IL-NET T&TA Center’s IL Philosophy and Practice Summit: Reclaiming Our Movement
Presented by: Rosalie Eisenreich, Paula McElwee, Amber Smock, Mary-Kate Wells
September 17, 2024; Session One

MARY-KATE:
Welcome, everyone. As folks are joining thank you so much for joining us today for the IL philosophy and practice Summit Reclaiming Our Movement. We have a whole team behind this two day event and we are really grateful that you chose to join with us.

I am going to jump right into the housekeeping so that we can get into the conversation and discussion of the next two days. Today's presentation is brought to you by the administration of community living in the United States Department of Health and Human Services. In conjunction with the IL-NET. IL-NET is operated by ILRU in collaboration with in CIL, APRIL and the University of Montana. My name is Mary Kate Wells. I use the pronouns she/her. I am a white, 30-year-old woman with short, reddish hair wearing a black button down. I am the director of programs at the National Council on Independent Living, or NCIL and as mentioned it's part of the IL-NET technical and training assistance Center and I will be your moderator for the summit.

On the screen is the logos of the key partners for the IL-NET.

IL-NET is the training and technical assistance Center for Centers for Independent Living, statewide Independent living councils, and designated state entities.

We are going to just take a few moments to review some housekeeping items to ensure...

Access captions by clicking show captions in your Zoom bar. I'm just going to pause. Jenny is there.

SPEAKER:
Can you repeat yourself there? I think you froze for a couple of seconds.

SPEAKER:
OK. We are going to be doing some accessibility and housekeeping notes. Today's event will be captioned in real time. You can access captioning by clicking Show Captions in your Zoom menu. Or through the stream text external link that can be accessed in the chat.

American Sign Language is also available today. It should always be visible. They will be spot lit on the screen, but also access through the interpretation channel.

Please let us know in the chat if you have any issues seeing the interpreters. We also have Spanish-language interpretation which can be accessed by clicking the interpretation button in the Zoom menu and selecting the Spanish channel.

Due to ongoing Zoom up dates, as many of us have experienced, we highly recommend joining the summit from a desktop computer or lack-- laptop to have access to the full range of disability options.

A common question we often get is will the slides and recordings be available? Yes. The summit presentations PowerPoint and materials will be posted on the ILRU on-demand training page by September 23.

We ask that after each presentation we have a brief survey evaluation that we ask that you take some time to complete.

We are almost there. This is really important slide. We really want to engage with all of you today and tomorrow through this summit. There are number of ways that you can participate. As many of you probably know here we prioritized accessibility and our movement is across disability movements. We recognize that individuals have diverse, and sometimes competing access needs.

Access needs and supports or accommodations that a person needs to communicate, learn and participate fully in an activity. Today we are going to be using some new technology, but we will offer multiple options for folks to engage in participate in the activity.

Throughout the summit you will be able to chat to host and panelist at all times. We are trying to save the chat for accessibility and technology issues. We are going to be turning on public chat during specific times in the session. We will announce it during each session when the chat will be turned on and we will give an announcement before we turn on the public chat so that individuals can make adjustments to their resume notifications to address individual accessibility needs.

We will also verbally share the content that is posted in the chat. As a note when the chat is open we will not tolerate any discriminatory, offensive and attacking behavior in the chat. As that might challenge us and then trying to keep that conversation going.

You will also find in the chat along sessions resources for continued learning. This document is also available with all of the links on the ILRU training page.

Next we have the Q&A box. Please submit questions throughout the summit. You can get to the cooling box on the Zoom menu and enter the question.-- Q&A box

We are aiming for is much engagement as possible. Even though we might not get to every single question we are using a parking lot system, which essentially means we launch the questions and comments we might not get to are important, but can't necessarily be addressed right now. Attendees are welcome to stay after the final session for a social hour for some more informal conversation.

You can also email me. mary-kate@ncil.org with any questions.

Next we have the raise hand feature. We are going to have a call to action section and we invite attendees to raise their hand for response. We will invite you to unmute and please try to keep your question to about 30 seconds.

And finally, we are using a new platform called cold everywhere. We will use this as an option for engaging with everyone and provide instructions to follow shortly.

On this slide is just a quick agenda so folks know what to expect over the next two days. Each summit will have a kind of speaking presentation, or conversation section and then followed by or during that session a call to action.

The call to action is an opportunity to engage with the content that was presented and how you

might use that at your center. In addition to any questions that you still have. Today we will have two sessions. And a break in between.

After the second session, like I mentioned, we will have a social hour for more informal conversation.

To kick us off we are going to do a poll. On the screen is the question with two options to participate. I will read those out loud. Folks also have the option to put their answer in the chat.

The question we are going to ask you to use, so you're going to Hoh either a cell phone or tab on your computer. Describe your role. We want to know who is in the audience. The options are a, are you in IL skills trainer or peer advocate, B, supervisor manager role? C, executive leadership or executive director. D, board member. Of SIL or silk.

There's a number of ways you can respond to the poll. You can answer it on a web browser. If you are going to do that you are going to open a tab and put in pollev.com/disabilityled and wait for it to appear.

We are going to put the link directly in the chat and it is also found in the PowerPoint and confirmation email. You can also text your response to the five digit code. 22333. In the body of your text you will type in the keyword disabilityled as one word. From there you will reply to the text message with your answer. A, B or, C.

We are going to switch screens so that we can, and Sharon I am going to switch with you. So that we can look at who is here live together. I will provide additional subscription-- description.

On the screen you have the instructions on how to give your response. We have the four options. People are answering them live right now. It looks likely have about 45% of the folks attending today are skills trainers or peer advocates. 20% are in a manager or supervisor role. Another 25% are in executive leadership or executive director role. We also have some folks who are board members, about 3% which is really exciting. I also saw in the chat that there was a DSC, designated state entity joining us as well.

