IL-NET T&TA Center's IL Philosophy and Practice Summit: Reclaiming Our Movement
Presented by: Ebony DeLoach, Crush Rush, Kimberly Tissot, Mary-Kate Wells
September 17, 2024; Session Two

MARY-KATE WELLS:
Welcome back everyone. I see folks are rejoining. I hope everyone took a moment for themselves.

I am going to jump right in because I will repeat some of the accommodations that are available, just because we have some new folks who have joined for session 2.

Before we do that I did want to make sure we read some of the comments from the chat from our last conversation. I know he turned that on. Some final thoughts for further discussion later. What were some of these non-negotiable's. Someone set all of them, someone said this is a good and hard conversation. We are not being paid however work in most states either.

There are a few questions on recommendations for other funding sources and explanations of (indiscernible). Thank you for turning that on.

(Recording in progress)

MARY-KATE WELLS:
With that, thank you for coming back. For the new folks joining us we do have captioning available. You can click in your resume bar showed captions -- room

Or access it through an external link which can be accessed in the chat. We have interpreters, ASL interpreters. They should always be visible. If they are not visible, please let us know in the chat.

We also have Spanish interpreters available. You can select the interpretation button on your resume menu and select the Spanish channel --- zoom

This is a reminder the presentation recordings and the slides and transcript will be available on the IR LU on-demand training page. After this session we do ask that you complete our evaluation. We want to hear how these engagement opportunities worked for you and ways we can improve that engagement.

Next slide?

Finally the option for engaging with our panelists today for session 2, we will have chat open to host and panelists during the whole session. At certain parts we might turn on public chat so you can see everyone's post.

We will give notice to folks so that they can make proper accommodations on their end to adjust notifications. If you so choose. We also have the question box so please

continue to put questions in the parking lot so we can come back to. And our speakers might get to it.

During any call to actions we have the raised hand feature which we will allow folks to unmute. We are not using in this session, but tomorrow and day 2 we will be using the pool feature again.

With that, session 2 would be focusing on leveraging affirmative action requirement and title VII of the rehabilitation act to sustain IL movement and consumer control and power. Do not worry, if that is a little unclear right now, we have some amazing speakers that will dive into all of this.

Next slide?

Again, the evaluations are an opportunity for us to hear from you. Topics you want us to follow up on, engagement strategies that work for you. Please do the evaluation link.

With that, I will hand it over to Kimberly, and her team will do introductions. Let's get started.

KIMBERLEY TISSOT:
So happy to be with you guys today, I am the President CEO of able California... I have grey hair and tortoiseshell glasses. If I was presenting in front of you all today in person I would also walk on crutches. I have a high level amputation from a childhood cancer. And I have several invisible disabilities as well including ADHD, anxiety and several health disabilities related to the impact of human therapy and radiation.

I will pass it over to Crush. You are on the.

CRUSH RUSH:
Thank you for having me, that is my real name because people ask. I am an African-American man with curly, unruly hair right now. I have a beard and I am wearing a blue and light blue patterned shirt. I am one of the few who have invisible disabilities. I have ADHD agoraphobia, general anxiety and CT PST. I am so happy to be here.

Thank you.

KIMBERLEY TISSOT:
Ebony are you ready?

EBONY DELOACH:
Yes. My pronouns are fee/hers/hers. I am an African-American woman or person of color, and I am the disability health equity coordinator at able South Carolina. If you are seeing me in person today I'm a wheelchair user, sitting in a purple wheelchair from my home. I have a beige blazer sweater on because it is very cold in my apartment. And I have my able South Carolina badge. And a blue and yellow and green striped dress

underneath.

I am very happy to be here with you all today. I am also a person with a developmental and physical disability. Happy to be here.

KIMBERLEY TISSOT:
We will go to the next slide.

We are going to start talking about the history of the Independent Living movement. We are going to start everyone knows who Ed Roberts is. If not there is a visual of him on the screen, black and white photo.

He is using a sip and puff chair and he has it in his mouth and he is leaning in his wheelchair.

IL was created by people with disability for people with disabilities. Before I came along our voices were not being heard. We did not have movement. This was our first movement to really be able to make systems change and impact the lives of our peers.

We will go to the next slide.

I want to read a quote and it is on three different slides because it is lengthy. I want to quote what Ed Roberts said at the very beginning. "The leadership of cells and silk should be around political advocacy around political change, rather than around one advocate working to get services for one person. All things change when you get political power.

And if we are co-opted by the system, we are in trouble. More important that being service delivers his being advocates. We are too heavy into social services, yes it is easy to get money that way but harder to get advocacy. We are losing the ideology of independence.

A person with a disability should be running the center." That was the original intent and he says, "Yes we should include parents and friends which are allies as well. I would like to see much more teamwork at CIL under disability leadership."

This is what we will talk about in our session today, the importance of disability led movement. The importance of disability leadership. I know as a CEO for an organization, there is not many people in our state that have the disabled leadership. We really stand out a lot. I think many of you all stand out as well in your states. How do we leverage that and how do we (indiscernible)?

I wanted to talk a little bit about how we do things at ABLE South Carolina. We know every CIL is different to meet the needs of your community we are known to be disability let in South Carolina and beyond.

If people start coming to us to get a disability representation, if they want feedback from the disability community and we reach that every single day, nothing about us without us, they call us.

Just next week we are going to have the sisters of Charity event where they are specifically wanting to hear from people with disabilities, the first time ever, about poverty and the cost of being disabled contributes to even more poverty.

That is the first time ever, because we have been preaching this message "nothing about us without us." They asked us to help recruit people with disabilities and now disability will be in a data point, which is very important because we are often left out of those data pieces.

