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An American Journey for CILs, CIL Stories – The experience of four CILs in taking this journey
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TIM FUCHS: Okay? We're going to go ahead and get started. So, we're going to hear from Susan, Kim, Reyma and Ron, just about how this work, this journey, has gone at their CILs. So, here's that first step of getting more specific. I'll let you all take it away.

SUSAN DOOHA: Good afternoon, everybody. Can you hear me?

AUDIENCE: Yes.

SUSAN DOOHA: Excellent. I'm Susan Dooha, Executive Director of Center for Independence of the Disabled New York, and I'm a person with disabilities. I have a traumatic brain injury, and I have depression. I want to begin by telling you about the mission of our Center. We believe that it includes a mandate to remove barriers embedded in law, policy, structure, and practice; and it is these barriers that result in disparities for people with disabilities, which are much more extreme depending on your race and ethnicity.

First, my own journey. I grew up in Detroit, in the City of Detroit, a place that had been affected by many migrations, not only from the South, but also from the Middle East, from Mexico, and from China. I grew up in a place where discrimination issues loomed large. We had a largely White government. We had segregated schools, segregated housing, and we had job discrimination run amuck.

We also had prominent leaders on the local, state, and national stage who were both racially and ethnically diverse, including Grace Lee Boggs, who was Chinese American, Coleman Young, John Conyers, George Crockett. Some of them you may have heard about from their careers in Congress. And I was fortunate to have a very community organizing and political action-oriented family and so I got to go to meetings with people where we talked about school segregation, police violence, civil rights, civil rights marches.

We talked about redlining, and we talked particularly about issues affecting people who are poor in Detroit. And we talked about issues that were affecting the Black and Latinx communities. We were very involved in electoral politics and so I began very early getting a political education and seeing things through a political lens.

I experienced discrimination with my ‑‑ that was against my friends who were Black and against me as a Jew. We faced physical threats and violence when we rode our bikes down the block where my house was.

We faced exclusionary cultural norms. There were women in the neighborhood who came to our house to tell my mother that we couldn't have our friends over because they were Black. We experienced and I personally experienced the intense feelings of microaggressions. I remember against my friends, someone asking them if they wanted to look like Barbie. My girlfriends. And they were beautiful, young Black girls who became beautiful women. And they did not want to look like the bubble‑hair cut Barbie.

And I remember experiencing a young woman who said that her parents had agreed she could be my friend because Jewish men make good husbands, and so presumably I would introduce her to these good Jewish men. And she would get a good husband who would give her a good living.

There were people who showed me the opposite of this, and when women in the neighborhood told their children that they could not come and play with me, these women sent their children to my house, to come play.

And then I went on to college and to government and nonprofit jobs that focused on disability. I went to work in the HIV community before there were treatments, in the early days, and focused on race, ethnicity, LGBTQ issues, and gender equity.

I came to CIDNY in 2002, with this background. When I came to CIDNY, one of the first things I did was look at its history. I wanted to know: Where had the organization come from? What was its history? How did it see itself, and therefore what kind of changes was it poised to make? And I was proud to learn that CIDNY's first Executive Director was very proud of both his disability and Puerto Rican identities. I think he was a member of the Young Lords. If any of you are from New York and of my generation, you know who the Young Lords are.

It was an organization that had goals like the Black Panthers. Another leader was Latinx, Eduardo Drogue, and he was a Panamanian man with a disability. And in the 1980s, the Board included a Black Board member and several black staff members so that was the history of diversity to that point. From '78 to 2002, there was an increase in diversity on the Board, and in the staff and in management, but still less than half of the staff were Black, Latinx and none were Asian‑Americans and very few Hispanic or Latinx individuals.

Our personnel policies were the only policies that spoke to race and ethnicity and reflected an affirmative action orientation. There was at that time a very strong focus throughout that period on increasing the kinds of disabilities represented, because the organization had historically been very strong among people with physical disabilities, but did not have strong representation among people with mental health disabilities, cognitive or intellectual disabilities, people who were deaf or blind.

CIDNY had an aha moment. At least it was an aha moment for me when I came on Board. And in 2002, I observed, and I read about in the reports that Vocational Rehabilitation was required to provide about unserved and underserved communities, that virtually no Asian‑Americans were being served in Vocational Rehabilitation. And that caused me to look around and to recognize that very, very few Asian‑Americans were being served at CIDNY, or were not on our Board, not in our staff, not in our senior staff.

And I concluded that our policies and our practices needed to start to change, so that we would fully appreciate diversity. And we needed to begin to explore the issues of the people we had been excluding. We got together with community members, and we did a bit of a study looking through our community partners at the experiences of people in this case who were Chinese American, and who were not being reached by Vocational Rehabilitation, and were not being reached by Independent Living at all. And when they found out about the resources available, they were very angry, incredibly angry, because they felt that resources were being hidden and were out of reach, and that government didn't care about them, non‑profits didn't care about them. They were left to struggle alone.

And they felt very much a sense of isolation, with good reason: There were no staff who spoke Chinese, dialects, language. There were no materials in Chinese, in Mandarin. There was no community outreach, no relationship‑building. All of the policies, we decided, needed to have a diversity focus, and we needed to broaden and deepen our understanding of what diversity was.

So, we needed to get Board and top managers on board with a focus on diversity in 2002. Even though it had been part of our history, it was almost an accidental voyager on our ship, in the eyes of the organization, I think.

And we were increasingly finding ourselves in an environment where foundations and funders were increasingly emphasizing diversity. Wanted to know who was on our Board. Wanted to know who was on our staff, who was in management, who were our spokes persons? And this was very persuasive to our Board of Directors, which included some finance people.

