**Consumer Control: Our Foundation for the Past & Future**

Our presenters for this session... Before I get into our presenters, the same housekeeping tips as before. CART captioning and ASL interpreters are available. For the Q&A, we will run at the same way we just did. You can use the zoom Q&A tab or press\*nine into your phone. We will wait until the Q&A break to address them.

We will have a separate link for the evaluation for this session. We will ask you to full that out after the session, but then also after the second part of the session this afternoon.

To go into the presenters, unfortunately Judy was unable to make it today, so I will move on to Darrell Jones. He is the interim executive director of the national Council on Independent living. A former ILs net project director, and cofounder and first director of the Rochester Center for Independent living, one of the first title VII funded CILs.

We have Luanne Kibbe who is systems advocacy manager at Southeast Kansas Independent living resource Center. She is an activist in Western Kansas Association on concerns of the disabled.

We also have Paula McAuley here, she is the director of technical assistance at the Isle net training and technical assistance Center for Independent living at ILRU. She is also a cofounder of LINK.

Now I will hand it to Paula, Darrell and Luanne, and let them take it away. Whoever speaks first, I will spotlight you so that everyone can see you. Thank you all. Here is our next session.

SPEAKER:

Good morning, everyone. Good afternoon, depending on where you are. Welcome to the session. We will talk a little about the grassroots consumer groups that led to the creation of local centers, partly, and then some national consumer controlled centers or groups that also came out of that.

We are going to give you our own experience, and reference the experience of some of the others as part of that. We will talk a little about how that can get us to look at consumer control and independent living spaces. Because we saw then, and we see now various levels of implementation of true consumer control.

So we will talk a little bit about that, and how that impacts communities, and what we can do to make sure that that foundation of consumer control applies today to current situations.

So that importance of consumer control is -- as a priority for centers is the key focus of what we want to talk about. Let's look at the next slide, slide seven.

Consumer control, to start with, is not about compliance. I want to make this extremely clear. It is in the regulations, it shows up in the rehabilitation act. It is required. So centers must have 51% of their staff, 51% of their board and 51% of their leadership â€“ which if you only have one leader and Executive Director, that Executive Director would be a person with a disability. So there is this requirement in law, so we must do those things in order to be compliant. But it isn't about compliance.

Because I work with centrists who are out of compliance and help them to come into compliance, I have had a couple of disturbing conversations with boards. For example, I remember sitting with a Board of Directors, and saying to that Board of Directors, "You must have 51% of your board be people with disabilities." And one of the board members said, just started pointing at the members who said they didn't have a disability and said, "Well you wear glasses so you have a disability." And he started talking about things that were conditions that these folks had that he felt would qualify them to be a person with a disability so that they could meet this compliance requirement of 51% for the board.

The problem with that was, and continues to be sometimes, is that people who do not identify themselves miss the spirit of what was intended in the law. Because what's intended in the law is that people with disabilities who want to help control the center, who want to help drive the future, who want to actually make changes in their community, those are the folks that I consider to be people with disabilities.

So, they have a disability, but they also have a heart for consumer control, community access, equal access in the community, and that's much more than compliance.

There was another situation in the center had been cited for noncompliance by state review and they had a very small staff. They had a very small board. They wanted me to come out and do some training to help them accomplish their plan of correction.

I got there and they said, oh good news. We've hired a new executive director. I said, "Oh, you have?" I turned and asked the question, which by the way is always legal to ask of people after they have been hired, and before in most situations for affirmative-action purposes, but I turned to him and I said, "What is your disability?" He said, no I don't have a disability.

I said well you're out of compliance with this issue of consumer control. You have to have 51% of the leadership be people with disabilities. He said both of my staff have disabilities. I said, yes and it meets that requirement, but you are the leader and the leader also has to have a disability his response was, well my wife has a disability. That counts, doesn't it? My answer was no. The person in leadership must be the person, 51% of leadership must have disabilities.

Charlie made an excellent comment in the last session about this issue of is there-- is it okay for there to be a nondisabled Executive Director at the center. You have to look at this issue of where things are related to the heart of consumer control.

And what they ended up saying was we will make all three of our staff leadership. We will give them different titles and be in compliance. They missed the point that the voice of their center, the leader of their organization was someone without a disability who is only going to speak on behalf of his wife and he's out in the community? Do you see the problem?

And so I have a lot of concerns about how sometimes consumer control is for compliance, when it really ought to be for activism. It came out of activism. We will talk about a few examples of that.

Luanne will lead off about how a grassroots group in Kansas met some transportation needs before we even knew what a CIL was.

