IL-NET T&TA Center for Independent Living Presents

Disability-Led and Consumer-Driven Systems Advocacy

Presenters: Rosalie Eisenreich, Felix Jordan, Edward Mitchell, and Jessica Podesva, J.D.

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Live captioning by Ai-Media

MARY-KATE WELLS:
Welcome, everyone to today's webinar on disability led and consumer control system advocacy.

My name is Mary Kate Wells and my pronouns are she/her and I am the program director of the national Council on independent living. NCIL is a partner of the IL-NET Training and Technical Assistance Center and we support the coordination of the webinar today.

Today your moderator will be Jessica Podesta the director of advocacy and public policy at NCIL, National Council on Independent Living. She will join us momentarily. Next slide, please? Awesome.

Today's presentation is brought to you by the Administration for Community Living at the United States Department of Health and Human Services in conjunction with the IL-NET T&TA Center. IL-NET is operated by ILRU in collaboration with NCIL, APRIL, and the University of Montana.

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ASL interpreters are present today and should always be visible. Please let us know if you are not able to see the ASL interpreters. We have Spanish language interpreters as well. In order to access that you can go to your zoom bar on your screen and choose the language you would like to hear the presentation in.

Finally: public chat is turned off. But you are able to chat with the panelists and the hosts. We ask that you reserve the chat for any technical support and not to submit any questions in the chat. We are going to have a limited time for a question and answer period today but if you would like to submit a question for future follow-up you can use the Q&A box which is at the bottom of your screen.

And you can enter your question there. And with that also at the end of the webinar we will have the typical evaluation. As always we appreciate any time you are able to fill that out and we will share that link at the end. With that I will hand that over to Jessica Podesta and she will be our moderator for today's webinar. Thank you, Jessica.

JESSICA PODESCA:
Thank you Mary Kate, hi everyone. Thank you for having us today and I am really excited to be here for today's webinar. So before we dive in to our panel and I introduce the panelists for today I thought it would be good for us to go through and talk about what our goals and learning objectives are for today.

So the first objective is to learn why systems advocacy is important to the independent living network. And it strategies for disability lead and a consumer -controlled systems advocacy. And then strategies for consumer engagement and consumer control and systems advocacy. Next slide please?

Today we have to define a little bit if we could jump to slide nine? For the purposes of today's webinar I know that in systems advocacy a lot of these definitions are used interchangeably but for today we will define disability led as being people with disabilities being the lead decision-makers

So in the context of SIL's the disability led component is 51% of the management team are required to be people with disabilities out of SIL. That is one concrete example. Consumer controlled: consumers are identifying leaders and decision-makers. Another context in SIL's that 51% of the board being people with significant disabilities the board oversees an executive director.

That is the consumer control piece there. Then consumer driven consumers are the driving forces of the focus and input for the advocacy efforts. So consumers voices are having adequate input into whatever advocacy issue you are focusing on.

We could now jump back to slide seven? So, with that I am going to go ahead and introduce our panel and our first question. The first question for our panel today I will go ahead and introduce them and if you could introduce yourselves? Could we go back to the slide?

Thank you. If we could go ahead and introduce we will go ahead and introduce ourselves and I will call on you one by one but I will ask the first question. The first question for today: "what is systems advocacy?"

Can we go to the next slide, Mary Kate? What is it systems advocacy? We will start with Felix. Since you came on camera first. (Laughs) we will go ahead and start with you, Felix. Felix is a community organization's manager at the Boston Center for this if you could start the next question?

FELIX JORDAN:
Absolutely. As a Jessica said I am in Felix Jordan I am the committee to organizer the Boston Center for Independent living. I think as people who work in independent living as folks with disabilities who sort of collaborate and get service with the state I think a lot of people who work in SIL's and get services from SIL's or get services through SIL's, rather, I guess, I think we sort of know these issues and we can connect the dots that a lot of people are not.

And I think systems advocacy is sort of the way that people are able to sort of get our needs met but I also think it sort of extends the legacy of disability rights and that larger movement, I guess, if that makes sense.

JESSICA PODESCA:
Thank you so much, Felix. Our next panelist is Rosalie Eisenreich from the southeastern Center for into Bennett living and she is the strategic innovation's director. Rosalie?

ROSALIE EISENREICH:
Thank you just got my name is Rosalie Eisenreich, you were close, Jessica.

JESSICA PODESCA:
We also received a request for a visual description. So real quick for me folks this is just Odessa and I may white woman wearing a white sweater sitting in my home office with long brown hair. Rosalie? Sorry.

ROSALIE EISENREICH:
No worries. My name is Rosalie Eisenreich. I am located in Minnesota and I am a 30 something Caucasian woman with long wavy brown hair that is up in a bun and I have this crazy color patterned sweater on today and I am coming from my home office.

My role is with SEMCIL and I am with the invented state living counsel and systems advocacy€¦ For me it is about relationship and it is about relationships and power dynamics. So there is the element of understanding within relationships and on a larger scale where power lies.

And how to redistribute back to people who have less and people who have less. It is about being a necessity for change and systems advocacy looking at where those is to be a oceans are to make necessary changes and better for everyone. It is more than something that is just legal or policy. It is about community and community building first and foremost. It is essential to start their with systems advocacy those of the four main points for me.

JESSICA PODESVA:
Our next presenter is Edward Mitchell.

