idea of inter-dependence, but our independence is connected to other people's independence and nobody is able to do things alone and I think that's really -- young people really like that because we do rely on our families, our teachers and different people.

Okay, Suki in the back.

>> AUDIENCE MEMBER: Sorry about that. I just wanted to share that with my CIL out in Daytona Beach, Florida, they actually helped me with my transition to living independently, and I'm like so grateful for that because from that point on they've actually been with me every step of the way. I've decided to move out of my parents' home and into -- just to live with a friend. And they were there to help me make a plan, a path plan, it's an acronym. I don't know what it means right now. But they helped me figure out what I wanted to do at the time and make short term goals and then had a my long term goals were and then working with them and getting out of my parents' home, I was -- once out of my parents' home I was set up with a mentor who at the time was the president of the board of that CIL and that just opened my eyes to a whole new window of independence, seeing her -- we didn't have the exact same disability, but it just let me know that there are so many resources out there that I can live on my own. I don't need my parents.

I kind of felt better about breaking away from my parents and then I eventually got a job with my CIL and now I'm working with them as their education advocate. Not to say my CIL is perfect, but I can't think of anything that we should get off the top of my head, but I just wanted to share with you what my CIL has done for me.

>> STACEY: I think that really speaks to looking at who you are really serving.

Okay, the last person up here.

>> AUDIENCE MEMBER: Hello. Can you hear me?

>> AUDIENCE MEMBER: Very close.

>> AUDIENCE MEMBER: Hello. My name is Jessica Osborn. I'm with (inaudible) Independent Living in Galveston -- well, League City. And when I was younger, I'm a little bit older -- when I was a little younger, I wished that they did more activities about what the youth really wanted to do, not what they think they want us to do. Ask us what we want to do? What do you want to do for fun? Not just -- oh, let's take them there and they'll enjoy it. They'll make the best of it. And I really enjoy going to the movies, but I had a hard time actually enjoying the movies because me being hearing impaired, I don't know what they are saying, and I just really -- I just feel it's unfair how we are hearing impaired and we have a disability, why would you take us to the movie theater all the time when we can't understand what they are saying. And I didn't like that at you will a. And I got out of high school and went to college. (inaudible) and I really learned a lot about the deaf culture and hearing impaired people in college and I probably want to do right now -- I'm trying to find more activities and trying to ask the youth what do they want to do? So I think it's very, very important.

>> STACEY: I think that really speaks to the importance of youth in leadership roles. Youth get to go at the agenda. Youth get to go decide what happens. And just the final thing about why youth in leadership roles, on the screen it says accountability both ways, we really want to encourage people to remember that it's not just about hiring a young person, it's not just about creating a youth (inaudible) but it's about sharing power with the young people. So when you're sharing power, what does that look like at your CIL? A lot of times what that looks like is more transparency. So sharing like what's actually going on instead of keeping that behind closed doors. That also looks like really informing people about how decisions get made and where there is opportunity to share things and honestly where there might not be at the current time.

So moving on, No. 2, be strategic. Have plans. So oftentimes like I said earlier, youth programming is either done maybe when there is like a little bit of left over funds or out of (inaudible) and I feel like people learn the hard way that planning is necessary. So we really want people to think about like what is it that you want to create in your CIL and create a plan for how that can happen.

So what are your goals for this year? What are your goals for next year? What are the goals for the year after that. How do you believe change happens? A lot of times it's called the theory of change. What does your CIL believe creates change?

So in youth work, that might look like creating change means more youth as advocates. Creating change means more youth as activists or creating change means creating a disability culture, like being really Speck about that and including people in that decision-making process. Where does the money come from? What is the purpose? What is the goal? What is your CIL actually able to do and on the screen it says capacity. And capacity means like organizationally what you have the power to do, but also individually what are the skills that people in the group have. And then on the screen there is a picture and it says dreams don't work unless you do.

>> CINDY: I'd like to add to that just a little bit. Also when we look at the big picture, because as a youth, we have kind of a trust issue. So it's going to take a little while to build that trust and to build that look, but if you just disappear on the youth, then that's going to really hurt the youth movement, the disability rights movement in the youth because that's -- we're not going to go, oh, we understand that funds have dried up or anything like that, it's oh, they gave up on me. They gave up on us. They don't care about us -- that kind of mindset. So while -- (inaudible) -- whatever happens, trying to figure out how you're going to sustain it with whatever funding you have.