LOU ANN KIBBEE:

so, Paula and I were talking about years that this all occurred. In 1978 I had just returned home. Actually prior to that, 10 months after I acquired my disability I left for college at Gloria State University and got involved for the first time, this was my first introduction into disability rights and activism. I got involved in the handicapped student Association at the University. I became the secretary of the organization under Duane French as the president, for those old-timers that knew Duane three years.

Upon returning from college at the end of that year back home to Hays, Kansas. I got involved with a newly formed group that had just started working on some local issues not long before I came back. One of the things we began working on quickly was a lack of accessible transportation in our community.

It wasn't that there wasn't accessible transportation, it's that there was no public transportation. If you do not own your own vehicle or have a family member/friend to transport you then you didn't go anywhere. And so we really felt we needed to get some accessible public transportation going in the community so people were able to not only access medical appointments and shopping for their needs to be able to go to a movie or to a restaurant and such.

Of course, there were a lot of barriers, access barriers back then, but things were starting to improve. We were working on some of that too. But what happened was we developed some communication with the Easter Seals organization in Wichita. They gave us this old, full-sized van with a manual ramp on the side which was great. We were so excited.

Here we have accessible transportation, and then the dilemma was we needed drivers. We worked with the local University, the Dean of student affairs there was very supportive of our group and the changes that we wanted to see made and so he arranged for us to be able to use some of the work-study students as drivers.

One of our members, Skeeter ran the dispatch from home. This became Access Transportation in Hays, Kansas. The system ran this way for a number years and it started to grow so much and there was potential for it to grow further that we worked with the IDD organization and they filled in the administration of that just because they had the ability to do that and the staff, which they still operate.

The transportation system is larger than ever and still doesn't meet all the needs in the community, and it's also been presented at national conferences numerous times through the years. But through that involvement in the organization, and I think Polly might talk about that a little bit more to, is how I became involved with LINK, living independently in Northwest Kansas, one of the first title VII centers in the country. Here in rural Kansas.

I will pass it on to, not sure who's going next. I think Darrell.

PAULA McELWEE:

Darrell is next. Please come on and tell us about New York.

DARRELL JONES:

Hello, everybody. Thank you. I want to thank the Lynchburg center area for independent living for letting me use their offices and Internet. I work at home, but my Internet is usually pretty unstable. The center that is closest to me is in Lynchburg Virginia. So, I am talking to you from their offices today.

I would like to take everyone back to the year 1976. That year Gerald Ford was president of the United States, the Pittsburgh Steelers defeated the Dallas Cowboys in the Super Bowl in Miami. Clifford Alexander Junior was confirmed as the first African-American Secretary of the United States Army. The Apple Computer Company was formed by Steve Jobs and Steve Wozniak in California. And also that year I left the vocational rehabilitation profession to become director of nursing home transition project for young adults with significant disabilities at the county chronic care institution in Monroe County, New York.

It was that position that introduced me to the world of independent living and disability rights. When I was a young VR counselor I was pretty naÃ¯ve about how the world works. I was given an extended probation by my supervisor because he said I gave my clients too much involvement in their VR plan.

I was told that I needed to be more directive because I was the professional and I was spending tax dollars, which we could not waste, on trial and error as people were trying to figure out who they were.

I was told that it was required that I would tell people who they were and what was best for them based on the testing and evaluation measures.

I left the medical model rehab world because it wasn't a good match for me, not because I had yet developed a clear philosophy about disability rights. I was still trying to figure out what rights and equity meant to me as a woman. In women's liberation was a very hot topic in those days.

I just knew there was something disturbing about not allowing people to be who they wanted to be, and I knew that the nursing home transition project was calling to me when I heard about it.

During that project I learned about Centers for Independent Living. My project didn't have the funds to send me to Berkeley, but it interviewed some of that CIL staff by phone to see what they were doing. I also interviewed someone at the Atlantis Community Inc Denver, which is another early center that has a very high profile.

And then I did visit the Boston Center for Independent living, which I have never shared with Bill Henning. But in 1976 I went to the dorm where disabled students live who needed a certain level of accessibility and shared personal assistant services so that they could attend school.

I also visited the Brooklyn Center for Independent living which had grown out of the muscular dystrophy league, I'm not sure I have that name correct, but it was a society for people with muscular dystrophy.

That center was focused on working with consumers with MD at that time who wanted to live in an apartment. And when I saw the modifications the center had made to the apartments in the 24 hour consumer directed personal assistance services they had negotiated with New York State health Department I was blown away.

My life was never to be the same again because it gave me a vision of how the people that I was working with at one Rekha -- Monroe community Hospital could successfully transition to and live in the community.

