IL-NET T&TA Center's IL Philosophy and Practice Summit: Reclaiming Our Movement
Presented by: Christina Mills, Emily Munson, Brittany Zazueta, and Mary-Kate Wells
September 18, 2024; Session Four

Sandra Breitengross Bitter:
Hey everyone, welcome back. Hey everyone, welcome back for session 4 of our two day Independent Living summit. Mary Kay will be back in a minute, she's just taking a break. We are going to go over a few housekeeping items before we get started with the panelists for session 4. First thing, there is real-time captioning available. There will be a StreamText link in the chat where you can access that link individually outside of the Zoom platform.

You can also click on show captions. There is a button at the bottom of your screen in Zoom. We also have American Sign Language interpreters, they will be providing American Sign Language throughout the session. You can enable their view through the interpretation button or they will be appended to the top of the screen. In addition, you can access Spanish-language interpretation by clicking Spanish on the interpretation channel. Next slide?

A couple of reminders. This presentation will be on demand and it will be on our website at ILRU.org. It will be on the on-demand training page. We should have set up early next week by the 23rd. In addition, after this presentation and towards the end, you will see an evaluation. Where we will put a link in the chat and ask you to complete an evaluation on that specific session.

This will help improve our content and give us some feedback for moving forward. Next slide. In addition, we also have a couple of ways in which you can participate in the Independent Living Summit and have this be an interactive process. One, you can enable the chat box. That will allow you to send messages to the host and panelist at any time. There will be certain times where the chat box will be enabled for everyone.

That will allow you to click on a pulldown menu and choose everyone, and have your response be seen by everyone participating online. We also have a question and answer feature. That can be accessed at the bottom of your screen. It is called Q&A. You have a question for you. If we cannot get to them during the session, we will have them in a parking lot for later today.

You can also do the right-hand feature, which can be accessed at the bottom of your Zoom screen. That will allow us to unmute you for you to voice your question. We will also use the Poll Everywhere technology that we have used for the last three sessions. We will provide some specific instructions on that. Just a quick thing, we know there were some text response issues on the first couple of poles that we did today. That has been remedied. If you have difficulty accessing the polls, please let us know through the chat feature.

I will go over the instructions for the Poll Everywhere feature. You can participate in the poll in a couple different ways. You can go to a specific website which is pollev.com/disabilityled and participate in the poll that way. We will put the link in the chart. You can also participate by texting. We will put the specific keyword, number, and we will voice this again when we get to that point. You will text "disabilityled" all one word. And he will text that to the number 22333. You will participate in a texting response poll.

We are going to go ahead and go to session 4. This is our last workshop at the summit. It will

continue on until 5 o'clock Eastern. As a quick reminder, we will have a social hour at the end of this session. We will take a quick break and have a social hour and allow people to come on camera. Open your microphone and just talk out some of the questions you might have had from today's sessions.

Be able to ask questions, talk with your peers, and be able to debrief and decompress from all the things you may have learned today. The workshop focus will be on maintaining the IL Philosophy in new and existing partnerships and collaborations. And how these can support the authentic growth of our network and collective power. They will also be a call to action at the end of this workshop, where he will have some in chat discussions.

Here on this slide you can see our link and QR code for the evaluation that will appear again at the end of this presentation. You can also access this evaluation through a QR code which shows up on your screen. We will put the English and Spanish links in the chapter.

I would like to introduce our session normal for presenters. We have through the centers today. First is Christina Mills, she is an Independent Living Advocate and Consultant. I will let her, on screen and give a quick introduction.

CHRISTINA MILLS:
Thanks Sandra. I am Christina Mills, I use the pronounced she/her. For a quick visual description, I am a woman with brown, gray, curly hair everywhere. I am in my 40s wearing glasses now. I do not think I saw many of you wearing glasses last time I presented. I am in a black long sleeve shirt with gold stripes on it.

Thanks Christina. Next we have Brittany Zazueta. She is the Executive Director for Dayle McIntosh Center for the Disabled, in Anaheim, California.

BRITTANY ZAZUETA:
This is pretty. My pronouns are she/her. Sandra said, I am the Executive Director for Dayle McIntosh Center for the Disabled in Anaheim, California. We serve all of Orange County. I am a 36-year-old white woman with dark blonde wavy hair. I have blue eyes, I am also wearing glasses, and a black and white shirt. I have invisible disabilities. I very excited to be part of this conversation today.

Sandra Breitengross Bitter:
Thinks we are going to go to Emily Munson. She is an attorney and a National Disability Rights Leader.

EMILY MUNSON:
Hi, Emily Munson here. She/her/hers pronouns. I have brown eyes, dark brown hair. I am wearing a pink and white shirt. I am an early middle-aged woman. I am sitting in a wheelchair and having a beer today.

Sandra Breitengross Bitter:
Thanks Emily. Next slide. We are going to go ahead and turn it over to our session 4 speakers. I will allow you all to take it away.

CHRISTINA MILLS:
Thank you Sandra. We are so excited to be here today. This is Christina. I had the opportunity to join the first three sessions. I just want to reflect on what that has been like. I think Rosalie,

Paolo, crash, Amber, have all been fantastic and want Independent Living philosophy is all about. And really prove to our minds why we do this work, and what the organizations mean.