Disability representation matters. Funders and the community wants us. Think about how representations has really come into the light in the last couple of years. We do not want organizations that are about something that the leadership is not part of. We will continue. Next slide?

The disability act, CIL are not service providers. Paula said that earlier. We do not want to be compared to other service providers like (Name) or the blind agency or other nonprofits because we are not. We are a disability led organization... It is included in every single thing that we do and we are very proud of it. We really strut our strut and show off our disabilities because we want to create more leadership. We want to change the negative perception of disabled people in South Carolina, by really showing up and talking about having a disability. How we can lead organizations and work, do things to really contribute to our society and our community. And that we need to be taken just as important as anybody else.

In ABLE creates its Roundtable as well. I forgot to mention, we are at all tables. We are at tables where there is intersection of disabilities thinking about sexual and domestic violence, poverty, child welfare. We are at nutrition programs, food banks. We are at the table for all of these different programs because we know that disability does intersect with every population out there.

We have also partnered with black lives matter's rallies to make sure that people who are black and disabled are able to participate in the March. Really looking beyond that, there have been sometimes we had to create our own table. -- That looks very differently and because maybe we are at a table but not enough is being done. Not enough focus or sometimes people want to overlook it.

If you cannot convince somebody to change, obviously we have done creating a lot of tables including a statewide one. Our own coalition which has over 45 members. We have a South Carolina disasters task force that runs and coordinates disability services. And programs for people with disabilities. Policies around evacuation and emergency disasters. We live in a state that has hurricanes and so we are at that table a lot and really coordinating with all the state agencies.

We have a Public Health Data Systems Task Force now that really focuses on changing the policies around public health and accessibility, and even medical rationing. We saw that as an issue during COVID.

We had all the tables, but sometimes now you do have to create tables that are disability led and bring other people into it as well.

We will go to the next slide?

Why does disability led representation matter? We are going to talk a little bit about our stories and how he got involved. Growing up as a child with a disability, I had cancer at the age of two. I grew up feeling like I did not belong in society. Really feeling like I was getting special attention, not fitting in into classroom environments am really having to fight to be included. I remember when I was in kindergarten I had to fight to be at the same table as kids without disabilities.

Knowing that you have community bring so much confidence and you have the mentorship, you have those role models that you can see that disability â€“ you should be proud of being a person with a disability and it is a part of you and nothing to be ashamed of. When you do not see people with disabilities in the community, you do not think that we are there. If we are not talking and using the word disabled or disability, we are automatically almost becoming embarrassed of it and not something we have to continue talking about, continued talking about our disabilities.

You have invisible disabilities. Bring that to the table. Talk about it. That is something you should be very comfortable with discussing within a Disability-Led organization.

I am going to pass it over to Crush to talk about how he got engaged and why Disability-Led matters and then Ebony.

CRUSH RUSH:
Absolutely. My story starts with my youth, before ADHD diagnosis, life was very hard for me. Education wise, the things that I really, really loved and engaged, I excelled at, and other things I felt like I should be able to do I was unable to do. There was always a wall, there was always something, so many things that did not work out the way I thought they would and how society, my parents said they should work out for me.

I got in a lot of trouble for essentially not being able to focus. Before you get a diagnosis, it's easy to say, "That person is not paying attention, they are not trying." I explained that as a child, constantly getting in trouble for no reason in my mind because I know I give it my best. I cannot tell you why I I have been in my room for two hours, I know I have been cleaning up, I can't tell you why it's not done even though I know that's what I have been doing.

Fast forward, and then anxiety came, my childhood was very high-pressure, unable to

get things done by other people's standards and that accelerated my anxiety. There's a lot of frustrated and negative talk, a lot of pressure to perform. When I did not, there were always some words to be said, or punishments to be had.

So I became a person that worked in IT, one of the most demanding and completely demanding and high functioning environments that you can be in. There is always a task, always something that needs to be done, always a fire to extinguish.

I had my first panic attack. I remember having my panic attack and there was nobody there that can help me. There was nobody there that knew what was going on with me. Everybody was convinced I was having a heart attack. I thought I was having a heart attack. From that day on, my life really, really changed.

It was very hard for me to accept anxiety, initially. It was very hard for me to accept that I have panic attacks. That also came with a lot of shame. In the Black community, mental health and disabilities can be frowned on. They are not really taken seriously. I was told that I just needed to go to church more. There is nothing wrong with the church. That helps you, then perfectly fine, but I was told to go to church. That is what my issue was.

I knew there was something else going on. I knew what I felt like. I knew what anxiety felt like for me. I knew my life was changing. I knew I was losing friendship. I knew I was now working from home because I no longer go into the environment that I loved. I knew that things were changing for me negatively and my mental health was declining because of it.

At this point I left IT and became a photographer. I had been struggling with that, it was one of the things I kind of talked about and really brought me shame, and one day I found myself working with this lovely organization called ABLE South Carolina. I was hired through a third party and I go in and I saw so many people with disabilities, talking but their stories and I thought I was to open up and tell Kimberly how I feel. I open up and talk about this thing on my back that I really feel it I am alone with.

A conversation and some tears later, I realized that I simply have a disability and I have a family. I have people that I talked to that understand, and I met other people with anxiety, I met other Black people with anxiety, which is something that I had really not come across before. It changed my life for the better.

Now I talk about the fact I have anxiety, ADHD, C-PTSD, I use my platform on social media to talk about it. I feel like a lot of times on social media we only highlight the good things, we never talk about the bad things that happen or the hard days. I really use my platform to have that disability with pride to speak up and to speak up to say that disability is not a bad word.