And they understood that if we were going to ‑‑ they were ‑‑ this is how they looked at it: If we were going to move forward as an organization, they needed to better understand how to become a more racially, ethnically diverse organization. The diversity on the Board increased, and includes Black, Latinx and Asian‑American members. At this point, staff diversity expanded, and at the management level, our top managers in all areas ‑‑ administration, and advocacy, and direct assistance in education ‑‑ were people of color.

We needed to track the diversity of the community more thoroughly. At that point, we didn't really understand how to use data, and so we formed a partnership with the University of New Hampshire, and we began doing research together with them in partnership with them, to identify the diversity of New York City, to really understand better who are people with disabilities in New York City.

And we intentionally recruited staff and volunteers. We began to act in very intentional ways when we began to understand who was part of our community. And we began to very intentionally recruit staff and volunteers that represented Black, Asian‑American, and Latinx individuals for our Board of Directors. We emphasized diversity in hiring. We brought on advocates and volunteers who had begun with the organization, testing the waters, simply coming into volunteer or to work in the office. And we helped them grow into leaders within the organization and spokespersons for the organization.

We made sure that our management and our front‑line staff brought perspectives to the work, brought community alliances to us, brought a deeper understanding of issues to us. We engaged with coalition partners around issues that we share including health coverage for immigrants, for example, or housing and evictions, and the need for representation in Housing Court. And we began to review all of our policies and procedures, all of them, all of them. Our outreach policies and procedures, our finance policies and procedures, which needed to include hiring minority and women-owned businesses when we contracted out. We began looking at our outreach policies explicitly. We added language access policies that, for example, barred using family members, unless an individual sought that out. But in no case, children.

We began to add training. We began to add training for our staff to our annual trainings that we provided already on sexual harassment, on the Americans with Disabilities Act, on other topics that we annually train on.

Our bilingual and bicultural staff increased substantially, and we brought on an interpreter line, but only as a backup, because we believe that people who are bicultural and bilingual are by far the best peers. And we believe that if one must use an interpreter, that it imposes something of a screen, of a filter. And we didn't want that to be there.

We began to translate our basic materials into top languages spoken in New York: Spanish, Haitian, Creole, Russian, Korean, Chinese, Bengali, Italian, Arabic, and Polish. And we began to do very, very intentional outreach plans using data about who lives in different ZIP Codes. What are the resources in those ZIP Codes? Are there accessible schools? Are there accessible subway stations? Where are businesses and communities that are most strongly people with disabilities who are Black, who are Latinx, who are Asian‑American. And we made sure when going out that we were sending appropriate staff to work with community partners within the communities, and in appropriate languages. Our idea was: We're not waiting for people to come to us, and to find out that we were welcoming and that we posted our values on the door at entry. We wanted to go to where people are, to remove the barrier of coming to an unfamiliar place.

People with disabilities working with CIDNY began to much more reflect the demographic mix of the community, because we were constantly measuring, measuring, measuring, measuring, how are we doing? Because it's no good to do it, and then not look at whether you're effective or not. So, we began to look at whether we reflected disabilities. We began to look at whether we reflected race, ethnicity, newcomer status, gender, a whole variety of factors. And we reached a point where we did truly reflect the diversity of the community. 75% of our staff are Black, Latinx, Asian‑American. 66% of our managers are Black, Latinx and Hispanic and Asian-American. 58% of our staff are bilingual and bicultural and speak 23 languages, including 10 of the top 12 languages in the City.

And our materials are now in translation in a few more languages, and we're going to increase that. We advertise and we appear on Spanish‑language media, and in Chinese language media, in South Asian language media, and we seek out relationships. We seek out relationships with every kind of organization that is influential in the community and we work very strongly in Coalition, where the Coalitions are very diverse. And we are working towards goals we have in common, like ensuring that the public health system in the City, the public hospitals, have interpreters, have language‑appropriate services, have staff, doctors, nurses, clerks, who are of the same racial and ethnic mix as the community, and that they were accessible for people with disabilities, of every kind of disability. I want to thank you for listening, and I'm going to turn the clicker over.

[ Applause ]

KIM GIBSON: I'm Kim Gibson and I'm from disABILITY LINK. I'm going to pull out here. They actually gave one of the things that describes what we believe at disABILITY LINK, and one of our major practices here or at disABILITY LINK is the inclusion of all people that starts at the front door to say “is it inviting to all?” So, when we talk about that, we say really, seriously, when you walk up to our front door, is it inviting to all? And that was what kind of started off.

I guess my journey, I'm personally invested in creating a diverse CIL due to my personal experiences. I have several different disabilities. I pass the deaf test. I have severe asthma, I have several different things and growing up, I grew up poor. A mother who wasn't quite ready to be a mother. Luckily, I had a grandmother that filled in those spots. I witnessed child abuse.

We had cousins that were people with disabilities. I came ‑‑ my father is Italian, and Italians were not especially seen back then as a very great people. They were discriminated against as the acronym, without papers. If you take that, you know what that means but that's what I was called and had to face throughout growing‑up years.

And then I went to college for a little bit and married a black man, who then I got to see the face of what a different type of discrimination first as a White woman that was married to a Black man and being treated poorly because of that. And then also dealing with discrimination against my son, who was told by his teacher to cut his hair because his afro was distracting the people behind him.

And so, all those kind of experiences taught me to be an advocate, and it wasn't until… By the way, I didn't even know that I had a hearing impairment till after I was in high school. I had to go to speech therapy for 6 years, where they said, read my lips and I sat in front of the classroom and I don't know, I was a straight‑A student, probably because I was in my own little world and didn't hear half of what people were saying.