I was in Independent Living for about 23 years before I decided to be a consultant. I left Independent Living for a number of reasons. I really believe that Independent Living has a ripple effect and needs to be brought into other organizations and countries â€“ Mark companies around the country. I felt after two decades of IL experience, I have the skills and experience needed to make that happen.

I took a leave and join the Manage Care world. Full disclosure, I was laid off in July. I have been doing consulting since thought. I am super grateful because independent, disability culture, (indiscernible) is something I'm really passionate about. What were we? That is a whole other topic on its own. I will say the ripple effect of independent living does go far beyond what the walls of our independent living centers believe it is.

One time about 10 years ago when I brought someone in to work for me. They said to me, "Christina, you know Independent Living is just a bubble?" I really challenge us to not think about Independent Living and IL Philosophy as a bubble. But to think about it as a bubble that popped and rippled out into the world to make it a better place.

Whether it be in our communities, in our states, in our country, or across the ocean. I will talk a little more about that. I think Independent Living is so powerful that it has made an effect that I do not know many of us have realized it made in the world. One thing I did as the executive director for the center. Each year we make sure we are within our Independent Living centers across the state. It could also be across different community-based organizations. It could be across different school systems. It was a variety of different partners that we had.

MARY-KATE WELLS:
Christina, you are just breaking up a bit. I wonder if Britney and Emily turns our cameras off? Maybe we could try that so that it is clearer? It was breaking up.

CHRISTINA MILLS:
I am sorry, I did not realize it. In that program, we really created a ripple effect of making sure disability was our community. Where we saw flexibility really need to be talked about, elevated, and seen as a strength. One of the things we did at (unknown term) was an annual poster for Robert too. And Disability History Week is coming up in California in the second week of October.

We gave those posters to anyone who is willing to put them up in their organization or school. It had a profound impact. Not only on the people we were giving it to and able to talk through while we were putting those things out there. But a profound impact on (indiscernible) is part of our ripple effect.

When Ed Roberts was working with the other applicants at the time in Berkeley, California to create the independent living movement, it was much harder than seeing Independent Living inside a building. It was Independent Living beyond an organization. I want to thank IOU and to the University of Kansas for putting together this percentage of works. The format of our training has been really helpful and having a really honest conversation about it.

MARY-KATE WELLS:
Sorry Christina, after the video, maybe try with your camera off just a little bit because it is still

breaking up.

CHRISTINA MILLS:
Wow! I'm not even seeing in on my side.

MARY-KATE WELLS:
Yeah, I hate to tell you to turn your camera off but would you like to introduce the video and see how it goes?

CHRISTINA MILLS:
Yeah, sorry for the technical difficulties.

There is a lot of criticism about the amount of folks who have either worked in independent living or maybe went to Eye Center and did not get what they thought they were going to get from a center. And I thought a lot about that. Went to-- went to a center. If you are on social media you have probably seen this criticism. Went people say independent living centers should not be any more, I think the opposite. I think independent living centers are needed as much today as they were in the beginning.

I recently went back and reviewed one of the early films on independent living that we will show a clip of. It really reminds me that what we are doing, while it is 2024 and times have changed, the reality is what we are doing in independent living is still very much what the forefathers set out to do when independent living was started.

So with that, I will ask Eleanor to start the video.

MARY-KATE WELLS:
Yes. And just to confirm, they carry grey one is first.--Keri Grey.

KRISTINA:
Sorry! The technical difficulties got me almost up (Laughs) --

CHRISTINA MILLS:
And now it is saying I'm paused. My pause?

MARY-KATE WELLS:
No I can hear you right now.

CHRISTINA MILLS:
OK. My point is independent living is needed today. I will show you a video now that shows Keri Gray who embraces independent living and Disability Pride and she looks that how we can look at independent living and what we are doing with our community partners today. Then we will reflect on the video I was talking about with Ed as well to show where we are with independent living. (audio broken up) In the community today, many of us have partnered with Keri Gray for different reasons. So we will reflect on this with this video. Thank you.

(Video plays)

MARY-KATE WELLS:
Christina, it is still breaking up so if you can try turning your camera off please?

CHRISTINA MILLS:
I changed internet connections. I was hoping that it works better. Have I cut absence?

MARY-KATE WELLS:
Know you have been clear so far but I will let you know. --No.

CHRISTINA MILLS:
OK. Because before the video it showed weak internet but I switched my connection over. Thank you Marie Kate.

Thinking about that video, I'm going to ask that you open for this.

--Mary-Kate. How many of you feel like we are fighting for all people in the way that Carrie described?--Keri. And if we are not fighting for all people, do you believe that independent living centers should be advocating for all people and that we are doing that through the center work that we do now?

Yes, I'm seeing guess we should be. We should and I feel our Center does. Good! Good, good, good. Yeah, that is exactly why I believe Independent living Centers are still needed. So I'm saying no, I think there is room for improvement. We should be, I don't believe all centers do. No we are not fighting for all people. We should and we strive to at our center. We are on a reset. Yes 100%. We ought to. No I think we need improvement. There is room to improve. We are not as strong with certain populations. We are fighting against ourselves at times. Yes, but we are not.