In South Carolina, one out of three people are disabled. In the United States, it is one out of four. That means I have a lot in common with the people in my community, a lot in

common with the people in my state. Somebody needs to be a beacon. Somebody needs to speak up. I already had the platform due to my photography, why not use my words and tell the story to me and other people like me to say that we are here and we are out here doing the same thing as everybody else?

Disable doesn't mean we cannot participate. It doesn't mean we do not deserve a seat at the table. It doesn't mean we cannot achieve. ABLE South Carolina, it was literally a life changing environment, it was a life changing conversation. I am getting goosebumps just talking about it because I remember the conversation like it was yesterday. Now it has been years. That is my story.

KIMBERLY TISSOT:
Now he is a board member.

CRUSH RUSH:
Now I am a board member, speaking the gospel. Also talking about why Disability-Led representation matters. To me, it matters because I have been part of a lot of rooms, through my photography, where I hear people say, "How can we get people here that don't look like us?" And I look around the room, and I'm like, "Hey, it might be kind of hard to get programming for Black people because there is no Black people in the room, you have no place to start. You may understand, but you don't really live to the experience."

Allies are great. But you have to have somebody that truly lives and understands the experience, because we are truly thinking about it in multiple ways, multiple formats. There are things that people may not think about, if they do not live with a disability, a certain type of disability.

For instance, Kimberly Tissot, she has a disability, she only has one leg. I may not be thinking about something that Kimberly is like, "Hey, look, do you realize the grade of how that is affects?" That's not something I would everything about, even though I'm part of the disability community. Having the representation matters because we are always thinking about our living experiences and that is what is truly needed to facilitate change.

I will give it to you, Ebony.

EBONY DeLOACH:
Hi, guys. He was telling his story, so I don't know where I will start.

I guess I will start with my youth. I grew up in Jasper County, South Carolina, where no access, no access to transportation, no socialized groups will have nothing. I did work with a lot of service providers.

So after graduating college, I am a college graduate of the University of South Carolina. With a bachelor’s degree. I came back home because I had a caregiver who said, "You

are not ready to live on your own, you think you are but you are not." Sadly, I came back home with nothing to do. I was very isolated. I did not have any groups or any places where I belong, so I was always on the phone calling different organizations, trying to interact with groups.

I think I started working with the Center for Independent Living that was closest to me. But they also do not have any peer support groups. I stumbled across ABLE South Carolina just looking online, so I called them. I, surprisingly, spoke to Ms. Kimberly, who was the CEO at the time, and she talked to me.

But, it is funny now. I was very upset after our first conversation. Because she gave me a lot of tough love. She told me some things that I had never heard before. I got off the phone and I was like, "How dare this lady! Talk to me like this. She doesn't know me. She doesn't know what I've gone through. I don't know what is wrong with her."

I hung up and I went to sleep and I thought about it, and she is right. Maybe she is right. Maybe I can do some things that I do more. And it is OK to have a disability. And I do the things that I want.

So I started with peer supports. And Power Hour was formed, which was a peer support group. I did the peer supports, I would go every week on Thursday for an hour, and just talk about anything and everything. Goals that I had. One of my first goals was to live on my own. My family was totally against it, they were just like, "You're going live forever, you don't need to live by yourself, and we are going to take care of you."

But that is not what I wanted. I grew up watching different worlds, and the Cosby show, and I wanted to go to college and experience things. Having ABLE South Carolina in the peer support was great and I wanted more. I wanted to work. I did work in other disability organizations. I want to mention that I did work there.

There was no disability representation. There was not talk about reasonable accommodations, and in my job, with the disability organization, in South Carolina, I was drowning. I did not have the support nor did I feel like I could speak up for the things that I needed. I contacted ABLE South Carolina after that experience, it was a little too late.

I ended up resigning from the job and I remember two things, distinctly, after that experience. One, the executive director said, "You need to be with an organization where you shine." And I said, "No, I just need to be with an organization that understands me, and hears me. I don't want to shine. I just want to work.

I left the organization and reached out to ABLE, went on several job interviews and discovered I wanted to be an AmeriCorps member with ABLE South Carolina. I did a term, and after that, I got the opportunity to work with ABLE starting part-time. Now I am full-time.

Why disability representation matters is when I started with disability, in the first conference I ever went to, independent living, I met (unknown name) at one of the first axis and independence advocacy days. We started the young adult leadership network at ABLE South Carolina, and I went to that conference and lemon was there.

For the first time, I saw someone that looked like me. He was going around the room, and he was using his power chair. He said, "I am sitting on my throne." Wow. When he spoke, it was like he was only speaking to me. Every time I heard him speak, I was like, I want to do what he does and I told him one day. "I want to be like you when I grow up." I was joking, and he said, "You don't want to be like me. You want to be the best Ebony that you can be." That has stuck with me.

It matters because I saw someone with a disability that was living in his truth, and it made me want those same things. I began to develop that pride myself. That is why it matters. We need to see people that look like us.

KIMBERLEY TISSOT:
Presentation matters as well because we are peers. I was able to talk to Ebony because I heard a lot of what Ebony was telling me what her parents wanted from her. I was not hearing what she wanted from herself. That was tough love to promote that Independent Living philosophy but also be there and say, "we have a team here at that we have got you. We support you in your community."

We will go to the next slide.

Let's talk about the affirmative action - we missed it. I will pass this to Ebony because Ebony asked to do this slide yesterday.

EBONY DELOACH:
This is our mission. We are an organization leading the charge to equip people with disabilities with the tools to foster pride and direct their own lives. We also educate the community on how to eliminate stereotypes and barriers and we advocate for access, equity and inclusion of individuals, local, state and national levels.

We are the people we serve.