EDWARD MITCHELL:
Hello, everyone. I am an African American male. For me, systems advocacy or systematic advocacy to me is seeking change at the systems level. Working together at the systems level the try to influence decision-makers to address infrastructure. Systemic advocacy can play a major role in influencing social policy, public opinion, law, and most important, people's day-to-day long-term lives.

JESSICA PODESVA:
Thank you so much, Edward. Did we€¦ Lose a panelist? Let's dive into our next question and hopefully Felix is able to rejoin.

Our next question, and this is for Rosalie, Felix, Rosalie, Felix and hopefully Felix can jump on. Why do we do systems advocacy and why do we need it? We know it is an essential part of the independent living movement.

ROSALIE EISENREICH:
Sorry, some technical difficulties. This is Rosalie. Why we do systems advocacy at centers for independent living, is really the basis of white centers for independent living exist. It really is about that community aspect and community building of when we do not have as individuals what we need that we resource and connect and build relationships with others. In order to meet each other's needs and have a better life, a fulfilling life, together. It is the breath and foundation of really that solidarity piece that we have as part of our independent living network and progressing towards a better future for everybody.

And it is essential, basically, to all of the other things, the other services that we do. Because it really challenges the current status quo. Do we have Felix or others, Jessica?

JESSICA PODESVA:
Edward, since Felix has not rejoined and maybe call it, -- Colin, do you want to maybe weigh in on why we do systems advocacy from your point of view?

EDWARD MITCHELL:
The reason why we do that is that they SILC has many different ways to practice advocacy and different types come together in the advocacy campaign. The SILC or systems advocacy organizer will look at the gold chain. What do people who experienced the problem want? How will the change affect them? Who can make the change? What will be convincing to decision-makers and the public and what barriers will be all face? This can be done in a wide range of things such as awareness raising, solidarity, as well as decision-maker engagement.

JESSICA PODESVA:
Yes, I think that is a really, really good point. Also, we are a disability led network. So, consumers control our representation. They control, we are really the only disability led network in the aging and disability relationship like that. It is a really unique system. The other really key piece to this point and white systems advocacy is so necessary is it is also about creating space for new leaders, people, and communities and really making sure we are as inclusive as we should be. Acknowledging that, and the culture of the CIL and how all of that fits is really important. I think Felix will be rejoining materially. With that, I think maybe we should move to the next question.

Next slide.

So, what is disability led and consumer-controlled systems advocacy? I wonder, Rosalie, maybe we can start with you on this.

ROSALIE EISENREICH:
Yes. I really appreciate the work of Ella Baker in her history of leading activism. She has this famous quote that the people who are most impacted lead. When we talk about disability led and having people with disabilities as decision-makers, it is really essential that they are the ones who are designing, or making the decisions, and who are really pushing the entire movement forward as well as shaping it in some way, shape, or form. And it has to be intentional to do this. And it has to be creative, and expansive, and different than what has been done in the past. Because power evolves over time, relationships evolve over time within all of this. And thinking about affected change, change is most beneficial when it is designed by the people who really are most intimate with the struggle.

There is something that just lacks, or it is very easy to then stray from what is going to be most challenging, but also the most beneficial if you do not have people closest to that impact who are making those decisions and so for me, that is why having people with disabilities regardless of, you know, their background or station in life, that they are there and they are part of your board. Because they are going to be the most passionate and they are going to be the most open.

You are going to need people who have lots of different skills and creativity to do lots of creative things. And so it really is, again, that community aspect, that relational aspect of going to the people that have the most experience. And this is really countercultural to American culture where you have to have a degree, you have to have all these different things or people that you know in high positions and really at the end of the day, we are most effective for making the change that our community needs when the community is the one doing the work.

JESSICA PODESVA:
Yes, and do we have Felix back? I think this next€¦ Felix is back. So, Felix, are you back? OK, there you are. Excellent. Yay for technology. Thank you, Rosalie.

I think that goes really well. In my question, Felix, for you is to some of the points that Rosalie said with the most effective one we are really meeting people where they are at and engaging. But, Felix, what is the role of, can you maybe talk a little bit about why the role of a systems change advocate or community organizer at a Center for Independent Living is so important to really ensuring that we are doing that dishabille -- disability led. What role can a community organizer play in that? Feel! Absolutely. I consider it a pretty big part of my job engaging with people who already interact with our CIL who do not necessarily engage in an advocacy way.

Jessica, you are familiar with the role, getting people connected with advocates. We also do advocacy here, are there particular things related to advocacy you are interested in? If so, you have our contact information and a big part of my job is that outreach.

I just think it is really important to know that when we talk about the services they get, it is not just, you know, I want this kind of care. But it is also making sure that people know they can sort of mobilize around issues that relate to them. So with the cuts that have been proposed in Massachusetts. Letting people who are PCA service consumers that people are trying to put care on the line, this is what we are doing. And what people want and what people need. I think it is a really important way of being like, "this is what is happening in legislature but also, what you need that is not happening?"

JESSICA PODESVA:
And maybe, Felix, in your work as an organizer is there a particular campaign and there is one I can think of because I used to work with you. That really took off and created some change that came out of real grassroots community input? I am thinking of the (Name) forums and the work of getting incontinence product. It really came out of work from organizers. I was wondering can you talk a little bit about that? That is disabilities advocating our healthcare right. It is in Massachusetts. Maybe talk about how organizers can play a key role in facilitating things like that to identify needs of the community that really, we would not identify without consumers.

How do organizers create that space?

