IL-NET, a project of ILRU presents

Disability, Diversity and Intersectionality
in Centers for Independent Living

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DDI Project Overview & Background
Presenters: Darrell Jones & Judith Holt

DARRELL JONES: Well, I hope you enjoyed lunch, and that you have your energy renewed, but I know for me after lunch is usually nap time, so we're not going to keep you too long, but we wanted to give you some information about the background on this DDI project, because we think it's important where we came from with this. How this all started. Because our process in the IL‑NET has kind of paralleled the process that's happening across the entire Independent Living field. It's been a process of growing, understanding, in consciousness and awareness, and that's what I see happening in the larger society these days.

I wanted to mention a book to you. This isn't part of my formal presentation, but I wanted to tell you about this book, because this book has clarified some things for me as a White person. And I have noticed that so much of the national conversation is around what White people don't seem to really get, what they don't really seem to understand. This book is titled: White Fragility: Why It's So Hard for White People to Talk About Racism, written by Robin DiAngelo, who is a university professor, and she really dissects this discussion in a way that I found so enlightening. I have always considered myself a pretty conscious person, pretty aware and paying attention, but what she did for me was to explain some of the terms that we are experiencing in our national dialogue in a way that I got this at a deeper gut level than I ever have before.

If you're struggling with words like privilege versus prejudice and what is racism. Is it prejudice or is it systemic structures and social norms? There are a lot of nuances. And the reason I'm suggesting this book to you is because I think a big part of our problem, both on the national scale, as well as among ourselves in Independent Living, is that we're not all operating off the same interpretation of what we mean by different concepts, because we all have different life experiences. So just wanted to pass that tip on to you.

The reason we wanted to tell you about the background on this project is because the way it happened was one of those sort of incidental off‑hand things that I found synchronistic because as Tim mentioned this morning, we had for years offered a number of trainings to the field on cultural competence and diversity and outreach to unserved and underserved populations and we couldn't ever get any traction.

One of the things that kept happening was that people just didn't show up for those events, so we were kind of talking to ourselves. And it wasn't for me personally ‑‑ I'm just going to tell you what my process was. For me personally, I didn't start to get a lot about this until I was introduced to the idea of intersectionality. It just wasn't coming together for me. So in 2016, we got this communication from our funder at ACL. We have this standard funding that we get that comes from Title VII to run this training and technical assistance project.

So, ACL came to us and said: You know, HHS, which is of course their parent agency, Health and Human Services, really wants to focus on outreach to minority populations, and we're trying to talk them into doing something around Independent Living.

And there is this section of the Rehabilitation Act that we can get some funding from, and we're going to make a case that this should go to Independent Living. It took them several months to make that argument, but they did, and they came to ILRU, and they said: Will you take this project on? We said: Absolutely. We just don't quite know where to start with this, because we've had this experience in the past of not quite knowing where the field is ready to deal with this conversation.

So, they said: What we want you to do is to take a look at what Centers for Independent Living are doing. So, we put together a team of people that consisted of a researcher that we were introduced to by the Cultural Competence Center at Georgetown University, by the name of Sharon Lynn Harrison who is out of Detroit. Stan Holbrook became a part of our team. Judith Holt became a part of our team and Richard Petty from ILRU became a part of our team.

And in a minute, Judith is going to walk you through how we actually came up with this process to find Centers around the country who seem to be making some progress with this. So we had this researcher and our purpose that we decided on was really just to identify Centers that had made some progress, and we chose to define this around cultural and linguistic competent policies and practices to improve services, programs, and outreach for racially, ethnically, culturally, and linguistically diverse groups. And what you're going to hear, I think, throughout the training is that ultimately, the work began to expand beyond racial and ethnic issues, and that was just an organic thing that happened. Because when you start thinking about being inclusive to any group of people, and you start looking at the way that you're structured as a nonprofit organization, the way that your Board operates, the way that your staff operates, the way that you interact with your community, and the partnerships and collaborations that you have, you realize that all of that affects every population of people. So, if you figure out how to do that for any one group of people, you can figure out how to do it for any group of people.

So, as I mentioned earlier, HHS had decided that this was a priority, because they were looking at social determinants of health, and they had this Advisory Committee that was focused on minority health. And this Committee reached the conclusion that as a member of a racial or ethnic minority group with a disability, it's a double burden. And that's because of the layers of sociopolitical challenges that you face, the more groups that you identify with, because of the social forces that impact every one of those identities.