Thank you for joining. We have some other in the chat. We have some board members, skill strainers,-trainers. Folks on consumer advisory. This is great.

I am going to stop sharing. It looks like the poll is changing and please feel free to do that. The majority of your skill strainers and peer advocates followed by executive leadership and supervisors. I'm going to stop sharing and go back to the slides.

Thank you so much, everyone, for trying our poll. Let's get into it. We just stopped sharing the poll, so that folks know, and we put the slides back up. We are going to start with session 1, which our speakers are going to review the aisle philosophy and its tenets.

As a reminder, and we will put this up at the end, we ask that you complete the evaluation.

We have three amazing advocates and facilitators for this first session. All from different backgrounds. Amber Smock from ACCESS living in Chicago. Rosalie Eisenreich which I forgot to make sure I pronounce your name correctly so you can correct you later, Rosalie. From southeastern Minnesota. Southeastern Minnesota Center for Independent Living. And then our own director of technical assistance, Paula.

With that I am going to invite Amber Smock to kick off with semi L principles and philosophy.

AMBER SMOCK: thank you very much Mary Kate, I am Amber Smock, Vice President of advocacy for Access Living which is the Center for Independence living based in I have a black shirt on, sitting in my office at Access Living and what I would like to do to help everyone get started his talk a little bit about some of the values and core ideas behind Independent Living Philosophy just to level set everybody as we get going on what we hope will be a conversation over the next few days on really staying centered on independent living and how it applies to running centers for independent living. Next slide, please.

So the first thing I really want to bring everyone's attention to is that we all come all of us at Centers for Independent Living, deal every single day with the legacy of institutionalization in America.

By that I mean our country is absolutely rich with the legacy of institutionalizing and segregating people with disabilities, not just people with disabilities but also about institutionalizing and marginalizing people who are poor, etc., etc., we live without every day and that's what we work to try to fight every day.

The origins of these institutions though date back to you in the 1600s, that's something a lot of people don't know, in the 1600s especially in the Netherlands they were wealthy folks who decided that they wanted to show their prestige and status by spending money on institutions or what they called poorhouses or work farms come these were places you could work, get a little bit of bread and water and live there, and that was really the origin of institutions, because that's about having a separate place for people who are considered the other thing.

But in America what we would really have seen is that idea of the work farm or the poorhouse developed into something called the American institutional, like jails and institutions for people with different disabilities and that came to the fore in the 1800s. So it's important to keep in mind that there is a historical background to what we do and we are making history as we go about our work. Next slide, please.

And just to continue on that frame of thought, we have to also remember that the individuals who have always been most at risk of institutionalization have also always been the poor. People of color and other individuals from marginalized groups who have no other options. This happens to people because there is nothing else. So, what is resulted is the dehumanization of people with disabilities. Dehumanization of different groups of poor. We know that institutionalized people are subject to experimentation, exploitation, abuse and neglect even still today.

So this is something to really think about as we consider, yes, I am interacting with folks with disabilities, I am a person with a disability working to support others, but what is all behind us? What led to this thing called the Centers for Independent Living? Next slide, please.

I want to focus then, keeping in mind we have a legacy of institutionalization that independent living also has an activist legacy. And this is one of the reasons why advocacy is one of our four core services in the five core services of independent living.

Independent living is a movement is both about building community and about fighting for change. So yes, it's about accessing services and yes it is about finding supports, but it really

has literally been about willing community and working together to fix what is broken, right?

So for us, direct action, civil disobedience and protests have always been necessary for disabled people to change society. This is what happens when people have nothing left to lose, OK?

Not only that but we also transform our society when we do that kind of work, but we transform ourselves every single day. Working at a Center for Independent Living is about self-transformation and the transformation of people around you every single day. Next slide, please.

So, you will hear more about these principles over the next couple of days as everybody does their presentation, but I'm going to lay out a few things that are very important. So, a lot of us know when you come to work at a Center for Independent Living there's a distinction between the medical models in the social model of disability. Under the medical model, medical way of seeing things, we know that disability is a diagnosis.

In it’s consider that the person who has a disability is broken or deficient and needs to be fixed or cured. But the problem with that model is that it dehumanizes us, right? That's why Centers for Independent Living focus on the social model of disability that disability is about the barriers society constructs around us in a person with disabilities should be accommodated.

It's not actually asked, people with disabilities. I am a person with a disability, I am deaf, it's not me, and it is the way society is built around me. Next slide, please. So there are some other things around the independent living practice and one of them that has really come to the fore over the years especially now is the tension between care and support. You know, when we think about people doing independent living, people practice it and what it means to be independent in the community, considering care versus support is very important. You have to ask yourself this question, who is really in charge?

This is very important in the independent living world, the person who gets to be in charge of the person with the disability, right? But that's not always a given so we are thinking about who is really in charge in a given situation. For us at Centers for Independent Living it is also very important to focus on the fact that what people want is self-determination. People don't want to be managed, they don't want to be controlled, and they want to be able to make their own choices.

There's a difference there between care and support, which thing feels like care and which thing feels like support? I'm asking you to reflect on that. We also know that in care versus support there's a tension between listening versus prescribing or assuming things about a person, right?

Is listening a form of care or support? Is prescribing or assuming care or support? It depends. We also know that for us it's very important to really think about person-centered consumer directed planning. So again, the person with the disability gets to be the one in charge, right? Versus the other way around where case manager plans things for people.

And, you know, they are going to be people with disabilities out there who say I want a case manager, I want people to do things for me, but there are a lot of people with disabilities feel like that takes away control and have been wronged by case management practices, so trying to find a way to support the person in a person-centered planning and consumer directed planning is very important.