FELIX JORDAN:
I think there is a lot of that outreach piece. Getting to reach out to people being like, "hey, we are having this space." It is a lot of engagement, it is consistent engagement. Like Rosalie said, it is about building those relationships. That is a really big part of it. I think, I am so sorry I am a little frazzled because of the tech snafu I had earlier.

JESSICA PODESVA:
You are doing great, it is all OK.

FELIX JORDAN:
I think with that, there is a lot of facilitation in those scenarios. It is like my job has never been easier because it is letting people talk about what they need. And then being like, "these are things we can do!" And sometimes I feel like a really big part of working in community like Rosalie said about -- people having different skills, some people have really big important imaginations and are able to conceptualize things and think about organizing in a way that I necessarily don't as someone who loves organizing but has only been doing it for a couple of years.

JESSICA PODESVA:
Thank you, Felix. I am checking with my timekeeper. Maybe, let's go to the next slide. And Edward, Felix this is for you. We talked about the role organizers can play but how can SILCs dissipate in systems advocacy?

EDWARD MITCHELL:
So glad you asked me that. We can participate in system advocacy. One: it involves clapboard of efforts to affect copperheads of modifications in policies, laws, regulators at the municipal, regional or national levels. SILCs can implemented long-term strategies that implement change for individuals with disabilities. The reason for this is that SILCs do not provide the right services. SILC embodies the disability committee. We collaborate with all organizations promoting independent living philosophy. Some of the other key takeaways from the SILC is the role of the state plan. I don't want anybody to think of the state plan as a massive nobody can understand. Estate plan is your Google maps or Waze of the state plan. It establishes goals and benchmarks of the independent living services provided to all individuals without --'s abilities -- disability is in your state. Read your estate plan. To help guide the plan, SILC solicits continual public feedback on the effectiveness of the independent living services and the communities’ changing needs. Again, the skill of ever adapting and ever evolving and your job to publicly comment on it and be there because the state plan lasts for three years and we are about to enter a new three-year plan.

Next, the biggest part about this is healing the network. We need to bring back relationships. Relationships have been damaged or fractured due to personal egos and we are all in the bus together. We all entered the bus of disability at different rates but we are all going to the same place. Let's put down the division and let's go far when we go together. Again, with me, I am making sure in our state we are building back relationships with counsel and other state councils because we need to heal to move forward because we all have strengths, and we all have weaknesses. We have to identify those in order to make these changes. We have to form new paths and with other state councils as well. We need to collaborate, we cannot be isolated in our own states. We have to be able to reach out to our neighbors, put our arms around them so again we can all bring out the best of one another.

Again, take on what you can accommodate. No one wants you to sign in and then sit in the backseat. I spent a year kind of sitting back and listening and observing and now I am trying to step up and be on committees and drive change forward. The SILC and SILC relationships if you are a marvel fan think about it is the infinity gauntlet. This is the independence gauntlet. I want us to collect infinity stones from different groups.

When we put those stones together and snap it we can make anything happen. When we make that happen that systems advocacy is for everyone and not just one specific disability group but all disability groups. I believe you with this: some people refer to systematic advocacy at upstream meeting you work on other issues before you move downstream and cause problems so let us work on systems advocacy upstream. Thank you.

JESSICA PODESVA:
Thank you so much, Edward. To that point having everyone work together is an important piece of systems change so Rosalie, could you talk about different examples on how to bring different voices together in your state and how maybe we can use those voices to continue making progress in systems advocacy even when political environments seem impossible?

I know we are dealing with that. Maybe you could talk a little bit about that?

ROSALIE EISENREICH:
Absolutely, Jessica. I want to acknowledge that there are several people who asked and I feel like I glossed over because my disability has my mind go everywhere and I have a lot of anxiety so I want to make sure that everyone knows that we all here today are people with disabilities leading disability led systems advocacy and I identify as a CPS D posttraumatic stress disorder batty.

It has pitfalls as well as some benefits. As is with everybody. I want to make sure that that was clear first and foremost. To your question, Jessica, Minnesota is one of the last states up until two election cycles ago was the only state that was politically divided red and blue equally.

10% of the entire population lives within the Twin Cities seven county metro area with Duluth and Rochester also included not. Then 90% of our land is rural and we refer to that as greater Minnesota and there is about a 50-50 split of people with disabilities living in greater Minnesota and 50% living in the seven county area which is something that creates a unique challenge when we consider how our regions are set up in Minnesota.

There is certainly a lot of conversations we have had over the pandemic with covid response and really this work is so essential that regardless of the politics or issues that are happening our message is that we are trying to eradicate ableism and we are saying that all bodies are essential. Everyone is important because at the end of the day we want all humans to be treated on the basis of the fact that we share humanity and not on whether you can walk or can or cannot hold a job or what country you were born in.

Versus just another culture. These are all things that we are constantly judging people on and we really as a whole community here in the United States, this just goes globally to we are subject to the political powers at hand and we need to understand that politics are a sensitive subject but we are nonpartisan in our mission.

Any political party or political issue that does not care for people and their bodies and makes a better world? That is an important thing that equalizes the conversation. So, systems advocacy here in Minnesota, you know, we focus on that message first and foremost. To really talk through a lot of the issues that are at hand and really again it goes back to relationship.

I personally live in the cities and I work with SEMCIL because they are doing really great work rabble rousing and I have also worked in a number of different states, Montana, New York, Washington, and now Minnesota. And I have worked in rural and metro contexts.