I was immuno compromised, which I have been since birth. But in those days, I had not identified as a person with a disability. I had not been aware that right there in Rochester New York was one of the most active and powerful grassroots disability rights groups in the country. They reached out to me when they learned about the nursing home transition project and gave me an award at their annual dinner for doing their job -- doing my job.

Then they invited me to be on their board, which in those days, acted as their staff for what work they were doing in the community, since they had little funding.

At that point in time, they had been in business for about 15 years already. Remember, we are talking about 1976. They had been meeting with the mayor and the city Council, and county officials to bring about systems change. They had been doing public education, they were working on developing a guidebook to accessible businesses and public accommodations in the county.

Names that you have probably never heard. People like Joe Petrillo Junior and Patricia Laird were my teachers. My education and indoctrination about consumer control, empowerment and systems change took off like a rocket, because I could see it in action.

Then, when the rehabilitation act was amended in 1978 to create the independent living program, it was a no-brainer that we were a natural organization to apply for funding to start a CIL. We were approached by the state VR agency to do just that. And now, New York State has the largest number of centers of any state in the nation, because we were successful in getting stated legislation passed.

One of my favorite quotes, if you would advance the slide, slide eight please. It's one by a former professor of communication studies at associate director for affairs for -- John McKnight, you might have heard that name.

Back in 1979, before it was popular to say such things, he said at a professional seminar, "Revolutions begin when people who are defined as problems achieve the power to redefine the problem."

To me, the most noteworthy thing about the CIL that we created in Rochester, and that center has accomplished a great deal in its 40+ years, but the most noteworthy thing to me was that they were a grassroots organization that had already been in existence for so many years. And automatically understood about consumer control. They didn't have to develop that knowledge or that skill.

They call themselves handicapped independence here, which stood for housing, education, recreation and employment. In so many ways, they were already a CIL, they just didn't have any staff or individual consumers.

I have often thought, if there were any researchers in the audience, I have often thought it would make a very interesting study to look at whether there are differences in the way CILs develop and how successful they are if they grew out of an existing grassroots group that had already established a sense of disability pride within a community, versus if the CIL was created simply by a nonprofit organization getting a federal grant.

By 1979, the year that we actually started the center, there were way more grassroots activities taking place across the US then I think most people realize. Most of you have heard the history of Ed Roberts and Judy Heumann because much has been said about them in the Berkeley center. The citizens in San Francisco, and the blocking of traffic in Manhattan.

Not much has been recorded or shared outside of the individual states about the literally hundreds of people in many cities that have been laying ground fruit -- groundwork for a couple of decades at that point.

Let groundwork ultimately led to the 1978 amendments to the rehab act. So many people have never been properly acknowledged because of their leadership, because the disability rights movement was in its infancy at the time.

I want to take this opportunity to share some of my history during this Institute, because there are not many people from my generation of IL pioneers left. Certainly, most of the people who preceded me in the earlier generations are now dead. I think it is especially unfortunate because of the time that we are in that the people of color who were founding members of the movement are pretty much gone now, and are not here to be part of the vital conversations we are having about diversity, equity and inclusion.

Before the rest of us disappear, I am glad to have the chance to encourage all of you to interview the IL pioneers in your state and begin writing down those stories. Because those legacies can be so empowering to the young leaders who are emerging.

My involvement in independent living for the past 40+ years is one example of how IL has reinvented itself and continues to evolve. We have way more resources today than we did back then. We need to remember that. Many people with disabilities such as mine, people with hidden disabilities, for example, are now on staff boards of centers, and are consumers of CIL advocacy services. All of us are continuously learning what true disability justice means. I want to go back to John McKnight's quote for a moment. I used this quote because I think he said something important for it being the year 1979.

He referred to the civil rights movement when he was trying to explain what he meant by his quote, he said that he believed that the civil rights movement was able to start getting traction when Black people were able to declare that it was not they who were deficient. It was the attitudes and barriers of society that needed to be changed.

This revolutionary ideal was adopted by other groups. He didn't name the independent living movement because it was probably too early to know about it, but he talked about people who were viewed as clients and perpetual patients.

Basically, a class of people who are considered deficient and in need of the help of professionals to be considered adequate. The self-help movement in general grow out of this movement. The problem was redefined. People with disabilities started saying, "I am not deficient. The problem is deficiencies in the community."

I would like to say that sometimes, ironically, CILs still run the risk of slipping back into the professional problem, as John McKnight called it. If we are not ever vigilant about who is in control of one's life, and to the leaders of the IL movement are.