KIMBERLEY TISSOT:
We will go to the next slide. In Q ebony.

EBONY DELOACH:
You are welcome.

KIMBERLEY TISSOT:
There is an affirmative action and title VII where people with disabilities are required to be staff, board members, and the majority of people (indiscernible) staff leadership. How do we do that?

The requirement says the plan shall provide satisfactory assurances that all recipients of financial assistance under this chapter will take affirmative action to employ and advance employment of qualified individuals with disabilities on the same terms and conditions required with respect to employment of such individuals under provision of section 503.

Looking at disability. Looking at how you are going to recruit. How are you going to hire people with disabilities? It takes that leadership down. Obviously our board, and I will talk a little bit about that, we are very much focused on building leaders, disabled leaders in South Carolina. Creating pipelines for employment. Making sure that folks do not have to stay with us for a million years.

We want them to go and do what they want to do. We want to push them into the careers they would like to be in.

How do you do this?

There are some things that you must be careful of with the ADA and the rehab act. You can always ask somebody about their disability experience or put in the job announcement that people with disabilities are encouraged to apply. But also say we are a disability lead organization ran by majority of people with disabilities.

That is something that if people are reading that, and people with disabilities are truly reading that they will bring and be ready to talk about their disability. But also make them feel very safe during the interview process. Are you asking if there are reasonable accommodations they need for the interview? Asking that with everyone.

Those are some things that you can do but we have to hire and seek out people with disabilities. That is our requirement under the law and that is the only federal program that has this requirement. We really need to bring it and show it off significantly that we are a disability led movement.

The next slide?

Affirmative action versus what disability led is. They are mandated to be led by the majority of people with disabilities. The definition for people with disabilities is the definition under the Americans with Disabilities Act.

Disability led is the key lead of the IL philosophy and CIL culture. We are movement that was created by him around. That we should be leading... There are movements for parents of children with disabilities.

Again and is also looking at taking leadership away from disabled individuals. What can we do? And we will be talking about that and a little bit of some action alerts that we can do. Affirmative action and disability, it is a critical tool mechanism in the rehab act for

CIL and SILC to promote people with disabilities in the IL movement.

Who is going to be the next Judy Heumann? Who is going to be the next CEO of ABLE South Carolina? Who is going to carry our movement when our generation is done? Really looking at youth and young adults, making sure you are building them up. And really creating that pipeline. Because we should be focused on that leadership development.

We will go to the next slide.

Leveraging affirmative action to sustain the IL movement. As I mentioned before, drafting those job descriptions and indicating that we need to hire people with disabilities. That peer to peer relationship. Explaining that your organization's disability led. Describing who you serve and the philosophy of Independent Living.

Know how to ask the right questions during interviews. You do not just want to say, do you have a disability? What we say is, can you tell us about your experience with disability personal or professionally? A lot of times people feel so comfortable that they do disclose about their disability. That is something you want to hear and listen to.

I will say this, you do not hire people with disabilities just because they are disabled. That is tokenism. You need to hire people with disabilities because they are qualified and need to do the job with or without accommodations. Remember that, because we do not want to be at tables as tokens just because we have a disability. You can always build that person up, if they are not qualified maybe having them come to some of your programs within CIL and build them up to possibly work at the organization later on or volunteer for a little while and look at opportunities like that.

But do not ever hire someone because of their disability.

Recruit, train, retain and pay disabled staff an equitable wage. I have seen a lot of centers that will keep people with reduced hours and income because of the fear of losing social security. That is a conversation you have to have with that staff because there is a lot of (indiscernible) as we know but what is so wrong about getting off Social Security if that is something what you want? Your organization should be paying your staff equitably. You should have benefits and paid time off and retirement. We do not want to do what other organizations do, they de-value people with disabilities and pay them less. We do not want to be in that movement.

Collect disability identity. This is something you do need to collect, this can be anonymous. If you do get an audit from ACL they will be asking you how you collect that information and you will have to be able to show that... To document the composition and compliance of hiring and promotion of people with disabilities.

The PPR also asks about decision-makers who are people with disabilities and that is being collected. I know I am pushing and several other people are pushing the need to

really collect if the CEO has a disability. Our stay put that in our bill this year just to show that South Carolina is really focused on making sure that our IL network is completely, 100% disability led.

Next slide?

Impact of not being disability led. Ebony and crush can definitely jump in. Ebony, you can share with other disability organizations. But what it does is diminish the collective strain of the IL movement, especially that consumer control. It takes that voice away.

I will say that a lot of people have come to my office, a lot of staff or teams will call me because they need to talk to a who has been through something or get advice. I am running the organization as a peer and disability.

... I have seen that with C IL's with disabled staff very upset that the Executive Director is not disabled and that is not even respected. Really thinking about that. If your nondisabled Executive Director on here, we are not saying for you to step away immediately but you have to figure out how to pass the torch.

I know I always give an example, I am a female. I do not want to run a man's organization because that is not anything I would have that personal experience with. I would not - that is something to really think about. And I know for us females, we sure do not like it when males make decisions for us.

It is the same way for people with disabilities and without. We do not like it when nondisabled people make decisions about us. Often times it is ablest. The programs we have seen that have been created about us without us do not succeed.

It creates a disability lived experience disconnect with consumers. I do not think I would have been able to get to ebony what we talked on the phone or crush if they do not feel comfortable having a conversation about their lived experience.

Being able to have that front and center. Obviously I talk about my disability whole lot but I also talk about how we can make solutions based on our experiences. Based on what we are hearing from our consumers with any kind of discrimination or barriers. How can we make change in the way that would be effective and disability consumer voice (indiscernible)?