I have a heart for rural because we need each other. That is an identity that in our systems work gets lost in the mix, so I am using my privilege and my position geographically to try to support our larger mission of ensuring people with disabilities in greater Minnesota in rural areas of the US that their voices are heard as well.

Those are just a few points of how to kind of bridge that divide is being able to say that we have two different points of view but if we can agree to sit down and talk together and try to understand through curiosity and creativity and understand someone else? That is fundamentally where we can start bridging that divide and then coalition build.

People want to know that they are witnessed and cared for and if you can build that trust that brings someone else into the community. And you can hold different opinions while trying to do similar work or even mutual work.

JESSICA PODESVA:
Thank you very much Rosalie. Felix, maybe you could jump in. Doing network and when we talk about how divided we are and taking the time to listen to one another I think one really key aspect of systems advocacy is bringing up that multigenerational leadership within IL and how we make sure that we are evolving and being more inclusive and I know that is a divide that we as a network have struggled with so Felix I wonder if you could talk a little bit about how we do that from an organizing perspective?

FELIX JORDAN:
Yeah, happily. At least I will say in my experience both as a black person with a variety of mental health conditions as well as who comes from a family of folks who have mental and physical conditions a lot of particularly older people of color do not see themselves as disabled.

And they may see themselves as just having a condition or using a walker or XYZ and they may hold another identity as a bigger part of their identity. And I think historically what I have seen a lot of CILs being white, but I think there is a really important history of that cross collaboration thinking about the 504 incidents and how the Black Panthers were instrumental in that.

Like having Rosalie said those common goals and really wanting to bridge that divide I think now a big thing is wanting to meet people where they are at. Going into communities and a lot of that is knowing the community that you are a part of and what is here and what is around you and where the people you are trying to connect with our and going from there.

It is definitely not just being "we know there are people we are trying to reach in the neighborhood" but getting to know those people and seeing how you connect on those things.

JESSICA PODESVA:
Thank you. Meeting people where they are at is key. And that acknowledgment of your history not many people know how instrumental the Black Panthers were in the 504 incidents and we are talking about it now but that piece has been overlooked. Part of us being able to move forward is acknowledging the history of racism and ableism and how those two intersect.

To your point meeting people where they are at. No one owns disabled people's stories. How do we prevent tokenism in our organizing? Felix, I saw you jumped off, but this is for you. What strategies can we use to meet people where they are at to really prevent that tokenism and move forward together?

FELIX JORDAN:
I think that is really important. It is a lot easier said than done but once you have reached people where they are at it is keeping people engaged. My former supervisor was really good at calling in and checking on people and obviously there is a lot of assignment to resources so that is not always possible but that is honestly a great way of building and sustaining those relationships.

I think a really good way to avoid tokenism is to just be genuine, quite frankly. Genuinely connecting with people and doing that intentionally. Maybe you intentionally connect with people of color but at the back of mind you are saying "oh great a disabled person of color I have for this event" building and maintaining those relationships and developing leaders within a broader swatch of people so that does not mean when you are developing leaders who are only picking disabled people of color but you are picking people who are representative of their community and you are engaging and investing in learning and going with those people and developing them as leaders.

If that means making them feel more comfortable speaking out events and a lot of this is not intuitive and it takes a lot of time. But it is getting to know people and helping them feel comfortable in leadership rather than saying that we have an opportunity and is our turn to go speak at a thing. Yeah.

JESSICA PODESVA:
Thank you so much, Rosalie, do you have anything you want to add? I was going to call on you next.

ROSALIE EISENREICH:
I appreciate everything Felix said, and it reminded me of one of our best partners and absolutely a leader in deficit ability advocacy in Minnesota has been out front Minnesota which is a two spirited LGBTQ IA advocacy organization and nonprofit. So when I think about tokenism I approach their executive director Kat Roan as well as one of their training directors.

Basically I said "hey, you are doing amazing work and you are doing it effectively in public policy and that is how I initially got to know who they were. Their mission and their vision about community really aligns with our mission as independent living movement.

Just to see already that there was a partner from another community that is championing and seeing that solidarity? I said "Steve want to take this another step and then we can learn from you more about your community and start exploring our mutual history and the connection points? And building more intentional solidarity together?

Because largely the advocacy they were doing was with community on a small scale. We were noticing them at the capital. One of the first things that we did to build capacity was to partner with them and learn from them first and foremost because they are the authority of their community, and they hold their story.

That is something that I know that we have intentionally is the disability community and the IL network we really needed to learn. So, we invited them in and they had training with us and up front I was also like "hey, can we create a cross solidarity basically disability justice to spirited LGBTQIA training together so this can expand that repertoire that they have or also we could partner together in the future on education.

That happened this last year and we could get funding so I think it is really important that if you are going to build across solidarity as we say disability led and consumer driven these are the same things we say it is about a relationship and where that power lies. Are you sharing in the work and process together and are you distributing the decision-making among most impacted?

It comes down to that. That is why it is so important that we build relationships within the network and build a consensus because we do not have that right now in Minnesota and we are working on it. It starts with community building. If you are like "oh my gosh this is so overwhelming I have all these disability things and I do not know how to invite others when I have this capacity I am one person in a network" in the last six months I am now six people with each person in each SIL and we are meeting together in a peer support group and it starts with saying that I want to be in a relationship with you.

I want to witness the work with you and maybe we can support each other but let us start by having a conversation and cutting out intentional time to be together. That really is what it is. Having a phone call and an unintentional conversation with questions that you want to ask people and you genuinely want to learn.