And then one last little challenge in this area to think about in the realm of care versus support is you really have to consider about that the person with access to the most resources is not necessarily always the person who should be in charge of things, in a person's life.

And so, being able to hold that truth, that a person with a disability, that center for and up at living staffer might be working with might not be the person who has the most resources but it doesn't mean that they aren't going to have an opinion on how their life works, right? So whoever knows the most, isn't necessarily the person who gets to decide sometimes and we have to be OK with that. Next slide, please.

So, a different core tentative independent living we know is what's called peer support, it's one of the five core services, right? And there really is a definition for peer support and mentoring. And that is that it is a process through which people who share common experiences or face similar challenges come together as equals to give and receive help based on the knowledge that comes through shared experience.

This is so important, and it is vastly more meaningful to work on things and problems in your life with someone who really understands. The independent living in practice is about people with disabilities who have lived experience helping to support and empower their peers with similar disabilities lived experience, and you are going to be hearing more about that in the next couple of days. Next slide, please.

Another key principle behind the practice of independent living is that about having access to choice. Knowledge is power, and people with disabilities need and deserve to know and understand all the choices available to them to make informed decisions.

We don't always know what someone is going to think about making a choice, we just need to give them all the choices and then they get to decide in the choices should be communicated and explained to people with disabilities in an accessible way or format which might include but is not limited to written and verbal, spoken format, alternate print formats like large print and braille, ASL, plain language, you really have to communicate, OK? Next slide, please.

OK, very important principle behind independent living practices consumer control. Now, a lot of folks who are new to the movement might not know this but the idea of consumer control came out of the 70s to really understand how product's needed to protect consumers, like safety. For example there didn't used to be seatbelts, right? But the consumers were like don't put me in a car where I'm not going to be safe, right? I need some kind of seatbelt. So the consumer control and knowing what you are purchasing is very important, and in independent living practice this means that the person with the disability gets to make the choices about their lives, that consent and choice are critical, and consumer control, you should know, is not someone else deciding what is best for the person. And that leads us to the next slide. Next slide, please.

One of the deepest and most challenging situations in independent living practice is when you, I, you, somebody we see, does not presume the competence of those with disabilities who come through the door. Presuming competence is very challenging but very important. Far too often people in society make assumptions of the competence of people with disabilities, and independent living work is really important to start by presuming competence.

If something isn't clear, if you're not sure something is getting through ask the person questions to clarify like, you understand? Etc. It's really important to find a respectful way to engage in

meaningful dialogue that is interactive and reciprocal and accommodating. Independent living is not the movies. We are not barking orders at people, we are having conversations so the person can make decisions about what they want to do. Next slide, please.

OK, presuming competence, you know, can be challenging, I mean everybody has biases, right? You might think somebody is not competent to make their own decisions but you have to presume that they are. This is related to also being OK with the dignity of risk and the dignity of risk is a very important concept in the world of developmental disabilities.

So just like people without disabilities, people with disabilities can make choices about their own lives. And those choices can have positive or negative impact. But the choices belong to the person with the disability, not to anyone else, and we live with the consequences of our choices, again, just like people without disabilities. We decide who we want to date we decide what to spend our money, we decide where we want to live. We decide who we want to be friends with, not all of those decisions are going to have good outcomes. But, they are ours and when you take that away again it dehumanizes people. So independent living, once again is about putting humanity back in how the world is viewing people with disabilities. Next slide, please.

OK, this is my final slide, very important. Particularly when I started at Access Living there was a big â€“ and I started at Access Living a long time ago in 2005, and even then people were questioning the idea of what being independent really meant. Whether being independent meant you had to do editing yourself, and I think today we see with all of the various communities in the different kinds of families and all the different kinds of systems that people with disabilities live with inside United States, the interdependence is important and it's OK, and it's actually kind of really what we do.

People might assume that independent living means that a person needs to do having themselves, and that is inaccurate because independent living is really about people with disabilities being in charge of our own lives, and deciding who we want to be relying on, who we want to be in community with.

That interdependence, that choice and interdependence is independent living, so in the next couple of days you're going to hear a lot more about these various principles. You will get the slides, and I'm sure NCIL will make absolute sure of that, but you are going to hear some challenges, right? To the way a lot of people do things. You are going to hear things like "we need to think about the fact that we support people without question in what they want to do, as long as it doesn't involve their personal safety.", We need to think about whether we make assumptions about our consumers and our coworkers that prevent us from fully realizing the best community possible. You know, we need to think about, are we prescribing things for people that aren't allowing them to choose? All of this will play out not just in how the Center for Independent Living is wrong but how you interact with the community.

So I'm going to stop there, and I believe you're going to hand off to Rosalie. So I see Mary Kate just popped up so thank you for your attention.

MARY-KATE WELLS:
Thank you, Amber Smock, I think we could dive into each of those but we are going to hear those in application over the next two days. So, Rosalie, I'm going to hand it off to you.

ROSALIE EISENREICH:
I am coming to you from my home office in Roseville Minnesota. I am a white woman with

braids pulled back into a bun. I have a green shirt and blue vest on and I am in my mid-30s. I identify as a CPT SP-- CPT SP Betty and thank you Amber for setting that stage and being a support and congrats. You are almost at 20 years with access living. That is awesome.

Before I get into my bit we are going to do a quick poll. My helpers in the background, thank you. Before you start answering this is take two. I'm glad you are with us on this journey of trying out new communication tools. Please send your response to the following question either to the website. pollev.com/disabilityled. Select your response there or text message or response to disabilityled at 22333 and then type in your response.

The question is, "Have you read the independent living program purpose statement that is in the rehabilitation act of 1973?" We will give you a few seconds to go ahead and put your answer into the poll and we're going to switch over.