I hear you guys. And I definitely see it. Part of the benefit I have in management care is being able to work with CAL's across the country and really seeing what that looks like and what the advocacy agendas were really based on at different centers depending on they were in the country --NCIL's.

I got to see which health centers were taking what they knew, independent living and independent philosophy, out into the community and really have that ripple effect, again really building on Independent living philosophy with partners and coalitions.

One of the things I always have really loved is building coalitions for a variety of different reasons. Whether it is building a coalition or joining a coalition for a purpose. One of the things I think I have been very fortunate to experience is I came through independent living with the youth leadership form for students with disabilities.

So while I'm a wheelchair user, I have had my disability since birth, my family includes people with disabilities, my husband and my children, I did not have a strong positive disability identity until I went to that youth leadership forum.

I know some of you today are working with CILs and I appreciate that. It was not until I went to YAF that I learned what a Center for Independent living was. I want you to think about that! Because for Centers, while we are not talking about the number of people that we serve or come in contact with or are a part of our organizations in this presentation, I just do want to point out that we are not nearly touching the amount of people that we could be touching in the community. And of course one of those populations is young people. And so a lot of young people unfortunately have no idea that centers for independent living exists.

One of the things I learned about independent living at YAF was for different models of disability. I will specifically talk about 4 models. While we have been getting grounded in independent living throughout yesterday and today, I think it is important to hone in on the fact that some of us, from a different model. Initially, whether we are disabled people or not, we sometimes come from a different perspective of seeing disability.

Some of you it might be familiar with Ableist models of pity. The charity model, or the medical model. And in my case I was most knowledgeable about the medical model. But certainly aware of the charity model too, and I think that is really about the time in which you were born. I feel like I'm aging myself when I talk about the charity model nowadays!

But with that, next slide. I learned about, what was taught to me was the three-headed monster. On the screen is hundreds of three different men, Dr. Jack Kevorkian, Jerry Lewis and Christopher Reeves. Again using the chat, is anyone familiar with this three-headed monster?

Good! I see a couple yeses in there. Yes, yes, yes. OK mostly yeses. A few knows. The three-headed monster is the Ableist monster. For those of you less familiar with it, Doctor Jack Kevorkian was all about pitying people with disabilities and so-called putting as out of our misery and really pushing physician-assisted suicide saying that it would better people be dead instead of living with a disability because it was just not thought about as having the quality of life that you would want.

Then you have Jerry Lewis, again this is the person that I always feel like I'm aging myself when I talk about this person, but definitely during my childhood years I remember the Labor Day telethon where Jerry Lewis would get onstage all weekend and raise money on the backs of people like me and my peers, maybe some of you who are joining today, by telling these god-awful stories about how pathetic we were and how we just had nothing in our lives and our lives were just terrible because we had disabilities and people had to give money in order for us to have access to wheelchairs or any type of well-being in life. It was the sad story of my childhood and I always thought, "Oh my God. People are seeing this on TV and then coming to school with me the next day! And they are thinking 'oh that's Christina that is what Jerry was talking about.'" It was disgusting and dehumanizing. Then Christopher Reeves and the medical model, he talked about someone becoming disabled and being willing to do absolutely anything medically to be able to cure themselves and walk again.

Whether that was experiment of drugs or things that weren't even experimental, the life that Christopher Reeves was living as a quadriplegic, he thought it was so bad that he would put his body through anything to take the disability away.

There are a lot of opinions about all 3 of these people. Of course there is a lot of pushback against position assisted suicide. We have closed it down the Labor Day telethon, thank God! I don't know what it is like to become disabled later in life, I was born with my disability. But I think because of the independent living movement and the disability rights movement, we have a lot of people who become disabled that do not think it is the end of the world that they have become disabled, that their life can still be just as rich as if they were not disabled.

While there is a lot to be said about social media and the negative impacts, I think social media has done a lot of good as well. And for folks with disabilities it is often hard for us to connect locally, especially if we live in rural communities or we have transportation access issues.

But when we have access to social media, we can see people that we might not otherwise be able to see in our communities locally and it gives us a different perspective of disability then we might have had if we were kids of the 1990s, 1980s or before. I bring this up because independent living and the social model of disability is the furthest away from the three-headed monster that you can be.

So reinforcing this and revisiting it, unfortunately it was taught to me at the youth form for students with disabilities and it was reiterated to me when I joined the first Independent living Center. -- Youth forum. This is hard to say because often I hear people say that I did not get any training or orientation on independent living when I joined.

For those of you who did get training, I think it is important that we revisit the training and why we are embracing these Ableist models and why it is important that IL and the development of the social model exists.

A Model of Disability is more in line with Independent Living and social model and also the justice model but we do an entire presentation on it. It's got quite a bit of in depth that we would cover and some of it was covered in an earlier presentation.

Really it is honing in on the fact that the disability the -- disability is an asset and I heard every speaker talk about it in that way. Disability is an asset and that doesn't mean if you have a visible disability it is more of an asset, it is about your owning your disability and showing your disability pride. Let me just say, disability pride is a roller coaster and I am the first to admit that. It's not pride every day and it comes and goes and depends on the situation and sometimes it is challenging.

But there is pride and an asset in being disabled and having lived experience to be able to relate to one another. Having whether you have a visible disability or nonvisible, it's an asset. Because there's not enough people out there to serve as role models and peer supporters when it comes to talking about disability in a positive way and as an asset.