I am going to stop there. And turn it back to Paula, or Luanne, if either one of you wanted to add to what has already been said.

PAULA McELWEE:

Just a little bit. I don't know if Luanne wants to jump in here too. But so much of what we see today when centers are struggling to understand and respond to the community, the disability community. Sometimes, what we see is the very thing that Darrell mentioned, which is that the staff moved themselves again into the role of the professional, with the assumption that they know better than the individual.

Sometimes, I think this comes because we have a lot of people who aren't coming to centers anymore. They go through the school system and then employment in their life and they don't come see us at the centers. I wish they would because they would make our community much stronger. And I think finding ways to involve the folks who have never been involved in the center but have disabilities is a challenge for board recruitment and staff recruitment both.

But I think that as we look at that situation, a lot of times, the people who are coming in our door have a greater level of need than some of the earlier folks. And then, the assumption is, well, then we know better because they wouldn't be in the situation if they didn't... Whatever it is. Have a history of addiction. You know, if they were not homeless. If they didn't have... You know, other situations going on in their life that impact them in addition to disabilities. Some coexisting situation.

A lot of the folks we see these days are folks with a very high level of need for getting back into equal access in the community. They are a long way from that in their current situation.

That doesn't give us permission to become the professional. And I think that never forgetting that activism came first. Rules and regulations and core services came later. Consumer control is a principal that was in place for the purpose of some very interesting change, including those ramps poured out tonight that Richard mentioned.

Lots of active work to make change happen. So that the community was accessible, and that we all had equal access to the community. That is the thing we want to communicate most, right? That is the thing that we hope most will have an impact on you as you look at your center services, and as you think about what you can do to have true community, true consumer control. Consumer control at every level, consumer control in every activity, consumer control as you make decisions about planning and where you do and what you're going to do. All of that is so important.

We want to make sure that is in place at your center. We want to included in this Institute, a real focus on how to make sure that happens. I don't know if we have some other comments? I think we can go on to the next slide.

LOU ANN KIBBEE:

I think you guys have it covered.

PAULA McELWEE:

I got myself mixed up and give you information on the other side. There was one other point on the other side I want to mention and that this happened not just at the local level, but also at the national level. So, when you saw the development of those first 10 states that were funded under the Rehab Act to have centers granted in October 1979 and continuing through their, as you see that happen the other thing you see happen almost immediately is discussion about how to have a national impact.

And so almost immediately there was conversation about what became NCIL. How can we have a national Council? We like to make words out of everything, did you notice that? And April which came a few years later. But NCIL is the national Council for Independent living rolled out of those early meetings with the grantees, those 11 grantees actually, 10 states and Darrell and I because we were the walkies in the group and did not at the time consider ourselves to have a disability because everybody else had such clear disability and we did not. Hours were invisible and we weren't really sure at the time if they counted.

We were relegated as secretaries. We took all the notes and typed them up. I wish that we had had computers at the time. Can you guys even imagine that we didn't have computers? There were a few computers, but they weren't very useful. They were located within mainframes and personal commuters were just -- personal computers were just beginning, as was noted Apple was just starting. We took handwritten notes and then went to a typewriter and typed them up.

We both wish that we had kept the handwritten notes and made carbon copies that we could take because that would have been a really interesting historical conversation around NCIL which came out of those early days. Max (Unknown Name) and Mark (Unknown Name) were among those first 10 center directors and they were also the first directors of NCIL as time rolled out.

And then a little later, not a lot later, but later in the early 80s the rural centers began to say NCIL doesn't meet our needs entirely because they are so focused on urban things. Urban transportation is very different than rural transportation, for example. The Association for programs of rural independent living also came about shortly.

But part of what we wanted to make sure happen was that whatever was going on in independent living that we were sharing that with each other. That somehow we were communicating with one another all the best practices, the good ideas, the fun things we were running across. The ways that the counties were interacting, the way the state was interacting so that we could have the best possible result from that.

So, that was part of what we had in mind at the time. I don't know, Darrell if you want to add to that in your memories. The notetaking, the typewriting.

DARRELL JONES:

I do remember it. I remember going off into a separate room from the rest of the group to actually do some of our work. What I remember most about those experiences was that sense of empowerment that I gained by being with my peers because as a new center director, a totally new program that hadn't yet figured out what it was supposed to be doing, I mean we understood the consumer control aspect, but in terms of day-to-day operations what we were actually supposed to be doing was actually kind of terrifying to me. And we didn't yet have the level of guidance from the federal government that we have today. So, we were just making up stuff as we went along.