RP Ron the poll screen we have people sending in their answers but it looks like its holding steady at 51%. People say yes they have read that piece of the 1973 act. 34% said no and guess what? I am one of you. Before we prepped this I had not fully read that. And then 15% not sure and that's OK too. Awesome. We are holding around 50%. That's awesome.

We can go ahead and go back to the slides. I will go ahead just for the sake of all of us to review and then also introduce that purpose statement.

Up here on the slide is the title VII independent living purpose statement. "To promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access and individual and system advocacy, in order to maximize the leadership, empowerment, independence and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of America."

That is the purpose statement. In reading this and reflecting on our conversation today that is what was put into law in 1973 that made Centers for Independent Living part of a larger system of nonprofits and statewide Independent living councils.

As we go ahead and go through some more of the content here I just encourage you, just as Amber did, to think critically and engage in curiosity. What has been may not be serving us now. Really thinking about how we can open up and that's the purpose of today's seminar. Open up to community consensus and conversation around what does it mean now and moving forward to be a Centers for Independent Living while honoring our roots in that grassroots advocacy.

We will wait here momentarily. Looks like the slides got a little shifted. Thank you for the next slide.

So, with the review of that Rehab Act and the invitation to consider who we are is the independent living network now I took a little bit of a look back just as Amber did because history and what has been billed is important, and honoring and holding the good and owning where we need to do better is important. Up

On the slide just going to the hold the idea and concept of what is movement. Social movements have a planning goal. There are people who activate outside of systems and how things have been because very much so it's usually out of desperation, it's out of what was done and frustration, and it's asking for changes and asking for something different and better that

serves everyone. Movements bring people together and that's a core component. It is a relationship building exercise. It is something that continually grows. Again, it's a group of people with a common goal or identity that are moving together.

Movements do, at some point, just because it is a social thing can be co-opted and ceased to exist. So, where are we at the 'Where Do We Go From Here?' knowing that we are into federal statues-- statutes which are part of the system. Food for Thought.

The word by definition means there is motion or progress. We should be moving towards something together. Movements, we are trying to make something tangible in that change. We are trying to change social attitudes, rules and commonly held conceptions and often times that needs to be done outside of typical means. It starts with relationship and building trust.

Stagnation and movements is not an option because power begets power and powerlessness begets powerlessness. This is one of the rules of power. It's a law, force, it's neutral but if you are not acting you are being acted upon. If we don't move forward we will be forced back and we have seen a regression in rights of reason. Plenty of examples.

Next slide, please. As I said we start with our history because it is our roots. The people who pave the path before us and are continuing with us and passing them to the next generation. It's honoring those and the work that they did because this work is hard. We are all humans and capable of both good and harm. Really moving together as a movement in a community requires that we hold each other accountable and how do we hold each other when there is disagreement or we have differing opinions.

Maybe we have different processes. How do we create space for each other while also holding true to a set of values and goals that we ultimately have? Our community is built on cooperation and cooperation is necessary to have relationship and largely we need to challenge what is comfortable.

Curiosity. Questioning can often times be seen as dangerous when we need to approach all things with questions. We have a lot of conversations with my son about how do we capture the magic of being a kid where you just show up and you see the human in front of you and you look for the opportunity to get to know that person in front of you. Be a kid, stay curious. Curiosity is something that invites others into a space and for you to learn, and be in a space of learning with others to figure out how to best support each other. We all have something to gain from being with each other and keeping that communication alive. Next slide, please.

Real quick here I believe this is where we are opening up the chat. Before I continue on if you could put one word or a short phrase into the chat of what you think disability rights are, what it means to you and we're just going to take a brief moment. I will read out the different listings and responses that you're putting into the chat. So that everyone has the opportunity to hear what the community is saying.

Just as an exercise to build some consensus here. Important, equal, that some people think quality. Rights and independence. Freedom. Awesome. Seeing a lot of equity. Holy smokes you guys, it's going.

Pride, dignity, inclusion. Inclusiveness, collaboration. Under threat. There's definitely some pushing back on human rights for us. Civil rights, peace of mind, Honorable, code compliant. Relevance. Interesting. These are lots of great answers. They just keep on coming fabulous.

Valued enforcement and personal choices and empowerment, self-determination. Diversity.

We are gaining consensus here that this is something that's been very important and central to the work that we do. You want to go ahead and my support crew in the back if you can go ahead and close the chat we are going to keep moving on. Thank you all for that. Toothless. No teeth for enforcement. Interesting. I'm glad we ended right there.

Defining disability rights is something that's very central. Something that's been very integral to our movement. It has established a foundation of civil rights. The United States for us. It's a mark of where we started as a community. The work of advancing the top loss-- philosophy of fighting for independent rights and providing advancements in public accessibility is something that has been a huge piece in the legislation of the Rehabilitation Act for the Americans with Disabilities Act and so forth.

Civil rights largely have been a process that's been through legal and policy systems. At least in the disability rights. At its core defining disability rights is something that is important, but usually focuses on a single issue, or someone's single identity.

It's really helpful, it's a tactic we use on a regular basis to make change happen, but we have to recognize it's also working within systems and it's also why I think there was someone that put out there that rights are toothless because in some regard there hasn't really been a mechanism of which the general public has change their attitudes toward people with disabilities.

Largely we still deal with a lot of inaccessibility. We deal with a lot of discrimination, and sadly governments and the public, who largely get away with it even still. Looking at this it's important, it's a way to gain traction but it's definitely looking at a select few or only a single issue so it's not holistic.

But it does relate to all of us because that has been our history. Part of our legacy in the movement, and just real quick, a quote from Patty Berne who is a disability justice activist, she says at its core, Disability Rights centers people who can achieve status, power and access through a legal or rights-based framework which we know is not possible for many disabled people or appropriate for all situations.