So what we had not paid attention to at ILRU ‑‑ and actually, I had never heard it mentioned anywhere in the Independent Living program prior to ACL saying to us, we're going to give you this money under Section 21 of the Rehabilitation Act. How many people here are familiar with Section 21 of the Rehab Act?

Liz. Jesse. Okay. Maureen. I'm sorry. Deb. Okay, a few folks. Well, mostly we focus on Title VII of the Rehab Act because that's the Independent Living program. We also talk a lot about Title I, which is the Vocational Rehabilitation program. But here was the section that they said: We're going to give you some money to do this project, and so we had to go look it up and read it and really try to digest what it meant, and because they were not able to really articulate what they were looking for from us. I mean, they said, go forth and identify Centers that are making progress.

Okay, well, what does that mean? We had to sort of make it up as we were going along. So, Section 21 is written for the entire Rehab Act, but the language that you'll see in here sounds like it's talking just about the basic state Vocational Rehabilitation program. But in the first paragraph, it says that this is with respect to programs from Title II through Title VII. I don't know why it doesn't say Title I, because Title I is the basic VR program, and I tried to get an answer to that before coming here, but was not able to. But clearly, the language in here is about the entire Rehab Act programming.

So, this section has this statement about racial profile. Okay. The demographic profile of America is rapidly changing. Rose, did you have a question?

AUDIENCE MEMBER: A comment.

I was thinking about the Voc Rehab thing and another bill, WIOA, Workforce Innovation and Opportunities Act, I believe that would ‑‑ that sort of modifies the Rehab Act and I believe that would put these qualifications on the general voc rehab programming, as well.

DARRELL JONES: Thank you. So, Section 21 says what we all knew, that the demographic profile of the country is changing. While the percentage increase for white Americans is 9.7%, the percentage increase for racial and ethnic minorities was much higher, 43% for Latinos, 12.3% for African Americans, and 43.2% for Asian‑Americans and other ethnic groups.

It goes on to say that ethnic and racial minorities tend to have disabling conditions at a disproportionately high rate, and this is confirming some of the things that Keri shared with us this morning. These are statistics from 2011 that Congress chose to include in the Rehab Act. Among Americans ages 16 through 64, the rate of disability was 12.1%.

Among African Americans in that age range, the disability rate was more than twice as high, at 27.1%.

And for American Indians and Alaskan Natives, more than twice as high at 27%.

So when I got to this paragraph, I realized what an indictment of the Vocational Rehabilitation program, including the Independent Living program, which is part of their definition of the rehabilitation program, what an indictment this was for Congress to include this statement in the Rehab Act.

Patterns of inequitable treatment of minorities have been documented in all major junctures of the VR process. As compared to white Americans, a larger percentage of African American applicants to the VR system is denied acceptance. Of applicants accepted for service, a larger percentage of African American cases is closed without being rehabilitated.

Minorities are provided less training than their white counterparts. Consistently, less money is spent on minorities than on their white counterparts.

Then it goes on to talk about recruitment of staffing for the VR program. And it makes a statement that all of the employment efforts, including pre‑service training, continuing education and so forth, must focus on bringing larger numbers of minorities into the profession. And I especially appreciated the fact that whoever on the Congressional staff wrote this language, that they added the statement: To provide appropriate practitioner knowledge, role models, and sufficient manpower. I don't recall who was talking about the peer ‑‑ was it Reyma was talking about the peer aspect of Independent Living, and if our staffs aren't reflective of who we're serving, we can't really claim that we're providing peer support.

So, I added this slide because I know that you are familiar with this part of Title VII. This is the assurance that your Center has to sign off on to get your federal funding. It says that you will conduct aggressive outreach regarding services that you provide to reach populations of individuals with significant disabilities that are unserved or underserved by programs under this title. It also says that you will train your staff on how to serve such unserved and underserved populations.

So, this assurance is only part of the picture. The other part is what the rest of Section 21 was talking about. It's not just about who you're serving. It's about who you are. It's about who your staff is, who your Board of Directors is, who your relationships within your community are, and these are some of the things that we learned through this study that we did as we began to connect with Centers around the country who are making some progress on this.

So, Judith is going to share with you now how we did the project, and some of the things that we learned.