I think about how often, people don't know that they can connect to adult role models with disabilities through their center for independent living. Often times, I hear people say, "I don't need to go to the center because I don't need any of the services. They don't have anything to offer me."

I thought about this for years and I really wish that we could create more community opportunities for people with any and all types of disabilities to be able to connect. I think it's hard to be in an environment where you do not have people you can talk to about your accommodation needs are -- when you're having a bad disability day. You want to have those connections and I think CILs are the place to have that. I used to say wouldn't it be cool if centers had a brownbag lunch networking lunch day just for any community members with disabilities that wanted to come in and connect? Think about the power of that. It's bringing into professionals with disabilities you know working other places that think they don't necessarily need to come to your center for anything? But they could come to your center and get the peer support that I think is the most powerful thing that centers have that we own, that we don't spread enough about.

Disability is also a part of diversity. I think we have seen some folks catch on to this over the last five or six years. We have seen organizations and companies take on DEI agendas, Diversity Equity & Inclusion. We saw people go to the next level and say they were going to add for

accessibility.

And then you see some companies and universities who are wiping it away. One of the jobs we have in the ripple effect in the IL community is diversity as part of the DEI agenda and inclusion work being talked about at all levels and it's something we can advocate together in the community and it's not about whether you are in need of something at your center or not. I think a lot of people want to pitch in and be a part of pushing that particular issue.

People with a lived experience, we are the experts. We know what it is like to be on SSI and to be an overpayment. I always used to share my story about what that was like in the lessons learned through that experience. I am so glad to share that story because I am hoping that I'm helping someone else not to get in that situation or, being able to really give someone the peer support that they did go through that situation and maybe they had to make payments back to the Social Security Administration like I did for months. And being able to understand what that is like.

Our disability identities as more beneficial than harmful. Nobody knows that unless we are able to go out and share that and tell people that.

Next slide. Thank you. After all that being said, I want to share a video on (indiscernible). A lot of people will say, Independent Living is old-school, not needed, Independent living, needs to be updated. Independent Living is either that or this. But when people say that, I often think they need to watch this video. This video, might be from the beginning of Independent Living, but my goodness it feels like it is incredibly relevant still in 2024.

I will ask Eleanor€¦ Thank you.

(Captioned video plays)

CHRISTINA MILLS:
Thank you. How many of you have seen that video before? Freewheeling? Great. Few of you. I think it is important to revisit videos like that at staff meetings every now and again to make sure we all know what our purpose is.

One of the things we as disabled people are really good at, is relationship building. Often times, we have to build relationships because our lives depend on it. In building those relationships, it might start from childhood if you were someone worn with a disability you might have had a paraprofessional or aid with you at school. You learn how to talk to medical professionals, you learned how to have conversations with adults at an earlier age then maybe your nondisabled peers. Relationship building is sort of like a natural thing for many of us as disabled people.

Relationship building, is something we get to take personally and transition into our work at independent living centers. And build coalitions and community partners with.

We have to make tough decisions and sometimes, it is not easy by any means, but it's worth it when we are building coalitions with people to really change the systems that impact our lives and make it more inclusive and accessible for all.

I realize that we are short on time so I will go through these faster than I expected. A lot of times, people in Independent Living don't necessarily talk about their diagnosis. We talk about that we are a person with disability. Sometimes, there's a time and a place. When we are

building coalitions or relationships, you really have to decide, is this particular situation where explaining what my diagnosis is, especially if I have a nonvisible disability, if I talk about my disability here is it going to be more effective in understanding where I'm coming from in bringing Independent Living to the discussion?

And being able to talk about the environment that we come from, the community we serve, the community we are part of, that Independent Living is very intergenerational and that getting our access and accommodation needs met is a part of the life we live.

I will skip this one and move forward so I can get to my buddy Whitney. Brittany can you come on screen? I'm hoping Technology will be OK thank you Brittany.

I ask Brittany to be a part of the presentation with me for a couple reasons. One is, Brittany is a newer director and she is a younger director. She has done some phenomenal work at the Dale McIntosh center. She has built some coalitions and working in partnership with folks that I would call or refer to as strange (indiscernible). People you may not think your Center for Independent Living would work with.

I asked her if she could share a little bit about what that looks like and when I asked, she brought up this quote because I think it is a really important one to point out when working with folks that aren't necessarily coming from the same place as you.

BRITTANY ZAZUETA:
Thank you Christina for bringing me in to the panel but also the conversation that's happening now. As Christina mentioned I am a younger Executive Director and am actually in my second year of this role but I've been at my center for 12 years now. I have a lot of experience with partnership and working across IL whether locally, state or national level.

The quote Christina is referencing is the one on the slide which says (Reads) "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has." From Margaret Mead.

The reason I brought this quote into the conversation as it really highlights the powerful of small groups in creating an equal change. That's exactly how Aiello got started and where our movement came from is small dedicated group of advocates who really believed fiercely in the value of lived experience. Like Christina was speaking to.

And of course that right to self-determination. The whole theme of our summit these two days has been reclaiming that movement so when I look at how we started and where we are going, it will be that small group coming together as we move forward.