So again it's really asking that question Amber put out to all of us which is who is in charge and who should be in charge? And, you know, how do we want our advocacy to be more holistic moving forward? What progress do we want to see together and who needs to be there? And who needs to lead? Alright, next slide.

Oh, and I apologize I just went through all of that and forgot to say next slide so just so you all are aware, again, on the slide Disability Rights bases work on single issue identity often at the expense of others and focus solely on political or legal systems as the basis of change, and historic leadership and action has centered white disabled people with mobility impairments. This is a reality that we need to acknowledge, and again honor the good that has been done but how can we own and move toward progress, which is being more inclusive of those most marginalized in our disability community.

Alright, next slide here, I got off a little bit. Alright, I'm going to pause here, I got a little messed up with my slides as you saw, but we're going to open up the chat again just for one more consensus building exercise. So, get ready.

This is going to be very similar to the last, before we get into Disability Justice AP to defining that, what does disability justice mean to you? Go ahead and put your responses in the chat and I will read them out. Important, quality, confused, rights being enforced, accountability, centering those most marginalized, choice. Something is nonnegotiable, breaking chains. Freedom to exist in society, accessibility, recognition of accommodations needed, reliable, whole inclusion, accountability, systematic change, society meeting where everyone is not just able-bodied people. Full inclusion, making sure everyone is regarded and has what they need, OK, fair treatment, period, intersectionality, no social barriers. Fairness. Alright, alright.

Willingness to wield the sovereign power of the states to remedy an invidious legacy of isolation, I live with a bunch of academics and I'm not even sure I know that word that I just wrote off, but I'm sure it was great. This is the lady justice means disability seriously and not just the ones with codes and regulations. Looking at who is not in the room. The right to stand up for yourself. Great, great, thank you for engaging this exercise, if we can try to save those and make sure we all have access to that and what the community is saying about rights and justice.

Freedom from inequities caused by capitalism and commodification of humans for work. Alright, Rina, that was definitely something right there. Alright, so defining disability Justus, just moving back into conversation, really great responses everyone. No right or wrong responses, really it is a matter of building a consensus of understanding, where are we all that and what do these words mean? And do we know and have a solid foundation together of what that means? Again, consensus is this form of understanding as a community what we want to build together.

And so, disability justices related to, right as disability justice, excuse me.

MARY-KATE WELLS:
Do you mind holding on one second, Rosalie? Brenda, ASL interpreter, we cannot see you. I think we may have lost our other ASL interpreter, are you able to come on in to interpret, Brenda? Cool, thank you. And I will check in with our other interpreter to see what is out. Thanks! Continue.

ROSALIE EISENREICH:
Do I need to go back at all? Do we need to move forward?

MARY-KATE WELLS:
You go back couple sentences? I think it just happened, but just in case.

ROSALIE EISENREICH:
OK, so disability justices related to Disability Rights. It is more expansive, it is a justice framework that understands all bodies are unique and essential, all bodies have strengths and needs that must be met, and we are powerful not despite the complexities of our bodies, but because of them.

So it's this unifying idea that we are more than our productivity, we are more than just our trauma, and we are more than this is part of our human experience. So, next slide, please. And that focus of the body is really attributed back to disability justice activist Patty Burns, Stacey Milbern and Sins Invalid.

We have the link to the 10 principles of disability justice for you all to just check out that framework, it is not a how-to guide, but it is something where you very much like the Independent Living Philosophy, this is what we need to talk about as a community and build

consensus on and what does that look like. In all of our little corners of the United States and beyond.

So defining disability justice, largely this is something that we just â€“ it expands what we can think about when we are thinking about advocacy, building solidarity and understanding how power honestly gets manipulated and systems continue to keep us in a position where we are having to fight for survival.

All bodies are confined by race, gender, sexuality, class, nation, state, religion and more they cannot separate them, that is another quote by Patty Berne. Again, she is the author and one of the many authors that collectively works with Sins Invalid. In the disability justice movement. Next slide, please. Awesome. So, again, disability justice is part of our collective human experience. Focusing on rights is the starting point, and it is a useful strategy and tool, however we have to acknowledge that we are people beyond work, people beyond systems and community.

Community building is the work that we have been charged with, I mean, that's why the CIL's initially got started. Yes, services access and support but it was also solidarity, recognizing each other, recognizing that we all have value in this community, and not everyone's gifts and bodies and experiences are going to be the same and that should be celebrated. And we should all be working towards space for everyone.

So, just on the slide, disability justice is an invitation for all people to benefit everyone. Disability justice is led by people with disabilities who have been most marginalized, so considering all of the multilayer facets of the many identities each one of us hold, I am a white woman, I am a disabled person, I have invisible disabilities, I'm the oldest daughter, I am a dog mom. All of these things are identities that I claim in so many others claim, and my body takes up space and does so many things and has been so many places, we all have this integral layering of who we are on the basis of our experiences in time and space.

And disability justice tries to recognize that. Disability justice is a way for building community power, not just a movement for single issue or group of people. It is really thinking about all meeting all. And, next slide, please.

So, again, got to love Patty, she's pretty great. She has another great quote I want to put out there, the root of disability oppression is ableism. And we must work to understand it combat it and create alternative practices rooted in justice. Next slide.

And so, thinking about what the A word is, Ableism, I wanted to offer up Talila Lewis' definition, she created in community with other people, she is an amazing activist, she's part of the African-American community and she's part of the Deaf and Hard of Hearing community.