>> STACEY: We can't stress the importance of that. All disability work is important, but honestly if you are doing youth programming at your CIL, you will be working with young people who are experiencing self-determination for the first time. Where people get to say like, actually, I want to do this. Actually I don't like that. And that is huge and that's really, really important to people.

and so we really want people to understand that as a responsibility, that like Cindy said, you can't just create a program and then, you know, quit on it the next year. You have to create plans that say like we understand that we're opening the doors to young people and we want to make sure that they are able to stay. And also like as we do social justice work, how can we do work for the community from a way that's good? Because there is a history of harm happening where people do come into a community and maybe don't do what that community needs. So it's the same thing with young people. You have impact.

And just like Cindy said going back to the big picture, we want to remember and just kind of open up the idea that freedom of people with disabilities is not going to happen in our lifetime. So what can we do in the next 20, 30, 40, 50 years to move us closer to the world that we imagine? So oftentimes I think when we're doing -- maybe this is just as a young person -- but oftentimes when we're doing work I think in my head I imagine like people aren't going to live in nursing homes ten years from now or that all transportation is going to be accessible by the time I have nieces and nephews, kids kind of things, but actually like the likelihood that we need to figure out how to create a movement that's going to last a long time and have people support you in that. Are we getting a time check?

>> JUDITH: You have about 12 minutes.

>> STACEY: The third thing we wanted to talk about is be political. We're talking about how the work that you will be doing or that you are doing is about creating the future of the disability rights movement.

So oftentimes it's been interesting to see the disability rights movement not really talk about oppression. So we've talked about the need to advocate, but we haven't actually used the word ableism. And ableism -- so basically like other social justice movements have language to describe their experiences. We have the language of racism, of sexism, of heterosexism, of classism, but the disability rights community hasn't really used ableism. And so in our work with young people, how can we identify what is happening in their lives so they can connect the dots and see how people with disabilities are treated in the world.

Ableism, which is a word that's used to describe a system of power that favors like able bodieds in at the expense of people with disabilities. So how can we talk about that and introduce that as an idea and really get to the core of it? And just a reminder that being interactive is really important. There is a school of thought called popular education, and popular education started in South America and it's an idea that all the knowledge people need is in the room already with the people. And it's a matter of facilitating to get people talking to teach each other. That means you don't have to bring in a fancy big speaker, that it's about sparking conversation and learning from people's histories and so popular usually works with story telling, songs, poetry and that's the things people can look at online to find out more.

>> CINDY: And we've talked about making sure that there is space for youth to be themselves. We can't describe that enough. Because we all know that as the, quote, older population and you look at youth and you're like I just don't understand them. Why don't they just get it. Something like that.

Well, youth have their own ideas and there was once a time that people thought that about yourselves. And so you have to allow that space. It seems that happens that the person with the disability, the youth, the disability kind of defines them and they aren't able to let you know what are the they are cultures. You have the disability culture, what else is going on with them? Are they experiencing racism? Are they experiencing other things with the S. word, sexuality? What is going on with them? You have to give them that freedom to kind of explore that, and I know that's scary. I know that's very scary and especially when you talk to the parents about that, but we as a CIL, you being a CIL for disabilities, you can give that space for that person, for that youth to kind of explore that themselves.

You can let them know what you went through and things like that, but don't tell them this is what you have to do or this is what you should be. Don't use the word should. That's one of the things we get told -- well, you should be feeling this. Or you shouldn't be worried about that -- things like that. Hmmm. So as a youth, you just have to have a conversation that discusses the disability, but you also touch on the other parts of that person.

And like we talked about cool -- I know as a youth with disability I was the only wheelchair user. I again -- I cannot remember the lady on the back table, but she discussed how she tried to not highlight the disability. I tried to do that, too, not saying I was ashamed, but I didn't want people to see that about me. I wanted them to see Cindy.

And obviously now I realize, hello, they saw this. And so -- but the cool part is you don't want people to see it. You don't want people to realize it, but as you work at a CIL, it kind of becomes normal. You talk about things like you never would think you'd talk about because it's just a part of our lives.

You talk about spasms and when people say, you know, man, I remember when my chest -- oh, yeah, you have that? And when I spas -- the it kind of gives you a comfort. It's okay if my disability does things, if I spasm at the table and everybody saw it at the big function, that happens. And so -- but you also mostly with youth, you want to have fun. Not mostly, but you have to have a fun environment. At least in the beginning. It's got to be inviting. And the youth -- while we have disabilities, we like to have fun. We do things. So you want to have fun, but you want to in that fun do the mentorship, but you want to show them that you have fun, too. Because we may as a youth think, I don't want to get older because every time I'm with Ms. Sally, she's complaining and griping at me and dictating to me what I need to do. I don't want that. So, you know, you want to show them that it's cool. Life is cool with a disability. We live past that.

So that's just -- you want to give that safe space to a person -- to a youth with disability. You want to give it to all people with disabilities, but a youth, it's critical.