So, for me the sense of empowerment and collective voice and power that coming together as a group of centers was something I will never, ever forget because it was transformative.

I kept saying over and over how that are relationship-- are relationship opportunity was beginning to transform the world, beginning to transform me personally. So, it was clear how it was operating in the larger world. Thank you for sharing those memories, Paula.

PAULA McELWEE:

The powerful nature of the group itself. And I don't know whose idea it was when the grants were first developed. Somebody decided instead of having 11 grants we will save one grant to make it possible for these grantees to meet together. And that was why we were able to do that, and that was really great.

If you all have any questions feel free to put them in the Q&A box. We prefer that to the chat, but if you drop them in the chat we will try to catch them as well. Feel free to do that. Policy be kept the notes on the formation of our center. I was a little bit involved in that, so I'm glad to hear it.

We need to respect our history. The other thing just to promote ILRU a little bit it was already in existence prior to these grants. People don't always realize that, but Lex (Unknown Name), who is our leader still, was very involved with the development of ILRU in 1976 was the start and provided some training to those first centers right out of the gate.

Came out to CS in western Kansas and I took a picture of him out in the middle of the main Street at 6 o'clock when the only cars were down at the bar and nothing in the business area (Laughs).

LOU ANN KIBBEE:

Paula, I remember when they came up to do that. I recall Lex, his hand controls went out on his car when they were a ways out from getting here and he ended up he used a stick or something to actually drive the rest of the way to get down. I don't know why that's always stuck in my mind.

PAULA McELWEE:

He had to get those repaired after he got here. You know, I think it was in here somewhere. Charlie (Unknown Name) mentioned some of those early BIPOC leaders that Jody is asking about. And I think probably that in some of the questions up above.

Shannon asked about self-reports of the people in the disability rights movement, and there are some YouTube videos, quite a few of them from some of the early folks. You might be able to take a look at that.

I'm an NPR fan and I've wondered sometimes if storyboard might be an option, to do some story core interviews. I think that would be really interesting for us to do at some point.

But yeah, to capture that history because I think we learn from it. I guess that's where I come from. If I go back to my roots I'm better at remembering what we do and why. I know for some of you this seems like old history. Hopefully it's useful for you to begin to think about what consumer control really means, and it means something more than those numbers.

Any other questions? We've got five minutes before we can drop off.

How do you embrace consumer control in IL in a positive way? This was actually from the last call but I thought it was important. Anybody want to jump in on that one?

I think my response would be you embrace it by really realizing who is in control and making it more the numbers. Because if you have a few shy people on the board who don't speak out the fact that they have a disability doesn't always make it consumer control. If they are dominated by people without a disability in that discussion.

Charlie said that Lex did simulated CIL trainings early in Houston, yet it wasn't an 81, Charlie. The simulations were from Cornell. They were how to be an executive director and they simulated all kinds of events and emergencies. And then how you handled that and they gave you the outcome at the end of the simulation, but it was pre-fun.

Did the panelists feel that the movement is still currently aligned with the original spirit and intent of the law? Or has there been a shift in strategy and priorities that guide our work? What a good question.

Darrell, do you want to speak to that?

DARRELL JONES:

That's a very hard question to answer because from the national level we see bits and pieces of things. We don't have a comprehensive profile of what's going on at the Independent living movement. And that something we could get funding to do. We could really do some tracking of what centers our accomplishing over time, to show the growth, the evolution and have something concrete to be able to answer that question.

Because I honestly don't know.

PAULA McELWEE:

Anecdotally I would say I see some centers that are drifting. I say that sometimes that drift has to do with... I don't want to misstate this, but that professionalism, and I don't want to say that staff should be unprofessional, but assuming a professional stance that causes the consumer to feel less in control is one way that I see that drift.

Another way that I see that drift is chasing after money and some of the ways in which centers have him-- approached employment contracts. I see a little bit of a drift there sometimes.

We are out of time because I see Jenny.

JENNY SICHEL:

Probably about 30 seconds. Go ahead, Darrell.

DARRELL JONES:

Could I just add I see the same drifting that Paula is talking about. By the same token I think she and I both also see some very powerful, effective work being done all across the country that's very consistent with the original spirit and intent of the program.

So, it's some of this and it some of that. We just don't have a comprehensive profile at this point in our development. So, if there is any funder on this call who would like to fund a really fabulous project there's one I'd like to suggest.

JENNY SICHEL:

That's a great way to end the session. I want to let everyone on the call now to come back again. You should have a new link for this afternoon session. These lovely ladies are going to finish off their session this afternoon at 3 PM Eastern time. Then, we will also go into the future of IL diversity.