She also is a practicing attorney, and her definition is basically calling ableism's system of assigning value to people's bodies and minds based on societally constructed ideas of normalcy, productivity, desirability, intelligence, excellence and fitness. These constructed ideas are deeply rooted in eugenics, so trying to literally erase the existence of people, Anti-Blackness, misogyny, low nihilism, imperialism and capitalism. And so we think about ableism under that name, we have a charge as people who are advocating for bodies, like humans who are in these bodies, we are all valuable and we all deserve that equity and that a quality of life and it shouldn't be a power struggle between all of us who are marginalized but rather we are under a common umbrella of we want our bodies, our cultures, us as human beings, to be

recognized, loved and cared for. We want to all the long, and that is the basis that I think really is just very unifying definition of how ableism really should connect us all in our advocacy work.

Alright, and next slide, please. Alright, and then just to wrap the quote up, ableism is systemic oppression that leads to people in society determining people's value based on their culture, their age, language, appearance, religion, their birth reliving place, health or wellness, quote unquote, whatever that means to the given culture and time. And or their ability to satisfactorily reproduce, excel and behave.

We should be moving towards this concept that our humanity and our freedom is bound together. Alright, next slide. So, ableism is what unifies all of us. If we really come from it, from Talila Lewis' perspective, she and many others are seeing how this plays out, you can be disabled and still perpetuate ableism, including that piece inside of yourself, were the ablest leaves you hold against yourself, and how are you harming yourself in this process?

It also invites people in who are not disabled to have a common understanding of what it is to experience ableism. I present as female and I have definitely felt that judgment because of how my body presents negatively and positively had that impact me.

There's really so much complexity to the human experience and our bodies and really thinking about when we think about advocating our power comes by numbers and all means all.
, Please.

So, as Amber said once again much of what we had to say really does tie through. History is being made whether we want to acknowledge that or not. I know for myself I get way too into the weeds and overwhelmed about the fact that there is so much to do, and for some of us we need to push ourselves out of our comfort zone and way of thinking and start questioning ourselves and why are we doing what we are doing? How did we get to this point in history and we are making history. Let's do that intentionally.

Disability rights and justice are neither in opposition or mutually exclusive from each other. When we think about our goals and that process we have to build consensus, but disability rights and justice fit in with each other, but I would say justice is definitely a goal that we want because if we can figure out what that looks like and how we want to create justice that means that we are definitely being more expansive and inclusive, which is ultimately what we want to do.

Recognition and acceptance of our incompleteness should drive our future action. When we call out and say oh it. When we say these things are happening and they shouldn't be its not necessarily we don't want to meet you all with punishment, and I certainly would not want that when I mess up will stop I'm not doing something I'm supposed to be. My hope is that I would be approached in care and again have a conversation, communicate, build the consensus of if things are incomplete and somethings causing harm or something we are not doing is not pushing us forward in a way that we need to make sure we are all acting helpfully together.

I would hope and ask that all of you think about what are those sticky areas. What has been said or will be said in the coming days. Have those conversations with each other because if we cannot figure out how to celebrate and hold space for our differences how will the rest of the world Accept us?

With that thank you all for listening. We are going to go ahead and go to the next slide and the

next speaker who is Paula from the independent research did (audio issues)

SPEAKER:
I have that silver hair and I am a little older than some of the other people today, but I am so thrilled to see these generations of others coming up and making a difference in believing in what we do.

Just a quick description. I'm in my home office. Silver hair, Scottish complexion, and ready for that next slide. I'll ask Rosalie to stay with me on this because we are going to talk, I'm sorry I hear somebody talking.

MARY-KATE WELLS:
I just wanted to pause and check in with Brenda ASL. If you are good to keep going or do we need, do we have a Jenny update?

SPEAKER:
There trying to figure out what's happening to our other ASL interpreter. Are you good to keep going or do you need a five or 10 minute break?

SPEAKER:
I can keep going, but if you can just let me know when the other interpreter gets back on that would be great, but I can keep going.

SPEAKER:
Great. Let us know if you do need a break and we can take a short break.

SPEAKER:
Thank you so much.

SPEAKER:
Thanks. One of the things that we talk about as we talk about what we believe in is the fact that we are not service providers. That might surprise some of you because we are required to do a set of core services. As Amber mentioned earlier that's part of what we do, but we do that because those services accomplish the change we are looking for. We are agents of change. Through consumer control We Work for equal and equitable access and through advocacy we maximize our power and independence. Through peer support we lift and empower each other.

Those things are related to our services, but they are really who we are and what we believe our purpose in IL is to push for and drive meaningful change that creates a society and communities that we are all fully part of and meaningfully engaged in that society.

As we talk about this, and some of what you said Rosalie is really related to this, not all of our disabilities are obvious. Mine is not. At least it's not on zoom. You can probably tell if I am walking around with you someplace. I do occasionally have a neurological thing that happens while I am on camera where I cannot speak for 45 seconds or a minute. If that happened somebody will jump in and take care of me.

We are partners. We roll with our disabilities. They are part of who we are. They are not something to be ashamed of or hidden. I have sometimes seen IL staff hesitant to say anything

about their disability. If you have a disability or part of the community and let's share that. Let's push together for that meaningfully engaged role in society for all of us. Let's look at that next slide.

There are complicated issues in this discussion. As Rosalie was saying we don't want to set anybody on edge. We don't want to alienate our partners, right? In our communities. There are some very complicated things that as we begin to look we kind of struggled a little. There is a question in the chat about the capitalism thing that comes up in ableism. That's not easy. That's not simple. When is capitalism an issue and why is complicated. It has to do with the fact that people have made money off of people with disabilities and sometimes in very prevalent ways.

But as we look at those issues it's not easy to untangle them because capitalism is so much part of how our society flows. We want to look at these difficult issues. These are things that have come up in our technical assistance with centers, they've come up sometimes as we have met with new executive directors or boards of directors. We talk to them about what they do at your center, their center.

Some of those things are troubling to some of us. Let's put it that way. We are going to look at some of those and talk about why we feel they are incompatible with, and in conflict with the IL philosophy, but we want to say from the outset the purpose of this is not to put you on edge if you are doing one of these things. The purpose is to alert you to the concern and have the conversation so that we can continue as a community to be more true to what we believe in, what we say we believe in. Does that make sense, Rosalie?