>> STACEY: On the have fun piece and the challenging idea of cool, like the most fun disability spaces I've been in have been like nights where we're like having to make puppets for our show the next morning or we're having to make like posters for our rally the next morning or buttons and it's really cool because in those moments there is like people playing music, there is people playing chess and people walking around the room and people chatting and letting people do what they want to do. And it's awesome. Not like forcing people to talk or engage in a certain way. And also to add on the planning tip and on the creating safe space, to really, really remember if you don't think -- for example, a lot -- if you don't think about including people with developmental disabilities, it's a good chance that it's not going to be accessible. That the only youth that are going to participate are college grads. If you don't think what it's going to take for people in group homes to participate, people are going to drop off. That has to be in your mind and that goes back to the planning piece about really thinking about who is the priority to be in the room and kind of remembering that.

So we wanted to leave you guys with rules of a creator's life. And this is found on a website. Basically CILs could do critical work. We are people's every day needs, like the work never ends and it's exhausting. But youth programming gives CILs an opportunity to engage with a different part of their brain. You get to be creative. You get to try and do things. You get to do community work.

So on the board it says rules of a creator's life. No. 1, do more than what you're told to do.

No. 2, try new things.

No. 3, teach others about what you know.

No. 4, make work into play.

No. 5, take breaks.

No. 6, work when others are resting.

No. 7, always be creating.

No. 8, make your own inspiration.

No. 9, love what you do or leave.

So our contact information is on the board. My E-mail is Stacey.Milbern@gmail.com. Cindy's is csingletary.life@gmail.com.

Any questions for us?

>> AUDIENCE MEMBER: I have a question. Maybe we'll get to this later, but I was curious what the speakers feel about the issue of just thinking the school systems where there is mainstreaming some of the challenges that may be some CILs that are smaller might have, is to have enough staff support or a volunteer base to have a bigger program offering for youth to be able to facilitate it happening in that we've had some parents who maybe they have adults -- a child or older child that they want to have involved in the summer youth program we have, but then they say what about my kids without disabilities? Or we've had others say is your offering only for those with disabilities? So what about the integration in the CIL environment as far as offspring?

>> CINDY: Something we try to do is have inclusive things to also -- we think that's also again teaching people without disabilities how it's cool to be -- its oh e okay to be comfortable with your disability.

Our activities are typically inclusive and we've also had what we call sibling support Alaska representative ties. We don't do everything inclusive. Because sometimes it's focused on that youth with a disability but we try to inclusive in most things and we find that to be very successful.

>> STACEY: And also to remind people that there is like -- I know this is a different aspect to the question, but that there is a lot of work in youth work and I know in the youth work I've done that the best volunteers have been my brother and sister. My best ally in the world is my younger system. So just thinking about how can you pull a different community member. If you're going to have a youth conference my first year hosting a youth conference sh we had like two Voss and everybody popped up with all these access needs that they didn't write on the paper which is always the case and you're running around and nobody is knowing what's happening and people aren't able to participate. So you always need to have a lot of people on hand, support people. Any last questions?

>> AUDIENCE MEMBER: What would be your suggestion to kind of get youth to be more active volunteers in your center? To get them more involved?

>> STACEY: To repeat the question, what is our advice on how to get young people active?

>> CINDY: To volunteer -- we do presentations at like key club, high school communities. Lots of high schooling nowadays, they have to have community service to graduate. And while it may at first start out to be, oh, this is community service, they end up -- they become involved and they are like just let me know whenever you have something else and so then you get a database of volunteers. And also if you get one youth they'll have friends. The one challenge is going to be you don't want to have a bunch of just high schoolers, because while high schoolers are fabulous, you need a little bit of direction. So you want to hit up your junior colleges and things of that nature that have a little bit more maturity also.

>> STACEY: I think on the programming bit, the reason why we picked these four things is we believe young people want to participate. No. 1 if they are in a leadership role, No. 2 if they experience self-determination and they learn about they leave with something that helps year lives or understand why their lives are the way they are. And No. 3, that you've made a plan for including them. And No. 4 like having fun. And people will be there.

>> JUDITH: And I'd like to thank Stacey and Cindy. They've done a wonderful job.

[APPLAUSE]

>> JUDITH: I don't know how we can start a conference on a better note than what they've helped us see and helped us think about. And I was sitting there with my own little checklist going a-ha, I had need to remember that. I need to remember that. I have to ask them a very serious question though. Do I have to try and learn to talk like teenagers talk?

>> CINDY: Please don't.

>> JUDITH: Thank you. I just didn't figure it was going to work. We'll have a 15 minute break now. I believe that they have brought a bell that they will ring to get you all back in here. Sometimes it's hard to find your way back from the hallway. And please leave your blue sheets in the middle of the table, your pre-assessments so we can pick them up. Thanks again.