[ Laughter ]

But, hey. But anyhow, going through that. So when I started off in Independent Living, I had served at Wyoming ‑‑ in Wyoming, as first an IL specialist and then as Executive Director. And we had different cultures, different people, different communities. Many times, one thing that I can say here, is many times, we say, and I've heard it around the room, I say: We don't have a diverse community. It's mostly White. I challenge you to go look at the stats in your area, and you'll find out that just because that's what you're seeing when you're walking around, if you're more intentional to pull those stats, you'll find out that there is 4%, or 1%, of different cultures or different communities in your area.

So, I took that experience and went to Pennsylvania, took a little bit ‑‑ and got to see a whole different viewpoint of different things, and then I took a break and then I came to Atlanta. And the first thing I walked in, and I said: This does not feel like it's reflective of the community we're serving.

And so, we gathered up as a team and we took a look at the different stats compared to our 704 at that time and the CIL staffing, the Board membership and consumer population taking an inventory. It doesn't stop, by the way, right there. I do this every single year when we do our PP&R, compare it, because populations change. Staffing changes. All that kind of thing. So, what may have been correct, or reflective of the consumer population a year ago, may not be representative of the population now, as well as your staff, as well as your Board members. So, it's an ongoing process. It doesn't stop because two years ago, these stats were what they were, as you see in your books.

And then we committed to the value of individuals. That's really important. I preach that for management, but it comes all the way down to the staff. Everybody values the individual as an individual, not defining by whatever.

We call people by names. I hear a lot of people identify by pronouns which is fine, but we identify people by people: Your names, and who you are, and try to recognize that as a whole.

In our data, we included data related to ethnicity, race, gender, religion, sexual orientation, and disability. And now we furthered it to include many other groups than that, but at that time, this is what we did, and we compared our annual performance reports, which I talked about already.

And then we listened to consumer input and prior surveys. So, when individuals put in a survey, we actually sit down, go through, and see what consumers are telling us. We also send out surveys to the general population when we were doing the strategic plan. We included everybody's input in that. We didn't just take a little group and say, oh, we're going to do this strategic plan and we're going to do it just with our staff, or we're only going to do it with management. We actually sat down and did mindfulness, and included two consumers that were voted in by the consumers. A survey was sent out saying: Who do you want as your representatives? To staff, same way. To Board members, same way.

And then, of course, I was there, and we had our strategic plan, but the survey, gaining input, was sent out to the community as a whole so that everybody had an opportunity to share with us. But we also take our outcome surveys and there's a comments section that's in‑house and on our website in order to gain some useful input.

So, this is very wrong, this second line. In our report, in the report, it actually lists our percentages. That actually was, that second line is Hispanic, Latino, Latin, Latina one. So, in the African American, on the Board is 55%, 55.5. And the other ones were right, so that last number is the only one that was wrong, and 55%.

Now, as I said, it's really important to take a look at your community each year. Now, our goal now is more than the focus. We're below representing our community for Caucasian on the Board -- I mean on the staff, not on the Board -- but on the staff level. And we're below serving other groups like Hispanic and Asian, and we're very high in the African American. So, it's always a continual process, but that's what we did at the time was look and see where we were at, and compared them at all Board levels. But then we go a little bit beyond that. We also look at other stats in our area. The LGBTQIA plus, plus disability group. Deaf, blind, all that kind of thing, so our Board, our staff, and everything that we are serving, we're trying to be Representative.

And then when it's the consumers, we're also looking at that, not just our Board and our staff, but are we serving our population and hitting those targets based on all aspects? It's a little bit of work but it's worth it in the end.

It's really important to have buy‑in from management and staff. One thing that we do is we empower our staff to bring forth ideas. And what we did for that, was we created a workshop request form. We asked staff: What do you want to do here at the center that is of value to you? Because if it's of value to you, you're a consumer, it's of value to the community we serve. When you give that freeness to individuals to come up with ideas, it brings forth a teamwork effort.

So, we have different things. We have the Respect Institution, which Bridgette, who happens to be here, leads. She's a Board member. We invite them in to do that, and she leads it. We don't have to do it. It's a peer support group that's done by that. Hearing Voices, we do refugee groups, outreach. We have voices for musical. We have a group LGBTQIAP plus‑plus disability. All those kinds of groups were brought out because it was empowerment not only the staff, but the Board, to say: What can you bring here? When I first started, we didn't have volunteers. And we have a volunteer coordinator and we have on average basis about 15 volunteers per month that come on a constant basis. That's in‑house, and then we help place volunteers outside.

Use of volunteers is very important. If you, you know, you're in my situation. We don't have millions of dollars. So how do you do that? You have to utilize volunteers. And advocacy with entities that don't provide disability services. I heard somebody said it's really important to think outside. So that's where we looked at us protecting us, and that's a collaboration of social justice organizations including Black Lives Matter. And what that developed into is something about ‑‑ first started off with, people of color with disabilities facing police brutality. And now we do injustices and it's the peer‑led group who targets whatever that group wants to focus on.

Again, we promoted feedback from the community with surveys for interest and comments. We invited feedback and ideas from the communities, consumers, staff, and Board members and we completed our strategic plan with all that.

Intentional outreach to different populations. The refugee population. The city of Clarkston is named one of the most diverse cities in the United States, and we're right there.

Jewish population, Muslim population, Hispanic and other underserved, so I said that there. Clarkston, a small city of 13,000, is the most ethnically diverse square mile in America, and more than 50 languages are spoken there. Our staff also speak different one's -- languages.