That is infectious. It leads to more and more connections and more people coming together around something. I am just getting started here in Minnesota. We have a lot of opportunity at hand. If you are starting from scratch because you have not intentionally done systems advocacy it is possible. Some of your first allies might be outside of the network. Get to know people hang out with them and find them.

JESSICA PODESVA:
Thank you so much, you made yourself a little. Can you just say your last 10 seconds or so?

ROSALIE EISENREICH:
Really it was just about looking for people who are really doing the good work. There is a Mr. Rogers quote on that. Have a conversation. Just be genuine and want to get to know people.

JESSICA PODESVA:
Yes and thank you Felix for raising it and Rosalie for all of your point. When I was working as a community organizer, those personal relationships are so, so important in being able to help do consumer driven advocacy more effectively. You know, a couple hallmarks I always told both organizers I supervised and that I held to myself and still do to this day is that no one owns someone else's story. The person whose story it is has the right to choose one and how that story is told all the time. When you are asking people to trust you with their story, that is a huge privilege.

And so those personal relationships are so key in being able to support someone and telling their story and I just could not agree more with all that was said.

I would like to now open it up to all of our panelists. And really start talking about what are the various dissenters for and appended living or -- centers for independent living and how can we better bridge that gap so that CILs and SILCs can work together? Edward, maybe we start with you?

EDWARD MITCHELL:
I can only speak for our SILC. One of the things stepping into this role is that one, it would be great if there was new updated black and white educational information. Because again we do not lobby, we only educate. We want to make sure we stay in compliance with our state and the ACL. If there could be clear guidance from both, if we look at a Venn diagram, this is what we are in for education. This is exactly when we step into lobbying. So that we can pass that information and make sure our board stays trained and up to date so they feel great and also center directors feel great to make sure we are not crossing over into being you know, a lobbyist. Again, we are educating and moving system changes forward.

JESSICA PODESVA:
Thank you, Edward. Rosalie? And then Felix. And then there is a really good question in the Q&A that I want to add in.

ROSALIE EISENREICH:
Awesome. I think for SILCs, this is something we constantly had a conversation about. I am trying to figure out how to expand our advocacy. One of the great resources, I want to do a shameless plug for is Alliance for Justice has a partner organization called Boulder advocacy and that was a huge support to me in understanding the roles of being a 501c3 Center for independent living. And some councils have a 501(c)(3) designation. The important three -- thing to know is what is a SILC organization designated as? Minnesota's is not so it is a unappointed position by our governor. We do not have any flexibility there. And I just got a message that my internet is unstable. Can everyone hear me, OK?

JESSICA PODESVA:
You are doing OK. You did come in and out. Maybe if it starts to go, you can go off camera, so we do not lose you. If that works. But we would hate to lose€¦ But, understand.

ROSALIE EISENREICH:
I think just not knowing has been a huge barrier to our system and CILs feeling like they can activate. And the answer is, yes you can. I will take flack for this, but you cannot use any federal or state dollars. That is one thing, I agree with Edward entirely is that having more clear guidance that really, we can have a deeper conversation of how that looks like on a national scale would be great.

I will say there is also a lot of isolation with CILs. Minnesota has never had a unified network. I might get flack from the locals for saying this and I am fairly new. I am willing to be proven wrong. But since my time over the last seven years, it is really critical that within our state that works that we really work towards building relationships together. Because there is so much good and so much support that comes from that alone and as a CIL, dealing with the concerns of funding sources and resources, again, power by numbers. Go back to the organizing principles just, when you have more people involved and all going for a common goal and there is a heavy lift, that boulder is going to be a lot lighter if there are more people lifting it with you.

So those are a couple of things that come to mind.

JESSICA PODESVA:
Thank you so much, Rosalie. Felix, before we jump to you, I want to touch on one point since there is a lot of conversations of advocacy versus lobbying and how to walk that line. One really important distinction that I don't think is really understood and I do recommend folks reach out to Boulder advocacy on this. Center for Independent Living and State Independent living can lobby they just cannot do it with federal dollars. If lobbying is something that I do feel like we as a network need to do more of for systems change, we just need to do it with nonfederal dollars and diversify funding of that. And I do think that is a conversation we need to talk more about. Because I think people are so afraid of this topic and I think that is another really great topic for us to provide more information on.

Both Center for Independent Living and State Independent living councils can lobby they just can't do it federal grant funds. They can do it if they have nonrestricted funds. I just want to make sure to clarify that. Before we move on. Felix, sorry to jump back. Felix, do you want to jump in on barriers that the center, your center, for independent living counsel encounters when doing systems advocacy and how can we better work together? And sorry for jumping around a little bit, we are on slide 14. I did go a little rogue to have a conversation. But we are on slide 14.

FELIX JORDAN:
I think the biggest one that comes to mind is that our CILs are spread out. Massachusetts has 10 which is really great. But it does mean it does -- we need to get better at being in contact. I think the directors talk to each other a lot more than us as advocates do. That has definitely partially been on me because I have not reached out to every CIL in the state and been like, "who are these advocates?" There are a few of us the network together really well and frequently but I think in terms of us having a united front, not necessarily working together on every single issue but just kind of knowing who each other isn't working together I think is something that I would like to see improved. Definitely.

JESSICA PODESVA:
Thank you so much for that. I also think it is about really listening and learning from each other as Rosalie stated. That is really the only way we can continue to move forward together.

So, for all of our panelists, and now, if we can go to the next slide.