It strips employment opportunities from disabled individuals. When our community has one of the highest unemployment rates and we have this amazing movement, we should be creating more positions for disabled people. We should be raising those leaders up.

Crush and ebony do you want to speak to this as well?

CRUSH RUSH:

I also think there is an impact, when it is not disability led, there is the soft accommodations. These things actually - we know it could be more expensive if we did it the right way, but we will do it our way because we know they can benefit both parties. Whereas if it is disability led, this is what needs to happen in this organization. This is what needs to happen in this business this is a hard accommodation and there are no cut corners. You cannot cut any corners.

I think that is also something that can happen. A lot of times some accommodations can cost money for companies. Some accommodations can take time and intentional effort. If you do not have someone who is directly on top of it and does not have that lived experience to say this affects today, it will affect tomorrow and a year from now because it is always on your mind. It is always a thought. Things can get lost in the sauce as they say.

EBONY DeLOACH:
When you speak about accommodations, I was with another disability organization, and I remember being in the organization and when I first went into the office, they kept giving me things that they thought I needed. Nobody spoke to me about your need to write your reasonable accommodation letter, and once they did, it was like, this is too expensive. Dragon NaturallySpeaking. That's too expensive, we are not going to invest in that. We need the cheapest option.

I really feel, I needed to answer the phone, I felt I needed a headset that would work for me. One of the directors at the time was like, "You can give her a headset but that doesn't mean she can do the job." All I needed was a headset that worked and I needed to do information and referral at the organization and I came to ABLE South Carolina and I did information and referral.

I was scarred, I did not want to touch information and referral for quite some time. With ABLE South Carolina, I was able to speak to, this is what I need, I had the letter written the way it needed to be and I was able to discuss and have the active process of, this is what I need, this is flexing time.

It was never even thought about what the other organization. Everyone thought it was too much, or it would cost. Nobody sat down with me to have any conversations until it was time for me to have my performance evaluation and I just felt attacked. And then I felt like I was drowning and what I could have done, probably could have saved myself a little bit, or gotten some solutions, but they were just ready to kick me out the door. That is what happened.

But, having those conversations where you, as a person with a disability, are able to speak about your accommodation, and your need and somebody asking you, like ABLE South Carolina did for me, "What do you need? How can I support you?" That is important.

KIMBERLY TISSOT:

Ebony, I will say this because I think we both have had some similar experiences. The organization that you did work for was another ACL funded program. That provides legal disability advocacy. That's a huge issue to see for us, even, and unfortunately we have had to take on a lot of the systemic needs of people with disability because they are not listening to people with disabilities.

We will go to the next slide.

And so, disability peer... oops. I think we missed and skipped one really quick. Just one before this. I guess not. We will go to the next slide.

I want to show you guys a little bit, I am sure you all are familiar with Crip Camp. But I want to show you a part of Crip Camp that really specifically talks about Center for Independent Living, and why they were developed. We will go ahead, Mary-Kate, if you can press start with that section. Or Jenny.

(The captioned video plays)

SPEAKER:
I said to DeAngelo, what you think about living at Berkeley? We were roommates.

SPEAKER:
Photos of Nancy with a beer and smiling, then of Judy brushing his teeth and cooking.

SPEAKER:
I want to see a feisty looking group of disabled people that will not exceptional without asking why. That is really what is so critical about CIL, it is not a card that you get handed at the door, it is kind of a demand that is expected of people in this community and that is, if you do not respect yourself and if you do not demand what you believe for yourself, you are not going to get a.

SPEAKER:
Writer and activist (unknown name) my first experience of finding hope was coming to Berkeley and hanging out at CIL. I had pretended like I was not disabled, and I could walk in stick the cane under the couch. The whole time I'm worried about the minute I have to get up in everybody's going to see me limp around.

I do not understand how heavy the burden was until his with people that I did not have to pretend.

SPEAKER:
The repair shop has everything, even electronic to fine-tune, battery-powered. The center also provides transportation rely on state, local and federal money, and the goal is to make the handicap self-sufficient.

SPEAKER:

Nancy answers the office phone.

SPEAKER:
How may help you? She counsels a woman in the wheelchair.

SPEAKER:
It shouldn't be any problem, I will give you a list of people who want to work in the house that you need somebody and you need their phone numbers. Anything you need, we are here. Excuse me.

SPEAKER:
Judy. You want to live in a house? That is your right. You wanted two-bedroom apartment, we will try to help you find it. Here's how you can apply for money to get attendance paid for.

SPEAKER:
Nancy Rosenblum. Do you need help? Ice cream? What else? And candy?

SPEAKER:
Corbett. When the whole game came, if you socialize with one, you want to hang out on Friday night, yes, but it met one of those people if not five of those people were always going to be there.

Camp traveled with them. There was a traveling camp.

SPEAKER:
How did I hear about it? I heard from Steve who was out here.

SPEAKER:
Neil had the computer training program.

SPEAKER:
Young Neil teaches the class.

SPEAKER:
I came to California to go to grad school in computer science.

SPEAKER:
Denise recounts. My first week in Berkeley. I got into a motorized chair for the first time in my life. It was very liberating.

Young Denise smiles at her wheelchair at the beach.

Next, Halloween costumes included Steven a blonde wig and corset, and recounts.

SPEAKER:
They took me to a Halloween party at CIL. I remember the day. Oh my God, they are all drunk, carrying on, all these people, all these cripples were dressed in costumes. I don't know, I always felt you had to kind of hide yourself. You do not want to draw attention. And there they were, all proud. It really struck me. This is different. This is really different.

SPEAKER:
(unknown name) club, San Francisco.

KIMBERLY TISSOT:
We wanted to show you...