And we're continually looking at our programs and revising to our populations. That's really important. What may have been okay, may have been a program that was highly invested in, and now nobody has interest in it, it's time to move on and change what your population is asking for.

We use data to identify different diversity groups, and we continue to do this. Atlanta is also home to one of the highest LGBTQ plus populations per capita which is 19th among major U.S. Metropolitan areas. An estimated 4.2% of Atlanta's metro population is gay, lesbian or bisexual so we take that into account. Atlanta is also the second largest majority Black metro area in the country.

I think I made my time, yeah.
 [ Applause ]
 REYMA MCCOY MCDEID: Hi, everybody. Hi again. I'm Reyma McCoy McDeid, and ‑‑ let me put this up a little bit. Okay. Can you hear me?

Is that better? Okay.

And I'm going to be talking about Central Iowa Center for Independent Living in Des Moines. Going to switch gears a little bit. This is truly going to be talking about CICIL's journey, and how this organization went from being a CIL that was literally about to close its doors in 2015 to winning the Organization of the Year award from the City of Des Moines in 2018.

AUDIENCE: Woo hoo!

[ Applause ]

REYMA MCCOY MCDEID: Hell of a lot of stuff happened in those three short years. But before we get into that, a little bit about me. So, I am Black. I am a homosexual, and I have the added bonus of being autistic. So, whoever in here raised the question ‑‑ yes ‑‑ about where are the developmentally disabled people in decision‑making positions, tada!

A note about the autism. So, if you know about autism, you know that folks who are autistic tend to be extremely blunt, tend to be extremely direct, tend to not have a filter. So, I say that because I want to challenge you to not misconstrue my emphatic nature ‑‑ because I'm going to be speaking about some very provocative things in a very short period of time. Please don't misconstrue that as anger, because the angry Black woman is a racist trope, and we don't have time for that here, so I just want to put that out here.

So, without further ado… So, going into a community with a “helping hands strikes again” perspective oftentimes does more harm than good. You have to go in with humility and the expectation that you will have to ask the community you're trying to help for help yourself. So, prior to coming to CICIL, I had a bunch of years of experience working for other providers of service, particularly Medicaid-funded providers of service, particularly service providers where absolutely nobody is disabled, or at least is not disclosing their disability.

Lots of people who are really super passionate about helping the poor, disabled people, but get really bent out of shape when they have a co‑worker who's disabled, or God forbid, a supervisor who's disabled. And so I've seen, kind of from both sides of the game, especially when I was a kid and I was a participant in services, a lot of folks who want to help doing a lot of hurting and so I call that "helping hands strikes again." So when I became acquainted with the Independent Living Movement, the thing that really gravitated me towards the Movement was the fact that the majority of us are disabled. We know the deal.

And so ‑‑ and we typically come into the work that we do at our CILs from the vantage point of empathy as opposed to sympathy. So that's what drew me in and got me to apply for this old position at CICIL back in 2015. And pretty immediately after I got my start at CICIL, I was overwhelmed with CICIL's very dynamic history and so let's talk a little bit about that. So, CICIL's been around as long as the Americans with Disabilities Act has been around. And it got formed in the basement of an individual who is disabled and had gathered together some of her peers and cohorts with the ambitions of starting a Center for Independent Living in Des Moines. And although the staff and the Board most definitely fulfilled the federal mandate with regards to maintaining majority of disabled folks, CICIL since its inception had really struggled with meeting other indicators of diversity, most definitely and most certainly, race.

And we're going to talk about how that absolutely negatively impacted the day‑to‑day operations of CICIL. And so, in '91, CICIL kind of got a promotion and moved into an actual space and was very tiny. We were working with an active case load of 15 back in '91. That number jumps up to 70 in 1997, and CICIL moved into a larger space in downtown Des Moines. And then the periods between 1995 and 2015, a lot of stuff happened, and CICIL was definitely what we would call an underperforming Center for Independent Living. So CICIL basically from the beginning struggled to maintain adequate documentation with regards to who was providing ‑‑ participating in services, and what those services look like. That resulted in a ‑‑ well, it would have been the precursor to the ACL in 2008, and ultimately, that led to a loss in our Part B funding and our State funding in 2013.

And so the big issues, all of our documentation was being captured on paper. There was absolutely no system put into place with regards to how we documented, and nothing was computerized until 2014, basically. And there was just a general disorganization and no central location for client files. To be very specific, my first day at CICIL I walked into the office and there were client files stacked on the Receptionist's desk. So we don't take Medicaid funding and so we're not beholding to HIPAA, but my goodness if I was a client, I would not want my file just chilling on the Receptionist's desk.

I walked into the office that was going to be mine, and there were a bunch of kitchen‑style cupboards. I opened those cupboards and they were full of client files, and we're not talking about neat rows of client files. We're talking about just files stuffed into the cupboard. Yeah, wow.

Each individual staff had client file areas that the arrangement was very similar to what I just described with regards to what was in my office. And so just really disorganized, to the point of being harmful to the people that we're providing services to. And so additionally, between '95 and 2008, CICIL transitioned its client services and supports mostly to volunteer staff. And so we got started in the early '90s with paid Independent Living specialists, and then as a means of saving money, that work transitioned over to volunteer staff, primarily individuals that had been referred to the organization through AARP's work program.

And so by and large, these were folks that were not receiving any kind of training with regards to providing services and supports to CICIL's clients. And so, these are folks that were basically doing the best that they could, and ‑‑ but there was absolutely no systematic supports put into place, or framework or infrastructure whatsoever.