We are now on slide 15. I am always curious every time I talk to organizers or systems change advocates, what makes you motivated to continue doing systems advocacy? This is always a fun question to ask. Maybe, Edward, we will start with you.

EDWARD MITCHELL:
What keeps me motivated, it is a multiple pronged attack. Where one, I am a member of a historic black fraternity. That helps pump me into this work. Sometimes we have to be able to step out of the disability space and be ourselves. When I see other groups and other affiliations really marching ahead, really kind of affecting change, that's what helps me bring that kind of enthusiasm into the workspace as well. But also again, knowing that the changes are being made are not for me, for the young man, the young lady and those who are coming up behind me. Those in elementary school, middle school, college.

The experience I had led me to try to make that better for them, because again, they are the ones bringing up the rear and eventually it will be nighttime. Though not right now to step aside. -- My time. We will go together, and I want to see us all go together.

JESSICA PODESVA:
Thank you. Rosalie?

ROSALIE EISENREICH:
I feel like€¦ It is so important to build relations within the network. But also, you need people, readers, creative's, people all over in your network just in your community. It is much broader to take care of you. That is something that is really critical that I have learned in this role. I recently have come to a better understanding of this new body reality that I have in my disability. It is essential, and regardless of disability justice principles, organizing and organizers are constantly taught if you go to a great organizing training, you have got to take care of yourself first and foremost. And find that balance for yourself. Because this work will burn you out. I identify as a millennial burnout as well and I am trying to recover. I am in recovery, trying to figure out that balance, because my disability specifically ties into being forced to be an advocate at a very young age.

I am just now finding that I choose this work, I am not forced to do it. Go to therapy. Have your network of people behind you where you can just the human and not talk about disability. Have people with disabilities outside the network of, you know the independent living movement. Find ways that fill your cup. Find the people that are going to truly care about you. Because at the end of the day, that is essential to making this change sustainable. And when you can take care of yourself, then you can take care of others. And that has to be balance. That is anticapitalistic, because we are constantly forcing our culture that you have to be productive, you have to be successful. Rest is resistance. Rest is essential, and you need to protect that for yourself as well as for all of the people around you. Communicate your needs with the other people you're working with in this systems advocacy. It is essential that you need to have that card out.

Burnout will kill you. It will. Stress kills. That is something that I just cannot emphasize more. Otherwise, you're going to take people for granted, you are going to become cynical. One of the huge issues we have had in Minnesota and one of the contributing factors is cynicism and leadership. It harms people at the end of the day. And it starts with not -- the leader not taking care of themselves. I cannot emphasize that enough, that you should be operating from a space of energy and I know that is very different for many people.

JESSICA PODESVA:
Thank you so much! You muted yourself towards the end there. You are doing great! I could not agree with you more that it is so necessary as an organizer to take the time for rest and recharge, and it looks different for everyone. For me it looks like sometime in a horse barn rushing a horse or going for a good ride.

I know for everyone it is important to find those different outlets for whatever it is that clears your head. I encourage everyone to Carver that time even if it is taking a nap. Even if it is taking a walk or going outside those breaks are necessary. Rosalie and Felix, I am wondering if we could take a step back.

We talked about disability justice and maybe Felix we start with you could we maybe talk about what disability justice is and the difference between disability rights and disability justice? Felix or Rosalie, whoever wants to touch on that? Because I know you both touched on disability justice in your points.

Sorry, I am going a little rogue here.

ROSALIE EISENREICH:
Felix, are you online? I feel like this would be great for you to start up. Might be having more technical issues.

FELIX JORDAN:
Hi, yes, I was having technical issues again. Yeah, I think disability rights versus disability justice are separate concepts, but I think they are both very important, so I think disability rights is really about obviously as we know making sure that people have access to the things that legally they are entitled to as a representative, right?

Thinking about people not accessing medical services or healthcare or not being able to get to schools and buildings that we all should be able to access, public buildings. That is where disability rights are. Disability justice is a framework I think focuses on examining disability especially ableism and how it relates to other forms of oppression.

I think intersectionality is a word that is often considered a hots word -- hot word and people do not think about what it entails but what does it mean for me to be a queer black person with a mental health disability? What does it mean for someone to be Jewish and disabled or any sort of thing?

And how these intersect and how this relates to the people experience disability and how they get treatment and services etc. Those are all really intertwined and that is worth disability justice looking in. Hearing what Rosalie said about that sort of anti-capitalistic notion of taking care of ourselves and stuff is baked into disability justice of not just working ourselves to the bones but also caring about ourselves and disabilities and our wholeness with people with disabilities.

Yeah.

ROSALIE EISENREICH:
Yeah disability, Felix you defined rights versus justice really well. This is something I continue to explore and I am fairly new to. My thought is a disability -- Maya Thorne is a disability activist and she brought about hereto Minnesota and we had community conversations for the first time. We are late to the game here in Minnesota as far as disability justice and what that means.

Together as a community we are talking about these things right now because it is something that we have not and I think the biggest thing I have learned in having these discussions because we need to have these discussions around independent living and disability justice is that these are two frameworks that work together and we need to be supportive of each other.

Rights is limited. Rights says that it is law and there is enforcement and these mechanisms. That is a great thing to have but I think all of us know rights only get you so far and this single issue and single identity. Justice is holistic and thinks about the whole person and their whole body and those identities within. It truly focuses on building community that is caring of self and other.

That is where it is not a wrote science about how to do this work, but you will get closer and it will speed up the process with systems advocacy and doing it in a way that is beneficial for everyone if you can start your conversations and community building around the disability justice principles.