(Video plays)

KIMBERLY TISSOT:
Thank you so much, Jenny.

We want to show you that because hearing Ed Roberts and Judy Heumann speak about the importance of CILs and bring us back to the history and intent of independent living.

Disability Peer to Disability Peer Framework. We are peers, just being able to connect with each other with the lived experience, being able to share some of the barriers in society. I will always talk about how discrimination is painful all around, no matter what kind of discrimination you receive, especially with your peers, to be able to really talk about the discrimination that you receive, as a person with a disability, is impactful.

To be able to talk about solutions, and developments of programs. So really thinking about from the lived experience. People with disabilities can absolutely be college educated, and have certifications, and have juris doctorates. We have Harvard grads on our team. People with disabilities can absolutely have these certifications and degrees, just like anyone else.

Lived experience is very significant as well. That is truly what we look for in our team, too. Not only lived experience, but the understanding of the philosophy. Of course, we do see internalized ableism with staff, sometimes. I think we all have had that. Since we have grown up in society that has taught us that disability is a bad thing. How can we talk about that with our staff? How can we talk about that with the peers that come in?

Staff are all peers working with peers with disabilities. The word consumer, we have always not like the word. We feel like the consumer gobbles up everything. They are consuming everything. We are unique. We should probably change the language eventually when we, if we can, authorize the rehabilitation act to peers. The folks that come in the door to the program, making sure we enter like that.

It underpins the needs to why CIL and SILCs leadership should be people with a disability. As its consumer driven, think about this. Why do we have the leadership that are not people with disabilities? Think about that, and we will challenge you in a little bit. Next slide.

Addressing power dynamics. This is a talk we have a lot within our organization because we have grown significantly in the last year. We have had to create different leadership peers. But peers with disabilities, consumers and local disability communities are the drivers of the CIL organization. If you have leadership that does not have a disability, you are kind of leaning on them to be able to listen to the consumers.

I have seen a lot of programs and CILS that are not consumer driven, and I will tell you the guardianship programs that Paula mentioned, the representative AE, if you ask folks, they probably do not want their rights taken away or they do not want their money handled in a particular way. How can we help support them in other ways?

Providing the service, how would you want to be treated? As a person, as a person with a disability, I know that I do not want to be treated no less than somebody when I go and get services or programs.

Disability-Led principal is to buy in pride, must start with the CIL and SILC leadership in the board and the council. I think our board is amazing. Crush, not giving you any (Laughs) within Columbia and half of South Carolina, looking at disability's within professions, so we have Lawyers with Disabilities, the list goes on and on.

So making sure that you have the buy-in from the top. So something happens that if I'm no longer with ABLE South Carolina, our board would recruit an Executive Director/CEO with a disability which would be the priority. Because the philosophy buy-in from the board.

The discipline pride is as important as we all share our stories today about being embarrassed of having a disability. Or not seeing enough peers or mentorship. We should not be embarrassed, if we're not embracing it at work, we are going to continue to be embarrassed. We want to make sure that pride, it doesn't happen automatically.

I probably do not have disability pride until maybe my early 20s. Just because, first, I wasn't really taught it in school, about my rights, but also I had some experiences in college with discrimination. And so, it develops over time, but once you teach someone and skill build with someone, and mentor and empower someone to learn about their rights as an individual with a disability and show them that they can advocate and they have so much power behind them, that is when they really start owning their disability and beginning to really truly make change. To board and council governance. I am going to (indiscernible) on this because he is on our board.

CRUSH RUSH:
I will take over. (indiscernible) raising my hand like I am in class. When it comes to the

board and the power dynamic and having so many unique personalities, it goes back to me joining.

I remember thinking "I should do what now?" I do not have these degrees or all of these letters behind my name. Why me? I remember you talking about the power you felt I had and the community. That I was not afraid to run my mouth.

Having a board, you have to have a board that looks like the disability community. There are people who love to run their mouth like me. There are highly educated people who are really good with numbers. I think that is the power of ABLE South Carolina's board and it speaks to the power of what we are trying to do as an organization for our community. Our community is so diverse and expands every demographic.

I think that is huge power for Centers for Independent living. Having a group of directors that looks like your community, which is everyone from top to bottom.

The Council of governments. The board of the CIL is required to be run by majority of significant ... People with disabilities (reads) Not employed by VR state agency... For implementing the mission...

We definitely, Kimberely is a tough cookie. But she is always in line, always thinking about the mission. Always thinking about how to further the community and community pride.

She is not afraid to speak on anything. That is what you need though, you need someone passionate and determined. You need like I said earlier, a group of directors that looks like the community and that is truly a very powerful tool to ensure that everybody is being given the right to equality that they need in our community.

KIMBERLEY TISSOT:
And the accountability as well. If I brought the board new funding, because every board meeting I talk about the new funding and grants we get in. If I brought in something about guardianship, which I would never do, our board would say "what?" Because they know this and they know the philosophy. Holding us accountable but also being part of our dreams.

I will tell you we are planning to start a capital campaign which will be epic. We are starting to tell the stories of people who used to be institutionalized in South Carolina. Our board has 100% jumped in on this, one of their passion projects we are all in because this is our community that we are promoting.

Next slide?

The SILCs recognizing disability lead and I think that is important. We try to recruit the most powerful people we know with disabilities to bring that lived experience on. As well as bringing board members that are going to be vocal.

I know when I originally started at the organization, our board was very weak. It was stacked which means people with disabilities were put on the board that were not going to say anything and that was not going to challenge the Executive Director we had to turn that around. That is not even what I want. I want to be challenged with the board. The board is very much a partnership with in my role. It is very important for them to not only get the philosophy, but also challenge and look at things to be able to make the best of the organization.