So around ‑‑ as that was happening, the patrons of Central Iowa Shelter and Services started to see CICIL as a place to hang out, and these were people that may or may not have experienced a disability, but nevertheless, were utilizing CICIL as a place to hang out: Use wifi, take naps, drink coffee, eat donuts, that kind of thing. And it reached a point where that clientele was alienating the bona fide participants in services at CICIL. And so CICIL experienced a very severe downtick as far as the actual provision of services to bona fide clients because of this.

So, with regards to the audit that occurred in 2008, several very concrete recommendations were made, including relocating CICIL to a geographic area that was more conducive to the provision of services, to actual target population of CICIL. That was a biggie. Obviously, the need for a diverse staff that actually resembled the demographics of the folks that were walking through the door. Until 2015, CICIL's track record with regards to staff and Board members was 100% White. CICIL had never employed or had anybody in a decision‑making capacity that was not White, and the majority of the people that were participating in services were not White. So big disparity there.

And then also, limiting the provision of services, with the exception of peer support, to actual paid and trained staff. So, these were the big recommendations that were given to CICIL in 2008.

Did CICIL move forward with making those changes happen? Liz?

[ Laughter ]

Liz actually, since Liz is in Iowa, with her CIL, you have a better understanding of the years that I'm talking about than I do, certainly. And so, no, CICIL did not move forward with making any kind of changes based on the recommendations that had been given to them at the federal level, and so ‑‑ thank you, sir ‑‑ so fast forward to the summer of 2013. Concerned advocates basically camped out at a CICIL Board meeting.

[ Applause ]

Yes, bless them. And they made it clear that they had some serious concerns about the organization and its ability not only to serve the people that walked through the door, but to be a Representative of the disability community in Central Iowa, because we had reached a point where fellow service providers and other disabled people were frankly embarrassed by CICIL.

So those brave souls came to that meeting in the summer of 2013. That directly impacted the decision that CICIL's Executive Director made in October of 2013 to retire from his position, and this is the individual that had been the Executive Director since the beginning so from 1990 to 2013.

Between that time and October 2014, CICIL's Associate Director made it clear that he wanted to be the next Executive Director, and that individual's position was actually eliminated in October of 2014, and that ended his tenure, as well. What I don't note here is that sometime between October of 2013 and October of 2014, the Board was able to determine that there was a high likelihood that this individual, the Associate Director, was making use of CIL's funds for personal purposes and so that was the big reason why that position was eliminated.

But also, this is a CIL that at the time employed 6 people, and so from an organizational vantage point, it didn't make sense to have a Director and an Associate Director for such a small organization.

So in January of 2015, CICIL's Board hires an interim Executive Director to kind of come in and put out a whole bunch of fires, and during that time, the former Associate Director -- again the individual that was misusing funds -- attempts to file multiple lawsuits and Civil Rights complaints against CICIL. So, a lot going on, is what you hear me saying.

And then in May of 2015, they put out a position description for an Executive Director, and I answered that particular call.

AUDIENCE: Woo hoo!

REYMA MCCOY MCDEID: I was hired in September of 2015 as the organization's new Executive Director. I attended my first Board meeting on September 19th of 2015. That meeting was 6 hours long. The meetings happened once a month.

[ Laughter ]

AUDIENCE MEMBER: Oh, no.
 REYMA MCCOY MCDEID: I sat there, I was like hell no! We're going to change this!
 [ Laughter ]
 REYMA MCCOY MCDEID: 6 hours long. We had Board members falling asleep during the meeting. We had a Board member ask if I was the new secretary. He asked if I could get him a doughnut. I said you can get your own, because we're about Independent Living here.
 [ Laughter ]

And in my actual first day was September 24th. I broke up a fist fight. Thank you, MANDT certification. And I walked in on an individual using drugs in the bathroom. That was my first day at CICIL.

And so, I realized that we had a lot of work to do. And so I at the time, the team was four full‑time staff and four part‑time volunteers. Absolutely none of them had had any kind of training whatsoever with regard to services and supports. The paid staff literally sat in their offices with their doors locked because they were frightened of the clients, but primarily the individuals from Central Iowa shelter and services. And our volunteer staff were typically homeless people. And so that brought a lot of challenges as far as ability to maintain a consistent schedule and that kind of thing.

And then a week after I started, the Office Manager quit without notice and before they left, they changed all the passwords for everything including grants.gov, so that I couldn't get into any of that stuff. And so, thank you, Deb Cotter, may she rest in peace. She was absolutely pivotal as far as being a strong support in the midst of all of that.

I closed CICIL down for two weeks on October 1st. My daughter's first birthday, by the way, because there was a lot of things that we needed to take care of in a short period of time in order to provide any semblance of service with any degree of functionality. So, we shut down for two weeks.

We organized client files. We purchased CIL Suite. We got a third‑party accounting firm, and then we did some pretty significant training during that time. We regained our Part B and State funding as a result of a lot of that work that happened in those two weeks, and just basically rebooted the entire organization.

Now, keep in mind, I haven't mentioned anything about intersectionality, right? It's like: Where's the intersectionality? One of the perks of being a person of color is that a person of color, mind you that is fully committed to confronting my own internalized anti‑Blackness, and anti‑person of colorness, that resides inside of me is that that also comes with a commitment to organically infusing everything I do with intersectionality. So let that be a promo for those of you who are in positions where you can hire people. When you hire people of color, to do the work that needs to be done, there's that added bonus.

Now, that is not an invitation to ask people of color to take on any more labor than you would expect from anybody else so please don't misconstrue that. But I'm just putting that out there.

We also, unfortunately, there was a lot of transition with regards to staff and Board. I've heard it said a lot today that we should be supporting our staff to take the time that they need to get to where they need to be in order to do this work in an intersectional capacity. Sometimes people need to get off the bus. I'm just gonna put it out there.