One of the things I have seen in IL and the expense I have is like Christina was speaking to with that bubble concept is there is a tendency for us to remain within our familiar networks, the places that feel comfortable are the places that "speak IL" or speak IL disability language.

As we are looking at her overall feeling and what we are building too, and we work to reclaim our movement we have this opportunity to meet responsibility to educate and uplift others to bring them on this journey with us.

Doing that is how we pop the bubble and we brought in our region strengthen the impact of our collective efforts. And if we know that are responsibly and what we're supposed to do and how

exactly does that look? So the image description for this next slide shows a meme of Yoda which is a character from Star Wars and it says (Reads) "Build it you must! Come they will!"

Looking at our center, the Dell Macintosh Center, we have been able to cultivate a lot of valuable partnerships, one of them was more recently with our political Children's Hospital. We also have a partnership with the city's government around emergency planning and preparedness. Several housing shelters, our LGBTQ Center and even a fellow nonprofit that is serving the recovery for substance use community. All of these collaborations actually came to us very naturally. They were sparked by a conversation, a question, and interest in wanting to do better. Whether it was one small part of wanting to do better, or bigger questions about the disability community as a whole. And what we have done at our center is instead of just giving the answer to that one question, we have taken that as an opportunity to explore other avenues for collaboration.

So really looking at those opportunities where there is mutual benefits and we can all come together.

I will show you an example of the Children's Hospital collaboration. This came to our system change advocate. They were approached by a hospital with a question about website and access and then they were very interested in collaborating and wanting to learn how to do better. From that sparked a conversation about€¦ Well we can help with the website, but what else is there? And how does that look? How can we come together to share our resources and also learn amongst each other? I think for a lot of centers because the Children's Hospital is a medical setting, and they would typically follow that model, it can be difficult stepping into that space and being vulnerable and choosing what to share. Your lived experience is what you bring to the table. So please answer the question about website -- so they answer to the question about the website and they looked at how this can be a long-term collaboration. And was this something that we formalize through a contract? And how do we share resources? Especially during a time when other nonprofits are closing their doors were facing a significant loss of funding. -- Or facing.

So part of what we also had to look at was the person centered model and how we as individuals with disabilities want to be supported and recognized as whole, intersectional beings.

When we were building these partnerships with the hospital and the city and the fellow nonprofit, we also had to apply that same perspective and we continue to apply that same perspective to our partners. Looking at their whole entity like identity, what lived experience do they bring to a table? Where can we learn? Where can we collaborate? -- Whole identity.

As we have had these conversations focusing on education, training, consulting, and addressing the full scope of the operations and interactions. So with the Children's Hospital example it started with the website, but then we looked at all the other pieces of their operations. They have pieces that are patient basin, so -- patient facing, so the kids that are there for medical care along with their support people. There is also public basin, website, people who are may be interested in learning more about their services and possibly applying to work at the hospital. Then there is the internal part too of the people who are working there or volunteering.

And for us it was really important to make sure that as we grow these partnerships and we are looking at that holistic place, that we are asking all the questions and approaching it from each layer so that we do not miss opportunities as well.

The image for this next slide shows the sketch of a light bulb shining brightly inside a conversation bubble. And the text reads "From assumptions to insights". So imagine assumptions working with a medical provider or someone at the city level who does not have much knowledge or exposure to disability. We really have to get past those initial, uncomfortable feelings of the fact that they do not speak the IL language. Or maybe they inherently value the lived experience and they were trying to hear what we were saying but they did not fully understand it yet.

The ways we got past that in our collaborations was to first approach the situation with a curious mind. So do not just make the assumption that they used the wrong word intentionally, but ask yourself, "Does the fact that they used that word or misstated their question actually come from a lack of education or awareness or exposure? Or are they actually being intentionally insensitive to us?"

Another thing you can do is model that IL and disability language in the conversation. So as you hear them use a term that is not acceptable or not appropriate to you in that conversation, taking that into spending it by using the appropriate word so they can see in real time a better way of doing things -- taking that and spinning it.

We can actually ask them the direct question: how do our lived experiences become an asset for your organization? So instead of telling us your lived experiences an asset, tell us how it can be because we know that it is.

Is there something we think we can teach them about as practices? And also not making assumptions, letting them show us and answer the question too. And I'm really important one is to be open to learning from them as well. Just as much as we want them to speak IL and disability language, we also need to step back and learn their language and where it comes from and where there may be some spaces where it is OK to me in the middle. -- Meet in the middle.

There are things we can learn as well. By understanding their unique challenges and perspectives, that is how you can enhance the collaboration from both sides. This one is for Christina.

CHRISTINA MILLS:
Thank you Brittany! I will also invite you to participate in this discussion because I think what you are saying is invaluable. And again, while you asked those hard questions when you are working in partnership with folks, how do you get to a point making sure that you avoid mission creep? Has that come up as an issue for you guys?

BRITTANY ZAZUETA:
This is Brittany, can you define it for the audience who may not be familiar? Then I'm happy to answer.

CHRISTINA MILLS:
Yes! So sorry. I will read what is on the slide too. CIL or SILC organization takes on programming/services/activities that lack outside of its mission and core values and do not align with or support the IL philosophy and its principles.