JUDITH HOLT: Thank you. And since Tim has been trying to make eye contact with me, I think that is signaling that: Don't get long‑winded.

[ Laughter ]

He probably would say it more graciously, but...

I'd like you to ‑‑ Darrell, will you move the slides for me? I'm pretty sure I can't read, talk, and hold this at the same time. It's acknowledging when you have a problem and then asking for support, right? It's not having the problem. It's asking.

We selected 9 sites for case studies, and I won't ‑‑ I was going to have everyone stand up and introduce themselves, but we've already done that. I wanted to acknowledge folks from Milwaukee are here. I think we have all the sites represented.

I'd like you to think about these 9 folks, these 9 sites, not as the experts in the room, but to emphasize the fact that they're making progress, they're moving toward it, and it's on their agenda. It's on the table. It's being discussed. That's part of the problem. It's not saying, I believe it's a good idea. It's actually intentionally working forward. And each of these sites are doing that. They wanted us to be sure we said: And we're not there yet. There's still progress to be made. But the progress is moving.

The next slide.

AUDIENCE MEMBER: Would you read them please?

JUDITH HOLT: I'm sorry, the sites are: Access Living, Chicago. Center for Independence of the Disabled in New York, Susan.

Central Coast Center for Independent Living, Elsa, in California.

Central Iowa Center for Independent Living, Reyma.

Community Resources for Independent Living in California, that's Ron.

DisABILITY LINK in Tucker, Georgia, that's Kim, and we've heard a lot with their gracious hosts here in Atlanta.

Illinois/Iowa Independent Living Center that would be on the Mississippi where it goes east and west, not north and south, right? Gotcha. I'm okay, Liz. I'm trying. IndependenceFirst in Milwaukee, Wisconsin, and the Metropolitan Center for Independent Living in Minnesota with Jesse Gomez. You'll be hearing from most of these people later.

Basically, there's been a lot done, and we've alluded to that. But I want to refer you to the IL website. It's www.CIL‑diversity.org.

And on that website, there's a lot of summary information, because this is just one more, if you will, activity in a long process.

On that site, you'll find the background of the project. You'll find the case studies for each of the Centers. You'll also find the webinars. We've had a series of webinars on different topics, and you'll find slide presentations on this topic from both NCIL and APRIL, and my guess is after this conference concludes and Darrell does the editing and looks at the videos, that we'll probably have video clips there, too, right?

Now, on the table in the foyer is a book that IL‑NET developed on Disability, Diversity and Intersectionality. These are the 9 case studies so if you'd like to get more in‑depth information on those Centers and on these case studies and then ask the folks that are here questions about them, this would be a good time.

The study itself ‑‑ next slide ‑‑ the study itself ‑‑ well, we've got definitions here. On intersectionality I have to do one disclosure, okay? I decided I fit there, okay? It took me a while to figure out because first I just saw myself as White.

Well, okay. But it's getting more complicated. I'm getting older, and if you ever want to lose privilege that you've kind of had either systemically or for other reasons, get older, okay? You're talked to like you're 3 years old in airports: Can I help you find the gate?

Okay?

Yeah, I think so.

[ Laughter ]

You're not respected as much, in the sense that: Oh, well, you're kind of into retirement. I know you wouldn't care about this. What if you still care? So, as I'm losing some of my privilege and I'm better understanding intersectionality especially the disadvantaged piece, I want to say this activity has been one of the most valued that I've been engaged in, and one of the most meaningful.

Next one. Let's talk about the project itself. This is really quick. First of all, Darrell said, they said go forth and figure this out, so we started by asking people who were in leadership roles or roles of influence within the Independent Living Movement and some of our allied partners about Centers that they thought were doing a good job with disability and diversity. We got quite a list. From that list, we contacted 38 Centers to see if they were interested. Some of them were not interested for various reasons. We did in‑depth telephone interviews with 20, narrowed that down to the 9 case studies for the in‑depth interviews.

And this is what came out of it. And these are your take‑aways. First of all, to a person, the Centers did not want to be seen as exemplary. They said: We're not. We're not. We've worked on this. We're trying hard. We're making progress. We care about it. But we're not exemplary.

They shared their story, but wanted everyone to understand it's an ongoing story. It's not a static story. We don't get to "yes, this is perfect." We're on this journey, and the journey has to continue.