JESSICA PODESVA:
Thank you Rosalie and Felix. One more for you both before we start taking some of the questions in the chat and also Edward, feel free to weigh in on this as well. Why, when we talk about, we talked about defining this ability justice etc. could you touch on why being disability led and consumer control and consumer driven pieces that we talked about earlier are so essential to the disability justice framework?

And can we talk more about what that means? There is a little bit of confusion still on what we mean when we say that. Why is the disability led pieces so crucial to advancing the disability justice framework?

EDWARD MITCHELL:
I always think about the poem by William Ernest Henning I am the master of my fate I am the captain of my soul and I apply that to nothing without us, nothing without us. Again, we are strong enough to advocate for ourselves and our desires and again we know what is best for us, so we do not need anybody to step up and speak for us.

We can lead ourselves and we know what is expected so again for me it always comes down to convict as I am the master of my faith and captain of my soul.

JESSICA PODESVA:
Thank you Edward. Rosalie or Felix?

ROSALIE EISENREICH:
Could you repeat the question really quick? And Felix, sorry, I am waiting for you.

JESSICA PODESVA:
That is OK. There is still a little bit of confusion in the chat. I was wondering if you talk a little bit about why the disability led peace as we defined it earlier, the disability led and the other aspects of consumer control and consumer driven advocacy are so important to advancing the disability justice framework?

ROSALIE EISENREICH:
I am going to come out and say it because this is a point, I want to hit home and if there are people from Minnesota on the call, I might get flack but I am not going to hold back. I think there is a distinction between being an ally and an advocate. It is only in the disability space of advocacy that we have these advocates and self-advocates.

That is something that if I could abolish tomorrow I would do it immediately. You would not put a white person like me on a committee for African American rights. Unless I was in some sort of consultation role, but I should not be a decision-maker because that is not part of my identity and that would be counterintuitive to the community and that is not OK.

That is not OK and that is not moving forward, and it is not progressive so why do we do that and disability advocacy spaces? Why do we demote and devalue the voices of people with disabilities in the spaces and I will say that ties right back into a barrier. We are experiencing this in Minnesota. Minnesota's advocacy has been highly organizational and institutional in that regard.

There are great things that have come from Minnesota. We were the first in the nation even before President Kennedy to the institutionalized. But we rely so heavily on providers that now we have per capita the most group homes and we have one of the largest and hardest jobs in advocacy here because it is completely provider controlled.

The advocacy that wins and gets the sympathy of the legislators right now are two organizations that are 501(c) six is. They lobby for providers and they have massive amounts of money because we have so much money in home and community-based services and even organizations that historically have done good like the ark there are a lot of situations out there I do not want to name names, I just did but you need to stop using people with disabilities as props.

They need to be the masters of their own voice and be able to amplify that. It is probably one of the most infuriating pieces of trying to advocate in Minnesota is trying -- not knowing who your ally is because the history is so deep with that systemic ableism because we have not been able to clearly define that boundary of who gets to make the decision and who gets to mold the policy piece and who gets to speak on their own behalf.

It is hard. It is very hard. That is my two cents.

JESSICA PODESVA:
Felix I am wondering if you could jump in on that. Do you have anything you could add to what Rosalie said?

FELIX JORDAN:
Yeah, that is such an important point. Proximity to an issue does not make you an expert on the issue unless you are in that. I really appreciate Rosalie's point in that way. I think for me it is very simple. Nothing about us without us. We cannot be making serious decisions for a group of people that are not able to advocate for themselves.

In that way it is sort of€¦ It is extremely ablest to assume that people with disabilities cannot/are not interested in advocating for themselves. And we see that a lot sometimes. Sometimes there is a surprise or the feeling that people with disabilities are childlike. Which is obviously ablest, incorrect, and a tale as old as time.

But I think it is so important to have people shaping the world that they want to see for themselves and for people like them and I think that€¦ There is the phrase that people with disabilities are natural problem solvers because we have to figure out so many ways to do the things that we do in our everyday life and I think bringing that to advocacy is really important.

And it also brings that problem-solving piece. Like, yeah.

JESSICA PODESVA:
And this I think weaves into a really, if we really want to get real like when we talk about not only the providers but we also have really struggled, I think, with parents historically here in the independent living movement. It is those parent advocate groups that sometimes we have struggled to Gable to have conversations with.

So, if we are really not going to hold back what are some ways that we in the independent living community can engage in systems advocacy while not only educating persons with disabilities and providing that framework around their rights and systems etc. but how do we also pull in parents to be allies and to be allies in our work?

ROSALIE EISENREICH:
I was just going to add, I am seeing lots of comments about being a vested stakeholder and what about being a parent of a child? What about someone who is nonverbal who does not have the capacity? That goes back to my first point. You have to have a good definition and a community shared language of ally ship versus advocate/activist.

People most impacted lead. This has been a struggle in Minnesota. We have the ARC, and the ARC was established in Minnesota. It is a struggle right now. Not only do we have strong organizations but parents really they are searching and desperate right now for so many individuals who cannot advocate and would be taken advantage of because they do not have either the physical voice or the cognition etc.

Whatever the barrier might be. I have worked with really great parents who get it. They have learned to realize that disability and their efficacy is for their child. -- Advocacy but they need to view that child in a way that we do in enabling that child to participate as much as possible and clearly understand when they are advocating and where their interests are.