BRITTANY ZAZUETA:

This is Brittany, I love that we are covering this in this session, this idea IL Mission Creep, because I saw this at my own center 12 years ago. Sometimes we get away from the IL Mission due to opportunity or things that are exciting for people in leadership, if they have passion for employment for example it can be easy to get away from our philosophy and principles.

But for where we are now in the conversations and collaborations we are having, we are always looking at is what being asked of us outside of what we would typically do? For example we had a really great grand opportunity. But that grant opportunity required as to ask for medical documentation from the people who would be served for the grant. And that is against IL philosophy and the model of centers. So we had to turn that down to stay true to our mission.

CHRISTINA MILLS:
Right. I think that is really important, because especially during times when funding can be difficult and grants are not being renewed or maybe a contract has run up, then it is easy to look at what is in front of you and take it to save someone's job, not realizing that it actually is not in alignment with what your organization is all about. And sometimes people might need something concrete to go by to think about whether or not a relationship with different partners in the community or if a specific type of funding is in alignment with your organization. They might need an actual checklist. And I have seen that. And I think developing that checklist based on what the values and mission of your organization is, is a great tool to have.

And sometimes having that posted, your values for your organization, having them posted in your office is really beneficial so that way when you have members of the community coming in they see what you are prioritizing. And then also having it in each staff member's office, whether it is on a mouse pad or some other form. To make sure everyone knows what we are therefore and what we are trying to form when it comes to coalition building. It might be a situation where you build a relationship over time that changes the outcome and maybe you go for funding or you become a subcontractor of theirs because you did the work to get to a different place. And I think that is critical that you avoid mission creep.

So avoiding Mission Creep, I thought it was Kimberly and maybe Paula too that talked about regularly reviewing the Rehab Act title VII and IL purpose statement will stop and also review your estate plan for independent living -- statement. And also review your estate plan -- your state plan for independent living. Again regularly reviewing the mission, vision, and values. Do this at a staff meeting, at a board meeting. Just making sure everyone is on the same page with this. And build aisle philosophy activities into your staff and board meetings. -- Build IL philosophy.

I have seen that there is no difference in how they run a staff meeting versus how another nonprofit runs and their stuff meaningful to again take your disability asset into account at staff meetings and think, "How might I build an IL activity or disability activity into our staff meetings?" Is someone sharing something about a success story may be or are we watching a video? Are we watching something happening in the community? Make it feel different then another nonprofit.

Independent living is not just your average nonprofit and we need to feel that difference.

I know I'm going to have to turn it over because I do not want to miss our call to action. One of the invaluable parts of our presentation is to be able to actually have somebody from outside IL join us and give a Partner perspective from outside IL to Joan about ways that we can work together -- to talk about ways we can work together. Because recently we have had very critical

wins in changes in regulation. We are fortunate to have Emily joining us to toss about these things. Give us ideas about ways we can work together -- Emily joining us to talk about these things.

Let me say they are always, always, always countless ways we can build partnerships with folks in our communities. Whether it be -- the ones that Britney shared or some different ones. I have a ton of different ideas and things that I'm sure you all know can be worked on your community as well. -- Brittany.

Before I pass it over to Emily I will just say I think it is really important that we remember again that independent living centers are about advocacy, advocacy, advocacy! Not just about the services. Like we said on day one, it is about advocacy for those things, whether it be housing, transportation, employment, benefits, recreation, whatever it is. And there are endless advocacy activities we can work on in addition with others who care about these issues.

With that being said I want to bring Emily on screen. Thank you Brittany! (Reads)

(On slide)There are so many ways we can do that and Emily I will turn it over to you.

EMILY MUNSON:
Thank you Christina and Britney. As Christina mentioned I am an attorney in my day job I work for a protection and advocacy organization. Not representing them today, I am here independently. But I did want to ask everyone, put it in the chat, would you say, that actually, I think we have a poll. The poll question is, Mary Kate do you want to handle that?

MARY-KATE WELLS:
I can do that, if I can share my screen. We will use the same web link and texting that we have been using and I will put it on the screen. So the question was, do you have a positive and collaborative relationship with your P&A, protection and advocacy organization? So in the chat we will have the web address which is (Reads)

(Multiple speakers). (Reads chat) or you can text to disability led, 22333. Let that sit for a second.

EMILY MUNSON:
I'm seeing a lot of folks fill in "I don't know" I want to point out quickly that protection and advocacy organizations were created federally through the developmental disabilities Bill of Rights. We are one of three sister agencies. There is a protection advocacy agency, the Governor's Council for developmental disabilities, and the University Center for Excellence on disability in every state and territory in the country.

There's also, a tribal network, and one in Washington DC. So the P&A traditionally is the legal arm, Governor's counsel, for the developmental disability counsel and in Indiana we call it the Governor's counsel. It's seen as the education arm in the University centers are kind of a research arm.

It looks like so far, results are, 41% of you have a positive and good relationship with your P&A which is great to hear. 14% say no. And 44% of you don't know.

So that is really great information for getting started. I would say, one area where P&A's and CILs probably run into each other every now and then, is that there is an ACL grant called The

Client Assistance Program. Actually no, I think that grant comes from the Department of Education.

Protection advocacy organizations, can represent clients who are having concerns that Vocational Rehabilitation agencies, or Centers for Independent Living, are not being -- meeting their needs are upholding rights. I was worried some of you would have a negative relationship with a P&A but I'm glad to hear its usually collaborative if that relationship exists.