The journey changes. If you think back where your Centers were 10 years ago, what do your demographics look like now? What does your staff look like now? What does your Board look like now? What does financing, funding, programs, what does your state look like right now? It's static. You can't ‑‑ I'm sorry, I keep standing in front of you. It's not static. You have to keep moving. You have to keep thinking, you have to keep going.

They wanted the CILs to know that you have to know your community. And by "community," we mean the groups within the community. You cannot just say, but these are the folks who generally come to see us. We're doing fine. Our numbers look okay. You've got to know your community.

You've got to do your homework. You've got to be responsive to what the community needs and wants, not what you think they should get. One of my examples of this early on was working with Latino families, and we were working on transition. And from a U.S. middle‑class White perspective, all I can say is I was so happy when my kids left the house that I could change the locks on the door. And I knew they were gone, they were 18, 20, 21, they're gone. They keep coming back, but we won't go there.

[ Laughter ]

But when I was working with the Hispanic families, guess what? Families were important. Families were like ‑‑ I thought families were important for me, but for me, a family is independent. For them, a family is support. The 18 transition was not nearly as set in stone, or as important for them. And I began to recognize ‑‑ it took me a while. It's taken me a while to learn a lot of things ‑‑ that you have to know your community. Know what their values are. You can't just assume that you all have the same values.

Love of family, yes. How that translates, a little bit different. You have to be proactive, as well as responsive. You can't just say: Well, I'm here. If they want to come, they can walk in, right?

Huh‑uh. Somebody said, you're ‑‑ it was a mobile discussion this morning ‑‑ taking your CIL into the community. You have to be physically in the community. You cannot just sit back and say: Well, they don't come so I'm trying. It would be really nice if somebody walked in the door. Of course, I don't speak their language, but it would be really nice. But you also have to be, and I love this, intentional. You've heard that word this morning several times already.

This is not random. This is not casual. This is intentional, systematic, thoughtful thinking about how your Center can really be inclusive. The next slide.

Now, here's the painful part. And for those of you ‑‑ I think all of you are in the process somewhere, I don't think this is either/or, you're in the process somewhere ‑‑ even in Massachusetts, okay, where you work, even there, it's a process. But you do need to rethink and restructure aspects of how your CIL functions, and that includes your Board, that includes your staff, that includes your core services, that includes outreach. You can't just say: Oh, we'll do business like we've always done business and do a little touch here and there. You have to do some basic rethinking, restructuring, which is going to be painful. We're not saying ‑‑ if this were easy, maybe we would have done it years ago, I don't know. But right now, it's going to be painful.

The journey often involves new partners. Now, this morning when Keri was giving her great go‑get‑em talk, she mentioned how her identities, there's different partners she kind of has for different identities, and she used Black Lives Matter. Now, I think that as we're thinking about new partners, we literally have to think outside who our disability partners are. Yes, we all know we have a love‑hate relationship with voc‑rehab. That's a given.

[ Laughter ]

But that is not one of our ‑‑ it's really not mine.

STAN HOLBROOK: That's mine.

JUDITH HOLT: Stan! And I was in the middle of a good line, too.

STAN HOLBROOK: Sorry.

[ Laughter ]

JUDITH HOLT: We have to be able to say who are partners who care about the same population we care about? And if they don't, they're not into disabilities, guess what? You have an opportunity to share your commonalities with them, and maybe introduce them to the concept of disabilities, or to help them understand that there are people that they're supporting that do have disabilities.

But you have to get outside your comfort zone with your partners. I don't think it's going to work if you stay with your traditional disability-oriented partners.

Not that you need to leave your old partners. I don't mean that. You can have many partners. Here we go. I'm progressing.

The process that your CIL engages in to meet the needs, as Darrell said, if you go through this process and you begin to do your changes, meeting the needs, understanding the population, this same general process, not exactly the same activities, but the same general process, could be applied to other marginalized populations. And as you gain more insights and skills, you'll begin to see that your CIL can really represent all, not just one group of people with disabilities, but really reach out to all those who have disabilities and who are marginalized and who need the support, the peer support, the services that your CIL offers.

So that's what we found. You've got a great chance to visit on this. I'm so sorry, Tim. People don't have much time for a break. Are you going to allow them 4 minutes or more?

TIM FUCHS: We'll allow them a little more.

JUDITH HOLT: Okay, thank you.

[ Applause ]