And not represent all people with disabilities when they are doing their advocacy. That is a key piece. When they are in disability spaces, and they are in these advocacy spaces that they are not centering their self-interest or their credit or their limelight their voice. For their child. And then drowning out all of the other people with disabilities who are also present.

That is something where again disability led and disability centric people most impacted lead. Parents are impacted but they are not the person with the identity. Their experience is tied to their family and their child. It is not as broad as other spaces. That is what I would say to the comments that are there. You have to remain disability lead and disability centric.

JESSICA PODESVA:
Thank you so much, Edward.

EDWARD MITCHELL:
I am an 80s baby, born 86. I entered a disability space later on in life when I was in a hit and run accident in 2003. We cannot be afraid to lead, when I approach arid advocates. I tell them, you have to let your child be scuffed by life. It brings scars and calluses to your hands and that is what we apply when we are going forward. As much as we all say, we are going to be here forever. We are not all going to be here forever. Again, calluses and scars help shape who we are, and it allows us to go in the right trajectory.

Again, you cannot bubble wrap your child. You have to allow them to be scuffed by life. The scuffs form character and that some have experiences they would not have had otherwise if you led them to be bubble wrap.

JESSICA PODESVA:
Thank you so much, Edward. Felix, do you want to jump in? I just want to say, as what Rosalie said, parents are a key ally and we need to bridge that conversation, but I think, really, you both summed it up perfectly around that disability led peace. Felix?

FELIX JORDAN:
Honestly, I was going to say something I do not think I could have said it any more perfectly. It makes total sense that parents want nothing but the best for their children, they want to see their children succeed. They get involved because they want there to be more ways for their children to succeed. It went the -- they want there to be pathways for their children to succeed. However, you cannot, as Edward said, bubble wrap it. When it comes to supporting folks making decisions that are getting independent living services, we talk a lot about dignity and risk. And I feel like we need to ensure that we are allowing people to have that dignity of risk even in situations with their parents.

When it comes to advocacy, sort of like what Rosalie said. We need to make sure people who are risking the most or gaining the most are the ones who are most centered. Particularly when we still have so many places where it is hard for parents who are disabled to be verbal about their disabilities, for fear of losing access to their children. I think it is really, really important that we do not necessarily focus on people who accidentally or purposely are, like, marginalized or tokenized.

JESSICA PODESVA:
Thank you very much, Felix. I appreciate that. We have about five minutes left. Maybe we can touch on one topic, one question from that Q&A. For all of our panelists: and I really think this is a good one because it hits on that consumer -controlled peace. And the systems advocacy of our own independent living programs. The question is: because ILC's are often on profits and locally consumed by the boards, how do you recommend advocates push back on the priorities that are not in alignment with or disconnected from community needs? I think this is really good timing for this question because there is some opportunity for that. Edward, can you maybe touch on ways that folks can get involved in the state plan?

And then Felix and Rosalie touch on it from the CIL perspective.

EDWARD MITCHELL:
Getting involved in the state planning. Estate planning is up for public comment. To really affect change, anybody can do it. We are always looking for board members. Contact your local CIL. Talk to that director. Get on the board. Because again, we need to have everybody's voices. The CIL is a combination of everybody's voice inside their state and we need all different types of disabilities and people ready to serve.

ROSALIE EISENREICH:
You know, a few things. Everything that Edward just said. It is as PAL season right now -- SPIL right now. I think a piece might be writing a letter to the board, becoming a board member. If you are part of the IL network, one of the ways is that you can talk to ILRU about. Try to have some education around, again, maybe it is just lack of education and ILRU can help with that.

In going back to the actual statute. Having conversations first and foremost to communicate where the priorities are mis-aligning I think is a really important piece of just trying to have that understanding conversation. If you have to then escalate other ways, there is training, IR Bellevue, NCIL --

Public and staff members should feel empowered to be able to reach out to other people in the network to gain peer support. As well as contact our associations. You are not alone.

In Minnesota, we are a DSE 723 state. As it uses is the other. We have to work with VR, and they are supposed to be doing our reviews versus ACL administration and committee living supposed to be doing reviews. That is another avenue. There are lots of different resources.

JESSICA PODESVA:
Thanks, Rosalie. My timekeeper is giving me time. I think so we can go ahead and wrap up. But maybe we wrap up with this because everyone else got to answer this question and Felix did not. Maybe we end with this as a bit of a motivator. Felix, what keeps you motivated in systems advocacy? We kind of went down another rabbit hole and did not get to loop back to you. Maybe we can end with that motivating point and then close today's session.

FELIX JORDAN:
Yeah, there are a few things that keep me motivated. I have the privilege of being able to work with a lot of organizers who are sort of values aligned in terms of the way that we organize but also personally. We sort of bring the same energy to our work and sharing that load and having people to share with that are always going to come back ready to go even if we have to go back, lick our bruises, take a nap, take multiple naps. That has been really great.

I think also knowing there is so much to do which is not, maybe, as happy as it could be. But knowing there is so much to do. Got to keep going. Not in a constantly moving, moving, moving. But there is plenty to do. I have got time. So, yes.

JESSICA PODESVA:
Thank you, Felix. With that I wanted to and on a motivating factor for us. But with that, thank you all so much for joining today's session. There will be a recording made available for folks who are unable to attend today. And also, we ask that everyone fill in those evaluation surveys and I believe there is a link in the materials that were sent out and they put it in the chat. Please fill out that evaluation at the link and we would love to hear from you. Thank you so much for attending, and with that I will close today's session. So, thank you all.

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