What I would like to do today, is walk you through a couple of recent major federal rulemaking activities within the last year. That are going to bring major changes hopefully. To the disability landscape. And as I introduce you to some of those changes, we will think about how maybe you can reach out to a P&A or state agencies, to develop or strengthen your connections with those entities.

So in particular, today, we will talk about the Medicaid access rule. I don't think we have time to get to the two others, which are the Section 504 rule that references the rehabilitation act and the web accessibility for state and local governments rule. Please note, you will get the complete slide deck that highlights key points about each of those federal rules.

And in the handout with resources that you get from IL net I put in links to actual text, as well as plain language guides to each rule as well.

Alright so, one of the major changes in the Medicaid access rule, is that we now have or will have within a year of propagation is beneficiary advisory councils in every state. A beneficiary advisory Council the acronym is BAC has members that are dedicated participants, family members, and or caregivers.

This is a wonderful opportunity, for lived experience to be heard by Medicaid policymakers.

I say that, because you might be familiar with what used to be called Medicaid advisory committees. Or MAC's. They have been renamed from this rule, medical care advisory committees. And they have been giving an extended range of activities that they need to address. What's particularly important, is at least 25% of medical care advisory committee members have to come from the beneficiary advisory Council.

So, additionally, when talking about MAC's and BACs, there are more transparency requirements. State agencies are going to have to post membership lists and how individuals who want to be a member of a MAC or BAC can apply for membership. Of that, needs to be extremely transparent and on the state agencies accessible website.

Additionally, it used to be at the decision of the MAC leadership. Whether they would hear public comment. Now, it's a requirement that public comment needs to be heard at MAC meetings.

So these are a couple of really great opportunities I think, for CILs to get together do advocacy work not only do I think CILs should be applied for membership the beneficiary advisory councils but definitely showing up to public medical care advisory committee meetings. And providing public comment.

Also preparing people with disabilities that you serve to offer public comment and self-advocate.

There were some updates in home and community-based services provisions. Administrators of fee-for-service programs, now must offer participants a grievance process. Previously, only participants in managed care, got to issue formal grievances. Now, if you are a CIL that lives in a FEFA service estate you may want to consider offering to help your clients file grievances in FEFA's grievance estates. There's also management monitoring standards.

I don't know about other states within CILs but in the protection and advocacy area we see a lot of abuse and neglect in HCBS programs. States, didn't necessarily have standards where all of that abuse and neglect needed to be reported and investigated.

At least now, this federal law will ensure the bare basic minimum for reporting egregious issues.

More HCBS changes. Good news and I was talking about another advocate earlier this week but the Medicaid access rule within six years, will require that at least 80% of payments for Medicaid services, and must go to the direct provider of that care. Personal care attendant, direct service professionals, home health aides, within six years, there is a gradual percentage building up process. It will need to be given at least 80% of what the billing entity bills Medicaid for.

States will need to report wage rates and billing, to the federal government. Relatedly, another big issue I imagine, CILs deal with regularly is folks may be found eligible for HCBS but otherwise put on the waiting list or they are told that they can have so many hours of a service but because of the direct care, shortage, there is no provider available to serve those needs.

States are going to be liable for reporting on wait lists and timeliness of service delivery to the federal government as well moving forward.

I also wanted to ask Christina, and I welcome everyone in the audience to share in the chat, as well, would you say that your CIL has a good relationship with policymakers who handle Medicaid in your state? As an example, do you feel like things like the direct care workers have a shortage and stepping up payments and achieving any pay rates are things that you can advocate for in a meaningful way with your contacts at this date? -- The estate?

CHRISTINA MILLS:
I see some answers trickling in. -- The state? It is mostly yes but there are about 6 of them. I'm also wondering too if we can just ask how many participants are engaging with their state Medicaid Committee Meetings. Any Committee Meetings or public speaking opportunities that you get as his stakeholders, are you engaging in those opportunities with the state Medicaid department?

EMILY MUNSON:
We are getting a couple of yeses.

CHRISTINA MILLS:
Yeah, and we are seeing not aware of any relationships, but mostly they are yes coming in which is great. A few no and our Commissioner -- A few no's.

Our DBS Commissioner we had our great relationship with but he just retired. I'm not sure of the new person. Now is a great time to build that relationship!

EMILY MUNSON:

There are so many issues going on right now, now is the perfect time to pick one and reach out to ask a question about it! Even if you are in a wheelchair like me, to get your will in the door, if not your foot in the door. -- To get your wheel in the door, if not your foot in the door.

The PAs are the experts. They can interpret all of these legal provisions for you. But you folks really are the lived experience experts. It is not the case in every state that the P&A attorneys are going to be people with disabilities because there is no minimum hiring requirement, like SILs half. So as we thinking about -- think about moving forward in regards to these rules, I encourage you to think about --CILs have. I encourage you to think about if you do not already have one, two build a relationship with your P&A.

For example a lot of P&A's submit public comment on proposed federal rules. That is reading I think the Medicaid access rule was over 200 pages of very fine print reading from the Federal Register.