ROSALIE EISENREICH:
I'm just thinking of the great question from, it looks like was it back. (Unknown Name). That's a root question of this tension we are talking about because technically I would end this as some I am so excited to have a conversation with my community in Minnesota with the social hour and what are the ways? How do we untangle ourselves from a system we have been co-opted into because I stand in the position of seeing the six years I've part of this nonprofit network. Engaging in disability justice. How do you untangle yourself from the commodification and consumerization of everything? We even have it in our own language of consumer control.

Not to say that consumer control is bad, but we really have to be thinking about how we show up and how to show up differently because when CIL started they were not part of the system. They were acting as community organizations outside of the system completely. How do we build that community up when we are already in kind of survival state of just trying to hold it together? That's really difficult because you need to be still operational for your community and it's not just going to happen overnight where you're like, oh well I can just drop the services because I'm not supposed to be doing them. That wouldn't be wise. You're going to drop a whole bunch of people with disabilities who are getting services from you that need those without any support. It's not an overnight change.

Again, this is where we need to be more open about where we are not necessarily 100 and say, "How have you done it?" How are you managing this? How are you building community and empowering people with disabilities outside of CIL to have an actual disability community in your area because we are all isolated. I think that's one of the biggest issues I'm seeing in Minnesota and am trying to work on is we don't have a disability community. We don't have this comer Audrey of just knowing that regardless of difference of opinion the other people in my community are going to hold me. And we are building it. Not to say it doesn't exist, but we are a scrappy bunch right now for sure.

SPEAKER:
We must build it because I feel like we have drifted. When we talk about returning to our roots and independent living we have drifted from that act to this approach and that community approach and some centers are really in a place where they are in a business model and not a model of community. Let's look at that next slide and talk a little about some of these issues.

We are going to reset. This is our call to action. In a minute we will open the chat up again for everybody so that you can begin to comment on some of this. I see some questions coming up in the Q&A as well. Please feel free to go ahead and continue that process and we will see how many of these we can get to, but we are going to stir them up a little bit. Let's take the next slide please.

There are things that centers do for money. In fact, the law requires us to do resource development. We've got that challenge, and every center is supposed to do that. Here are some things, we listed them here that centers do for money that deserve a second look. Maybe your center hasn't done any of these things, maybe it's doing one or more of them.

As you look at them we would just challenge you to think about them a little bit. One of the top ones on our list is guardianship programming. If we say that people with disabilities should speak for themselves how can we provide guardianship and take the rights away?

If you don't know this there are other options for assisting people with choices who may have difficulty with that. There's other kinds of decision-making tools that can be used. When we look at guardianship this is one of the things that we want to challenge.

If you're looking at guardianship and you assist people in getting guardians I would challenge that that's difficult to justify with the IL philosophy.

ROSALIE EISENREICH:
And largely, if you're doing that what is the plan? Were you reaching out to in your estate, across the US? Who else is doing it and how can you rely on each other to create new solutions? To bridge that gap may be financially where you really relied on that service to keep the operations open, and move towards, you know, how can you become a supported decision maker proponent and how can you build that entire base and a program that really focuses on the well-being of people who have been subject to guardianship or are subject to guardianship and supporting building a community of, well, this is how I navigated getting out from under guardianship or this is how I build my community and create safety, so these are the people that I now know why go to when I need to make my own decisions.

PAULA McELWEE:
And we have resources in the IL community, nationally, that have navigated this. And so, we really want to remember that we have each other, and there are other centers who have gone the path of supported decision-making very effectively, and so we can certainly assist with that.

Now, you notice we mentioned adult day programming, so adult day programming is something that there is a fee for, and it resolves a concern that people have for someone who doesn't have anything to do during the day, and they want to provide activity.

Centers do lots of different things for that, we like to have centers that have people gather together, because we think it is exciting that they might work together on advocacy or, you

know, some kind of peer support. That is cool. Adult day programming, day after day in a center, from morning to night is probably (undiscernible).

ROSALIE EISENREICH:
I mean, how Minnesota has their day services written up, it is you show up at one place, which does not have any community access, like nondisabled public members are not there, present. Often times it has to be completely on-site unless there is some sort of agreements of like what is happening that day, but I've also seen day centers where, you know, we have a very large hub community and for the elders that is a service where they can show up and be with their community and for many of them they love it, and you know, there is a cultural factor they are of which, you know, it is their community but it is their own community space.

It is not a segregation, it's an exclusive space for elders from a very specific generation to honor themselves and be with their friends and the people after being violently displaced from their home country. It is not an easy answer.

PAULA McELWEE:
Now, and that is also true in some other communities, other cultural communities, where folks want to come together for something that they like to do together. And so you find that happening.

It is the day after day segregation that is troubling. When people are intentionally segregated away from the community at large and often away from other people with disabilities, because they are in a segregated room over here, and they are, I don't know, cutting pictures out of catalogs, I don't know if that happens anymore but I used to see some of that kind of arts and crafts with very poor materials. So we weren't talking about weavings that the mom community might like to do together we are talking about just, you know, makeshift kind of things.

I don't know how and when these are still happening, but I really do hope. I think we lost our interpreter again.

MARY-KATE WELLS:
I was just about to say, Brenda, are you able to hop back on again? Thanks.

PAULA McELWEE:
Thank you so much, Brenda, you have been above and beyond today.