Obviously using that disability lived experience, our board chair Corey is a person who had cancer so he is a cancer survivor. He has disabilities because of that. He uses his part of the experience uses, especially when we started doing the public health programs, how we could bring in Blue Cross shield because that is where he works.

Looking at different aspects of that. But that disability experience.

Sharing consumer impact profiles with CIL helps to reinforce being disability lead. Something we do, our board gets big packets every meeting but we do success stories - SILCs

Leave for this is of folks who have received and benefited from our programs. They were able to meet their goals and do amazing things. We share that with the board just so they can see the impact that we have made. If something happened to ABLE South Carolina we know it would be detrimental to the disability community in South Carolina. We are the ones to fighting to make systems change and individuals are being served and treated with dignity and respect.

We also share stories of not so nice things with our board, of really difficult situations. People being forced into institutionalization. People who have been abused, children who have been abused in PR TS. We share that with the board just to help get them to understand the barriers that we face in South Carolina.

Some of those same barriers that are holding our consumers back are those same barriers that we can make sure we are unlocking by either systems advocacy.

Recognizing disability as an asset. People with disabilities are an asset to the organization and they are part of the movement. They are carrying on the disability pride movement but also the Independent Living movement. Be proud of your disability identity and being part of the disability community. Talk about data tables.

I really encourage people with invisible or not apparent disabilities to talk about that. When you are doing introductions, sure that you are part of this disability letter organization and share about your disability.

If you are not there yet, you may want to practice that. Or it is a SILC the right place work as well. Not everyone comes in with (indiscernible), now everybody has it. But that

is something we should be talking about when we are at the tables with professional folks or groups and funders. Legislators, we should be sharing who we are in the park without apparent disabilities. There is more of you. There are more people with non-apparent disabilities then people who have apparent disabilities.

I know you could be a huge role model for children in the school system if you could talk and relate to them having an IEP when you were growing up, or the accommodations you had in place as a person with a disability. You just do not know, whenever you talk about your disability you will impact and who will be listening.

Crush?

CRUSH RUSH:
I can definitely attest to that statement. Every time I use my platform and I speak about disability rights, disability pride or having a disability and how I experience it in that moment in time I 100% of the time have somebody reach out to me in my inbox. Either saying A, I did not know I was part of the disability community. Or B sharing their personal story because they have not quite gotten to the point where they have the disability pride to speak about publicly.

What I have always noticed is that over time, once they have that one conversation, they tend to reach back out to me all the time whenever they are having an experience. Eventually, I will see the post or status messages and their friends start to comment on it.

Disability pride is like a wildfire. Once it gets started and consumes everything. Everybody is now full of pride and happy. Humans, we are built for community. Finding your community and finding people that know and experience and can also - those hard days we all need someone to lean on. If you have somebody you know understands, and makes it so much easier.

Whereas like me, those days I had a panic attack or those days I needed to go to Walmart. I cannot even step in the building right now, I do not know what I am going to do. I guess I will just splash some soap under my arms because I am not getting deodorant today.

There is no one to talk about that with which is why I had so much shame. I was dealing with everything by myself, in my own dark corner of my mind. The only thing that was there to brace me was sadness and depression. And shame.

That all changed with my disability pride. It is such a huge tool to pretty much show that we have numbers. This is everybody's experience. The thing about disability pride is, if you do not have it now you can get there. But also, it is one of those things you can tell people. If you keep on living which is the goal, we all want to be as old as possible, there is a good chance you might end up with a disability. I am prideful now so that if you ever find yourself in a position where you are disabled, you do not have to go

through all the barriers or worry about the roadblocks because we have done the work for you. That makes it better for everybody.

KIMBERLEY TISSOT:
Absolutely. I was meeting with a funder last week and we were adjusting conversations learning more about the organization. We were talking about my disability and he talked about how his daughter had cancer. And during the meeting we were showing pictures of me when I was bald as a kid. And him and his daughter. He was showing pictures of his daughter, a Theatrical effect because disability. Does impact tons of people. If you do not speak about it you will not be able to change that perception or be able to influence for your organization.

Go to the next slide please?

People with non-apparent disabilities, own it. You have the power. Do not be embarrassed because even sitting at tables with vocation (indiscernible) if there is anyone from VR this is not anything negative against you guys. But sometimes going to talk with VR. As a CIL yard can be challenging. Our staff who have no apparent disabilities can bring their perspective about people with no apparent disabilities.

I know they help them … that disability experience so they can see the world a little bit different around folks.

Creating a space, in place for everyone in our disability community to feel connected and safe. Really looking at cultural competencies as well. I know that crush mentioned the stigma within the black community. If you are promoting something that is not going to meet that community you are doing it wrong.

Making sure you are doing your research, looking at the communities in our state or your service area and making sure that you know how to approach, learn from your consumers and from the people around you.

Develop an environment within your CIL or SIL where staff and members feel comfortable sharing their disability... We do staff meetings and something our staff does is about presentations. When we have new folks they will tell a little bit about their lived experience. We very much incorporate lived experience in everything we do.

For example, talking about psychiatric disabilities, I am going to go to the staff that have experience with that area, to make the space comfortable and for all. Changing the lighting, lighting is very sensitive, but most important, making them feel comfortable. Making them feel like they have a family. Next slide.

Just support nondisabled staff to understand the importance of being an authentic ally and model this. They practice our principles and preach those. A lot of time the nondisabled staff will partner with disabled staff to be able to bring that representation when needed. That is really important.

That is also teaching other agencies, nondisabled run agencies, the value of coming to us to get the disability representation.