[ Applause ]

And nobody wants to be the bad guy and fire people, or invite them to resign or that kind of thing, but, you know, for an organization that literally had no choice, that's what needed to happen. And I would hope and I would pray that nobody's organization ever reaches this point, but we most definitely did, and we seized the opportunity to bring on staff and Board members that were as committed and are as committed to intersectionality and cultural competency as I am. We took care of all legal complaints with regard to our former Associate Director. That's one of the perks of having an autistic running stuff. Totally obsessed with making sure that this happened! And I kind of became a lawyer myself, because our lawyer had written us off, and basically said we were a lost cause, so I took care of making sure that that happened.

And then we also moved. We moved to an area that made sense to the people that come to us for services. We are now in the most culturally, racially diverse area, certainly in Des Moines, but probably in the state of Iowa, and so it makes a lot more sense with regards to the folks that we're working with.

So, a few pictures. Our first logo is over here on the left, and what you see is an eagle soaring towards the sun. I don't know, cheesy.

[ Laughter ]

And then in 1995, we got this really bizarre logo. It's got some things that are pretty self‑evident. The wheelchair logo, ADA, and then there's this creepy guy just standing here.

[ Laughter ]

Like, Dude, move!

And then in 2016, my team and I designed our current logo, so the evolution of CICIL, right there in picture form, and it continues, obviously.

We began contracting with VR. We provide supported employment services, including customized employment as a fee for service. We take very seriously the edict that CILs need to be generating their own revenue, and so we generate a fair ‑‑ a robust revenue stream doing that.

We have a program called Try Transition, which allows transition age students to try out work during the summer. It's basically a summer work experience program.

We do lots of advocacy around voting, thank you, through our initiative called Iowa Disability Votes COUNT. Next week we are going to be hosting in tandem with National ACLU, a Rights for All training that will train specific to disability policy, and encouraging people to go to candidates for offices events and asking them questions on the record with regards to disability policy. And we have reached a point where our state and federal lawmakers in Iowa reach out to us on a very regular basis with their questions, comments, and concerns about disability policy as and so we're really honored to be that resource for Iowa's lawmakers.

This is a picture of Notica, one of our TRY Transition interns, and she's working at a store called RAYGUN, which is this kind of hip downtown T‑shirt factory in Des Moines. Every year, in recognition of National Disability Voters Registration Week, we do a proclamation signing with the Iowa Governor. This is from our first one. That's the proclamation on the left and then that's the group of us with the former Governor of Iowa there.

In 2018, we won Organization of the Year from the City of Des Moines. That was ‑‑ I'm not going to lie, probably second to giving birth to my daughter, that was a real high point.

[ Laughter ]

Simply because I know what CICIL had to do to get to that point in such a short period of time.

Before Reyma, 100% of CICIL's staff was disabled, as was the Board. Everybody was White. 48% of the clients were White, 46% were Black. Board meetings were monthly and lasted between 3 and 8 hours. Today, 100% of us are disabled. 57% of the Board is disabled. 28% of the Board are parents of disabled children. We are constantly trying to bridge the gap between disabled people and parents of disabled people. And 33% of our staff are people of color, 48% of our clients are White. 52% are Black or other people of color. Board meetings are every other month and they last for an hour and a half.

AUDIENCE: Wooho!
 [ Applause ]

REYMA MCCOY MCDEID: What we know for sure. Our success is rooted in viewing disability from an intersectional vantage point. Again, I know I haven't spoken about intersectionality a lot in this particular segment, but it's infused in everything that we do, with regards to personnel decisions, Board recruitment, client support philosophy, our infrastructure, everything.

And we take our position as disabled professionals serving disabled people very seriously. We offer our expertise to sister providers on a very regular basis. We're known as the place that other providers go to when they're working with somebody that has complex needs and is also a person of color. Send them to Reyma. And, and the keys to full inclusion of disabled people, especially those of us that are multiply marginalized, is financial independence and political action. We do supported employment and we do voting advocacy. Those are our big things and we strive to be a hub for both.

That's it. Yes, it is. I've gone over all this other stuff. So thank you.

[ Applause ]

RON HALOG: Thanks, Reyma. My story. I have less than 20 minutes? They gave me 20 minutes. First of all, I want to say thank you guys for being here. It's like you're stepping out of your comfort zone, and I know it's a hard thing to do, so please give yourself a round of applause before I start.

[ Applause ]

And as you can see instead of having people go to us, we started to go to them. And I think that's one of the hardest things for a lot of people to do, because we get so comfortable in what we're doing and we think oh, we're perfect. Are we perfect?

AUDIENCE: No!

RON HALOG: Wow! That means a lot of you guys think you're perfect. Are we perfect?

AUDIENCE: No.

RON HALOG: No, we're not. So this little journey we're taking is actually something we really do need to take. Even though we think we may be perfect, I think in my little story that I had in there was that we're going to change your mind a little bit. We're going to try to change your mind a little bit and if you're going to be digging in deep saying, I'm right, you're wrong, that might not be the place you want to be. And Reyma, thank you for saying that. It’s going to be uncomfortable for some people and that's a good place. Because when we have uncomfortableness, we have change. Just to tell you a little story about me, I was born in Livermore, California. How many people here know Livermore? Wow! I'm impressed. It’s like Livermore back then – back in the '60s -- was a small little town. There's probably more cows than people, let's put it that way. So, I grew up in Pleasanton. Pleasanton now has grown to be a pretty wealthy area, but before that, I lived on the outskirts where cows and chickens and roosters were coming to my house waking me up. So,, it was a fun time. The hard part was though I was pretty much the only Filipino family in that area. Predominantly White. A lot of Hispanic were there because they had farms, and so we picked the farms.