ROSALIE EISENREICH:
So really, it's evaluating, who is in charge? Is this ultimately moving people that we care about, moving up the value and integrating people into an equitable society, or is this removing people away and isolating people that is going to cause further bouts of harm? Like what is community building versus what is isolating and segregating two

And, really it does come down to money or mission, and if your services that you are providing are not in fact increasing community, if they are not increasing the integration, it is not honoring the culture of somebody and their identity, then it is likely something that you really need to have a conversation around. I also know, like, we serve rural areas too, and I will be the first to admit some CIL offer PCA choices, it is self-directed so the person hires their own person and you cut the checks. But certainly that can't be our whole mission and it can't be the staple at which we operate.

And we have been working on, like, what does that look like? Because, you know, we don't want to leave anyone high and dry without services and there is not only a lot of providers providing that self-direct adoption in the area. Thank you, Amber. Yes, personal care assistants is the service I was referring to in that acronym, PCA.

PAULA McELWEE:
That's kind of hit these likely and then go on to discussion. Financial management services are services where someone else manages the money for the individual, and I think there's kind of a conservatorship, sometimes it takes that form.

So, again, removing rights and decision-making from the individual so you sometimes see that. Then, case management services might be one of the most controversial, I think it is the one of them that is happening a lot because your waiver services allow for case management services in many of your states, and it is a fee for service and you can use that to assist with many of the things you do in IL, right?

So when is it appropriate and when does it cross the line is a question that is somewhat determined by what you decide to do or what services you decide to provide. But, it is in easily slippery slope.

ROSALIE EISENREICH:
Yeah, I used to work in case management services, and again, money or mission. Are you solely reliant and this is a conversation, again that we have had, it's not just these services, but also like, our center is 99% funded on government grants through our state contracts and administration on community living. You can't really have a lot of flexibility to push for progress because nobody wants to bite the hand that is feeding you.

So really, this is a call to creativity and figuring out how to we diversify our solutions that we would bring to the table? How do we build that community power in such a way that we're doing new programming and philanthropy be? Out of 2020 and the pandemic there's a wonderful movement that started in the Seattle area called community centric funding where the community raises the funds and then the community together decides what they want to do with that and make a plan together.

It is far more responsible and ethical philanthropy because it is completely giving that control and choice back to the community, rather than a nonprofit or some private foundation calling the shots. But that is something we are even looking at because we don't have a background in applying to private grants. We've got a talk about where do we have deficits and then who in our community also has the resources and kind of has built this already? Which is how I know Amber, I reached out and I said hey, I am building a systems advocacy department and I have no idea what I'm doing. But we're doing it.

And you know, I looked at Access Living and some of the larger centers and said hey, how are you doing this? We are here for each other, you just have to reach out.

PAULA McELWEE:
Absolutely, absolutely. With case management sometimes your role is to reduce the services, to reduce the cost. And that is where you get yourself in a tangle. So that's kind of interesting to look at. Representative payee services where you receive the SSI check, and distribute it and then make payments on bills, again is removing some of the rights of the person, so we really challenge them on that.

Sheltered workshops where subminimum wage is paid, we also feel like is very problematic. Because you are paying a person less than full worth, and if we at any point think that people are worth less than, then we have bought into the ableism of the world around us and it's going to be really problematic.

So as we open the chat then go ahead.

ROSALIE EISENREICH:
No, no, go ahead.

PAULA McELWEE:
I was going to say we want to ask the questions which one of these are nonnegotiable? But, go ahead and say what you were going to say while people plug that in.

ROSALIE EISENREICH:
Yeah, I was just going to say I think the conversation in Minnesota has largely centered on, well, this is what people want. In the providers, there's really strong provider lobby groups that have really pitted the parents and people with disabilities who have known the structure against progress.

We really have to separate the fact that this is a civil rights violation, like, we are not paying humans for their labor that, in a fair way.

PAULA McELWEE:
Just because the law allows it does make it a right thing.

ROSALIE EISENREICH:
Yes, that's where we are having such trouble. Honestly, remove the whole, like, isolating area for a moment. We are not paying people what they are worth.

PAULA McELWEE:
Right, right. Well, are there any comments for the group about these kinds of things? So, which of these are nonnegotiable is the questions in the chat, and we are getting a lot of feedback that they are most or all, nonnegotiable. Now, that doesn't mean some of you aren't in one of these tangles. If you are, let us help you figure out what to do next.

Ideally, they are all nonnegotiable, we had our CIL's aren't paid what we are worth in most states either. Also true, and I think both the pan the benefits of staff I think are a very real issue for centers, we just need to get more money into the coffers, some of the things Rosalie mentioned as well as other strategies to make sure that that can happen.

OK, let's look at that next slide, we only have two minutes left. Oh, I don't think we're going to go into this one. Yeah.

ROSALIE EISENREICH:
No, we aren't going to make it.

MARY-KATE WELLS:
This is Mary Kate, we do want to make sure we take a pause for our ASL interpreters, but Paula, Rosalie, any kind of closing words?

ROSALIE EISENREICH:
I'm seeing in the chat this whole concept of ideally, and I think that is a key phrase before you go trying to condemn or say all or none is that we are all humans that have been put into the system and â€“ oh, hi.

PAULA McELWEE:
Oh my puppy came to see me!

ROSALIE EISENREICH:
I really cautioned you if you're saying all or ideally, also don't forget that the goal here isn't to condemn, the goal here is to support and communicate and build consensus so the hope is you take away from this conversation, go have discussions and make space for each other. It's OK to disagree too and still respect each other's humanity.

If there is disagreement it just means you need to pull in more information and more people to get a better consensus of how do we make this decision?

PAULA MCELWEE:
We do not need to beat each other up. We need to confront, discuss and rethink as Timothy said. But we can do it without being cruel to each other. We are community and we must give each other support. We cannot destroy each other.

MARY-KATE WELLS:
Thank you for facilitating this conversation Paula and Rosalie and call to action. Rosalie put it well of bringing this conversation back to your center.