Let the attorneys handle that. You guys are busy. Ask them for a summary and it then I'm sure it will be helpful for DNA if you share those proposals within your networks and provide back feedback from folks with disabilities in your area who can then inform the way that the P&A's draft their comments.

I always try when submitting comments and anyone who knows me knows my comments are very lengthy, usually about 15 pages single spaced for a typical rule, and I like to have real stories and scenarios about how real people with disabilities are going to be affected. And I think framing the narrative is a great foundation to build a stronger relationship between the CILs and to the protection and advocacy agencies. Since we only have 10 minutes left I probably need to stop here and open the floor for questions!

Does anybody have any? Not just for me but for Christina or Brittany as well?

MARY-KATE WELLS:
Hi Emily, this is Marie Kate. I'm just looking at the Q&A. Someone has asked (Reads) "How do we know if we are a fee state?"

EMILY MUNSON:
If you have Medicaid services in your program you are not a fee for service state. If there is no managed-care involved and it is (indiscernible) directly, then you are a fee for service state.

MARY-KATE WELLS:
Then I see another one. It says (Reads) "When you say let the attorney give you a summary, do you mean an attorney at your P&A?"

EMILY MUNSON:
Yeah. -- Let me back up. In-state agencies a lot we see memorandums of understanding in terms of one another in terms the division of aging will do this and the arms bud, and office will do this for example --Ombudsman.

I think it would be helpful for states to get together and showed a very limited resources to bring together the greatest advocacy impact might share their very limited resources -- and share their very limited resources to bring to both the greatest advocacy impact for folks with disabilities in the community. So they will already read these proposals at the state level as well, not just federal ones.

They have the know-how and the resources to alert the CILs and SILs of what is coming down the pipeline. Because the protection agencies do not have the lived experience peace that is where the CILs and SILs Ken Tom in return thinking about how those proposals could positively or negatively affect folks with disabilities at the local level. -- Come in and return.

MARY-KATE WELLS:
We have one clarification question and event we might have a little time before handing it back to Christina.

Someone asked her just for clarifying, managed-care states do not have the 80% rule? -- Someone asked just for clarification due managed-care states not have the 80% rule?

EMILY MUNSON:
The 80% rule I believe is across-the-board. I would advise you though to look at the links that Amber shared up above in the webinar chat and that lays everything out very clearly.

I don't have the ability to get the regulation in front of me while I have Zoom open. But the 80% rule should be in fact nationally within six years. Again we had to step up to that level so it will take some time.

MARY-KATE WELLS:
And I think this is a good closing question, someone asked in a Q&A box (Reads) "What relationship should the P&A have with the sale regarding grievances? Should the P&A be included in certain meetings or conversations outside of grievances?"

EMILY MUNSON:
My recommendation would be that you think of the client assistance program or CAP as its own separate thing. The chances are unless the topic is employment, you will work with another attorney completely on other issues. Most protection and advocacy organizations have an employment attorney, education, self-determination.

And in the chat I see a couple folks have asked for an example of how P&A's and CILs have collaborated. An example is working on a work group together to improve self-direction and to spread the word about self-direction and alternatives to guardianship and to advocate in tandem for the general assembly or your state legislator to adopt laws that recognize supportive decision-making agreements in lieu of guardianships or more restrictive issues -- for more restrictive issues.

I'm pretty certain that it is issues like that where you would not be dealing with the CAP attorney and all. And please keep in mind that even if you do get a visit from your neighborhood CAP attorney, we have the same goal as you! We want to make sure that the person with a disability is getting what they need to thrive and getting what they are entitled to legally. So our job is to -- our job as P&A is to not try to get anyone in a role or --or sue a CIL. It is really to help everyone brainstorm on how we can do a better job to make sure the client gets what they need. Because at the end of the day that is why we are all there.

MARY-KATE WELLS:
Awesome. Thank you. I will hand it to you Christina.

CHRISTINA MILLS:

Thank you Emily! And again thank you Brittany too.

I want to go back and hone in on something you were saying Emily. At the end of the day again it is about the relationship building. And no we are not trying to get each other in trouble, we are trying to create the IL ripple effect and independence and interdependence for folks with disabilities to be successful.

Just like building relationships with Medicaid agencies or the P&A or any other entity, change can happen over time!

I went back in the chat and I noticed someone made a comment related to Christopher Reeves and not being entirely a part of the medical model. I think that is a really great example of how IL has really impacted the Christopher Reeve's foundation.

The Christopher Reeve's foundation does incredible work and we have people from independent living that now work for the foundation. And I think that is great. It didn't happen overnight.

Again it is relationship building, building that partnership and working together towards something. Sometimes it starts small and sometimes it starts with something very serious. But it is all worth it and it really takes the experts of people with disabilities and independent living centers to make it happen.

With that being said, next slide please. We are actually I'm not sure if you are going to go down to the closing slide.

MARY-KATE WELLS:
Yes, we will go to slide 50.

CHRISTINA MILLS:
Perfect. OK. So we all know that Lead on comes from just in dart. -- Lead on comes from Justin Dart. --Justin. Leading with accountability to know that we are doing the right thing internally and externally to make a difference.

And with that, thank you so much ILU, the University of Montana, everyone for making the summit possible!

MARY-KATE WELLS:
Awesome, thank you so much Christina, Emily and Britney! I think that gave us a lot to think about leaving here today.