My family, my dad, was in the Army, World War II, and so a military family. It's like we wanted to make sure we stayed around in the area. And one of the hardest things for us was that my mom and dad and my three sisters actually immigrated from the Philippines out here. So, they took a lot of the brunt of the discrimination. When I was born, my brother was born, my mom and dad told us one thing: You speak English. Don't speak Tagalog, and I wish I didn't listen to that. They wanted to assimilate us into this culture and if you get me on the phone and I speak, everybody's like “Halog,” is that German? No. It's like they have no idea. And, so I wish I would speak a second language. It would help me out a lot more, but it really shaped me on what I wanted to do.

A wise person once said: I have a dream that a person's going to be judged by their character, not the color of their skin. And so, for me, that was one of those things that I actually took to heart. Because a lot of people when I grew up, guess what? I was judged by the color of my skin. I was put down. Back then, it was after the Vietnam war. And there was a lot of intimidation, scare tactics, both physically and verbally against me, and I learned really quick that you had to be a strong advocate, which meant I hate to say, I got in fist fights.

And one thing that my mom told me was that, first you respect people. And if they don't respect you, F‑em.

I said that politely, right?

[ Laughter ]

When I was older, she said that. When I was younger, she said: Don't respect them. And it's a hard thing to do, because you want to be, everybody wants to be accepted. Everybody wants to be loved. I think it's one of those primary things. But for me, it was like, you know what? I'm going to be who I am, and I have to do it.

I also had some great friends growing up. They protected me. I protected them. And if people didn't like you, you showed them who you are, and before you know it, it's like they actually start realizing that, okay, this guy is actually a halfway decent guy. And a lot of the fights that I got into, turned out to be some really good friends of mine afterwards. So, don't let people just jump off the bus right away. They're going to be arguing with them left and right. And I think that's one of those things that happened with us at CRIL, that ‑‑ by the way, this is not who we are. So, what I have on the screen is a picture of Krill, the little sea animals, and we're not that. And I tell people right away, we don't have anything to do with marine life. We don't do any of that stuff. CRIL stands for community Resources for Independent Living. So, I let them know. We just turned 40 years old, and we celebrated last week. Before I came here, we had a nice little event, but we're 40 years old. 1979 that we started. We're a 501(C)3. We are one of 28 ILC's in California and we serve a half a County, not compared to a lot of you guys out there who have multiple counties. I have Alameda County, which is actually from the San Francisco Bay out to the Central Valley, and everything from Oakland all the way down to Santa Clara County. So, a very small area, packed with a lot of people. And I have three offices, but we have it in Fremont; Hayward is our main office, and also Livermore.

Last year, we served 950 people. That's direct care, or direct, sorry, direct service. And we only have 12 staff. So, it's not too bad. We reached out to probably close to 5,000 people with what we do, but this is people who actually have Independent Living plans, and that we work directly with.

And we serve everybody, doesn't matter. When I sat down with my staff, when I first came on Board in 2015, same as Reyma, we actually took a look at who we were serving, and we found out that we weren't serving our total community. We took a look at the demographics from the County, and looked at those percentages, and looked at what we were. And what we ended up doing was saying: Okay, do we want to change this? And coming from me, my background, I said: Yeah, we're not going to stay this way. Plus, we were reaching out to all these other -- we were having these fliers in multiple languages sending them out to everybody.

Who do you think came? Nobody. Nobody came. It wasn't until we started getting out of our comfort zone -- going to them. And, one example that I have for you is that emergency preparedness. How many think United States, California, anybody, any states, go through disasters? Hurricanes. Earthquakes. Fires, floods. You name it. That is one area that we all are impacted by.

And so, when I looked at it, we started to do these great, I call them great, great emergency preparedness programs for people with disabilities and also seniors. I did it in a Spanish class, “Yo hablo Español un poquito”, and “es muy despacio”, very, very slowly. I don't speak Spanish. I had an interpreter up there. I did the class and they liked it so much, it blew me away. They actually referred me to another class. This one was in Tagalog. I don’t speak Tagalog, but they had a translator for me.

And so, it just goes on from there. It's the content and the delivery that you're giving is going to be more important than me speaking their language. It would have been great, but don't let that shy ‑‑ don't let you shy away from that opportunity just because you don't have somebody. Get out there and do it.

The way we actually took steps, and so again I touched a little bit on this one, is we first looked at our current staff and I found out that you know what? We did not serve ‑‑ our staff did not match what the community was. We had to change some things. One of the biggest things we found out is that Fremont, City of Fremont, has the fourth largest Afghan community in the United States. We did not have anybody who spoke Dari, Farsi or any of that so we said let's make that change. We hired somebody. Our numbers have blossomed from that point on. It's like, I did a class in Farsi, it was great. I had no idea what they were talking to me about. It's kind of scary, but again for me, it was getting out there and reaching.

The second thing we did was we took a look at some groups that we're not serving and why weren't we serving them? The hardest thing for us was to determine whether or not we wanted to do this. Because that's when you turn to your staff and you know, the little example that we had up here, where I was playing the ‑‑ we already do that, that was actually real for me. It's like we've tried that Ron, let's not do that. Then I turned to them and this is what I told them: I said look, we are a disability community. Community is the key word here, not disability.