Again, disability intersects with everybody. If you are not learning about the communities, again, you are not going to reach people. We have programs that fuse the cultures in South Carolina to make sure that we are meeting the needs, if we are talking about one community that is not going to reach them, but also looking at your disabilities as well. Are you serving people with intellectual and developmental disabilities? People with psychiatric disability? People who are blind, deaf, medical conditions?

For a lot of times, SILs refocusing on people with physical disabilities. If you're only equipped to provide programs for people with physical disabilities, people are not going to become people coming into your program. Know your people, next slide.

Strategies for ensuring a Disability-Led organization and culture through disability representation. Talk to your border cancel about creating a succession plan that ensures that executive and Board President/chair are individuals who proudly and openly identify having a disability. At the top of the organization, there are trickle effect when you have that.

If you are not disabled CIL or SILC director, talking to your board or council about really needing to pass the torch. I have had amazing conversations with nondisabled CIL directors that say, "I feel like I'm out of place and I need to do succession planning, because I think it's time to pass the torch to a disabled leader." It is OK to admit that, and we will help you, and feel free to reach out to us at any time.

Create opportunities for a pipeline of talented disability leaders as well. We do an AmeriCorps program, we have hired four people from this program. We have interns. We look at specifically people with disabilities that are in school. We also have a youth group, we are very big in youth. We serve several thousands of people who are in school and are young adults. Building them up to create your next Judy Huemann and Ed Roberts, but a lot of people are passionate about the work that we all do and are eager to jump in.

If you cannot find people with disabilities to fulfill your staff, and your leadership, then the CIL may need to reassess that, you may not be doing it right if you are not building leaders. Next slide.

Struggling to recruit. I have heard CIL's say, "I just cannot find disabled staff." How is that? I've also heard people voting polls say that there is nobody that votes that is disabled. Are you inviting them in? Are you creating the welcoming space? Are you creating the pipeline? You should be able to if you're providing programs to people with disabilities, you should be able to recruit within those programs, as well.

Again, raising it up where you are disability led organization, and opening it up and making it a safe place.

Ensure the majority of the management identifies as having a disability. I am happy to say that 100% of our decision-makers have disabilities, and over I think 92% of our staff are people with disabilities, and we are about 66 staff members.

Develop an employment plan to bring CIL/SILCS to majority disability status within a timeframe. When I started, I had five employees, and the majority were people not relating to having a disability. As we grew, I wanted to make sure that our disabilities are different. That we do have diverse people with different disabilities on staff. This is important because again if you do not have people that look like your consumers, they are not going to feel comfortable. If you have staff that cannot relate to the disability culture, it's going to be difficult. Next slide.

We are close to time.

Here is the call to action. What are one or two key things you learned from the session? That you are planning to bring back to your CIL and SILC to implement and put into action?

You can put that into the chat. You can email that or even think about that. What are one or two things that you are going to do? In one or two things that you learned from the session so far?

I'm now seeing the chat. Hiring more people in the disability community. Anything else?

Think about that. We took into a peer support through Zoom. We don't call it that because is not attractive to say that, we call it power hour, and for youth, we put hang out. We are looking at how to meet the needs as folks are unable to come to your office. Transportation is a huge barrier. Are you going out to them or are you having your programs able to be virtual? Absolutely.

Community building. I like to see more cross disability in our staff. Our staff currently only have people with non-apparent disabilities. Yes, that is really important. I want to find out how many employees in management and on the board are actually people with disabilities.

If you need any strategies, feel free to reach out. You can do that in a light way. I'm going to go back to my ED and asking her if she think I'm good to be the next Judy Huemann. That is my staff. Disabilities equitable. Find people that participate actively and not just attend meeting.

You don't want people to just sit there. You want to learn from them, you want to engage them and sometimes that is just asking questions different.

Is your content accessible? Are you asking open ended question? Are they comfortable sharing? Why should they share with you? Really thinking about that.

We can be better at encouraging people with disabilities to apply, absolutely.

Ensuring job postings.

Y'all have great recommendations.

Looking for the intersections of disability to increase diversity. Yes. Loving these.

CRUSH RUSH:
There's a question asking if you can define having a significant disability for an Executive Director?

KIMBERLY TISSOT:
Significant disability within the regs, within the ADA definition, with the exception would be able to receive services from CIL. That is what qualifies you as somebody with a significant disability. Would they be consumers at your organization? Thinking about that.

Yes, feel free to unmute yourselves if you want to talk about this. This is definitely a conversation I know will continue. Feel free to reach out at any time, to ABLE South Carolina, if you need strategies to talk to your Executive Director about finding out about disability leadership.

Real quick, just how might you recommend or make adjustments to your hiring and promotion policies and processes at your CIL? If you want to put some of that specific, put that into the chat, that could be something that we share. As well, in future presentations.

Do you define significant disability as self-determined? That is for somebody to decide. There is not any eligibility forms or anything or tools that is out there, for an individual to decide if they are a person with a significant disability or not.

Alright. Who can I reach out to? To see if management has a disability. You can reach out to IL-U, or me, to talk about the leadership. It should be listed in your PPR, maybe ask your Executive Director if they can share the PPR because you want to see the amazing work the organization does. That is where you will get your data points.

Oh, Timothy. I'm not going to read that.

Thank you so much. I'm going to pass it back to Mary-Kate.

MARY-KATE WELLS:
Thank you, Ebony, Crush and Kimberly for joining us today. That left a lot on our minds

on how to continue the conversation.

Before we go I want to advance the slide to the evaluation. We want to hear your feedback, what other topics does this training or session bring to you that you want to hear more about?

The evaluation link is a QR code on the screen. It is also in the chat.