It's like we need to make sure we are serving the entire community and if you can't see that, you have a problem with me. And we're going to take a step back, and I did. I pulled that staff person in, and I let them know very frank that our job is to serve this community. No matter how you look at it and if we're not doing that, I really need to take a look at whether or not you want to be here. It's hard. It is a hard thing to do. But it's something that's very, very needed.

From that point out, I had no problems. Make sense?

AUDIENCE MEMBER: Yes, sir, yes, sir.

RON HALOG: You don't need to call me sir.

[ Laughter ]

AUDIENCE MEMBER: Just a habit.

RON HALOG: It's okay. Does that make sense, though?

AUDIENCE: Yes.

RON HALOG: You guys think you're going to be having some of these issues when it pops up?

AUDIENCE: Yeah.

RON HALOG: Do you think you'll have those same issues with your Board?

AUDIENCE: Yeah.

RON HALOG: Yeah? Okay, one of the areas that I still need to grow is my Board of Directors. And I know this is being taped, so I have to be very careful with what I say. Darrell, please edit this one out. No, I'm kidding. My Board of Directors I love. Majority of them are attorneys.

No laughter. I like that. They're attorneys, so they think differently. They don't come from a business background, so some of the things that I have to go through is what motivates them? How are we going to get into their mind to make this shift? Where before, it would be, community, are we actually meeting that? Or finance, this is an area that we can actually tap into to get more money. With the attorneys, it's a little bit different. It's about justice.

And they get that, and ‑‑ but their justice is about financing and making sure that we have the moneys coming in to do this. Don't let money stand in your way. I can guarantee you this one thing: This change is not going to be coming from the community. This change is coming from who?

AUDIENCE: Ourselves.

RON HALOG: Who?

AUDIENCE: Us.

RON HALOG: Okay. Let's ask that one question one more time. This change is going to be coming from where?

AUDIENCE: Us.

AUDIENCE: Us.

RON HALOG: Us. We make the changes. Do you believe that?

AUDIENCE: Yes.

RON HALOG: I don't know. Do you guys believe that you're going to be making that change?

AUDIENCE: Yes!

RON HALOG: I still don't believe it. Serious. Do you guys think you're going to be making this change?

AUDIENCE: Yes!

RON HALOG: Okay. Stan, what do you think? Do you think that? That's good?

STAN HOLBROOK: That was a lackluster response.

[ Laughter ]

RON HALOG: I know I'm the last person to speak, but do you guys really believe that you are responsible ‑‑ not responsible ‑‑ but that you have the capability to make the changes in your Centers? Yes or yes?

AUDIENCE: Yes.

AUDIENCE: Woo!

RON HALOG: Thank you. You do have ‑‑ thank you. Okay, you're up. I want to hire you.

[ Laughter ]

You guys do have ‑‑ you have the power. You have the capability to make this change. It comes from you. It's your belief, it's your core belief. That's why ILCs make so ‑‑ is so perfect because it's not that we're doing something for somebody. But we're part of this. If we have an identity for this, we're going to make the change.

All four of us, you heard our back story. I think it's important that you heard the back story. You all have back stories. That's what drives us. That's what should drive you guys, as well.

It's like, it is a core belief that we want to make this change. Yes or yes?

AUDIENCE: Yes!

RON HALOG: Wow, okay, that took a lot of time. Sorry.

The third plan we took was this, we took a look at our short falls, and who we needed to speak ‑‑ we needed staff who spoke the language. That was very helpful. We hired them on. We got them. Developed a written material in specific languages. And here's the big thing: We actually introduced ourselves to some of these organizations. It wasn't so much going after the groups but, like, the senior services Coalition for Alameda County, we went to them. We found out, you know what, that Coalition is made up of multiple people. We better come together with them because if we want to collaborate and make it work, we had to make sure that we were meeting what their needs were.

I'm going to give you one quick story. We did a grant proposal with Cal OES, Office of Emergency Services, for disaster preparedness things. We did this with Pacific ADA and I'm happy to say, we have $1.5 million coming to the County of Alameda County.

[ Applause ]

To help support people with disabilities and also seniors with functional limitations. Now, again, that's something ‑‑ that's something everybody should be actually taking a look at doing. I think it's a phenomenal opportunity, step for you to get in there. If they're not going to you, go to them.

I also serve as the President for the DD Council for Alameda County, Developmental Disabilities Council. I’m also on the ALCO VOAD, the Alameda County volunteer organizations active in disasters, and we are also on the Senior Coalition Services for Alameda County. Here's the thing, once you're there, once you're at the table and you're sitting with all these people, you know what will happen? You will be volunteered to be on that Committee. Yeah, you will be and here's the beautiful part about that is once you're on that Committee, you make the changes. You let that committee know, hey, did you think about people with disabilities? Oh, yeah. Did you think about seniors with functional limitations? Oh yeah, we can't forget them. Before you know it, you'll have everybody wrapped up in that mind set. Last year, this was so effective. Alameda County took a pledge on for diversity. And so, we made these little pledges and gave it out on diversity for Alameda County. It was a wonderful thing. The mindsets start changing. It's contagious. You've just got to get them to actually start thinking about it, because we are all one community. We just have to make sure we reach that. And again, getting to the tables. It's okay to be uncomfortable. Embrace that.

Be uncomfortable. If you can find one person at your table that's going to be, oh, yeah, I identify with that, or oh, yeah, I can relate to that, you have one person that can collaborate with you. When everybody else will be saying, what are they talking about? Guess what? You're making a change. That's what happened with CRIL, and so again, I just gave you a couple things that we worked on, emergency preparedness, device lending, training. And you know, it's been a ride but we're still working at it. We're still trying to get there.

And so, I just want to thank you guys very much. I think I got my time.

[ Applause ]