IL-NET T&TA Center Presents…

Addressing Care Deserts: Supporting Rural Transition with Self-Direction and Other Models

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Presented by Erica Andres and Jennifer Kucera

Live Captioning by AI-Media

MARY-KATE WELLS:
Welcome everyone. To today's IL-NET webinar. We will give folks a moment to sign on. Alright, well hi everyone. Welcome to today's IL-NET webinar. Titled addressing care deserts. Supporting role transition with self-direction
and other modes of assistance.

My name is Mary-Kate Wells, and I use the pronouns she her. For visual description, I am a white 30 something-year-old woman with reddish hair, and wearing a gray sweater.

We are very excited to have you all join today. We have two phenomenal speakers. But first, I am just going to share a little bit of information about the IL-NET and some accessibility tips.

So, NCIL, the national Council of Independent living is a partner with the IL-NET training and technical assistance Center. And we support the coordination of these webinars, and today I will be your moderator, and help facilitate the Q&A at the end.

Perfect. So, today's presentation is brought to you by the administration of community living, and the US Department of Health and Human Services in conjunction with the IL-NET. And the IL-NET is operated by ILRU in collaboration with NCIL, APRIL and the University of Montana. Next slide.

And on the slide four is the images of all of the partners. A few accessibility notes for today. We do have captioning available. You can click show subtitles in your zoom menu bar to turn them on. We also have captioning running on an external link, and the link has been provided in the chat.

You can use that to adjust the view, size, font of captioning's. ASL interpreters are also present today and should always be visible on the screen. Please let us know at any time if you cannot see the interpreters.

The interpreters will also be available in the interpretation channel, which you can find in your zoom menu at the bottom of your screen. We also have Spanish interpreters available today. You can also access that from the interpretation button at the bottom of your screen.

And then select the language that you would like to hear the presentation and. And finally, we have public chat turned off, but you are able to chat with the host and panel us. We ask that you reserve the chat for technical questions only.

And submit any questions to our presenters in the Q&A box. We welcome folks to submit questions in the Q&A box throughout the webinar, but we do ask or we will answer the questions at the end of the webinar.

I mentioned that there is the zoom Q&A box, but you can also email me your questions at mary-kate@ncil.org. If that is more accessible to you we will put that in the chat as well. Next slide.

Can we go to slide seven? Or six. We will do six. Sorry. So, today just our learning objectives for today's webinar is we are defining what self-direction is, and this term we are using, care deserts and what that means. Identify innovative strategies to leverage existing resources at CILs to support self-direction and other transition related needs in rural communities.

And then also to educate and inform CIL staff on how to support consumers with accessing and using self-direction as part of their transition efforts. Next slide.

As always, we love your feedback, so at the end of the webinar we please ask that you complete our short evaluation feedback. This really informs what the topics we do and formats. That would be great if you could take a few minutes at the end of the webinar. Next slide.

And before handing it off to our awesome presenters, I just do want to put a plug for the independent living philosophy and practice Summit, reclaiming our movement in September.

This will be a two day summit, learning intensive on September 17 and 18th. We can put the registration in the chat, but there is also a QR code on the screen right now.

And if you have any questions, please feel free to email me. Next slide. So, we have two awesome presenters. We are good to be starting with aunt Erica Andrus from a senior consultant at applied self-direction, and then after hearing from Jennifer Kucera, and outreach coordinator at the center for disability empowerment, and she is also the chair of Ohio Olmsted tax force.

With that I will handed off to Erica. Thanks for joining today.

ERICA ANDRES:
Thanks so much. To tell you a little bit about myself my name is Erica, (indiscernible) my pronouns are she her, I am a white woman, in my 40 is. We will go with Mary Kate's description. I have shoulder length brown hair with blonde and pink highlights. Although the pink ones are very fated so no judgment.

I am wearing a green dress with a pink sweater over the top with little flowers on it. At applied self direction I work with case managers and participants in the self-direction programs, I work with case managers to ensure successful unbiased case management, and make sure that they are doing a great job for participants.

And I also work with people in the program to ensure that they are getting the most out of their program, and understand all the services available. I am also a self-direction case manager for about eight years, and I've been a support broker in self-direction for about three years.

But the bulk of my experience has been that I have been using self-direction to live in my own apartment for over 20 years. And that makes me feel kind able to say that, but whatever. Bulk of my, I mean, I have a form of muscular dystrophy called spinal muscular dystrophy. And I can very little move my arm so I need assistance at all times with all task.

And I have 24/7 staff in my home, and I managed an amazing team of eight regular workers, for weekday workers, and four separate weekend workers, and also I have several backups on hand just because sometimes my workers need off or something like that because they are human and they do get sick or have a life outside of me, which I just cannot imagine. Just kidding.

But also do not worry if currently you are saying that sounds really great for her I think, but I really do not know what self-direction is. I have no idea what she is talking about. We will go through that in just a second to talk about what that is.

But first we are going to start with what care deserts are. Because that is something that is common in rural areas, and it is something that we are talking about today. Care deserts are areas where the supports needs of people are not met because there is little to no access to healthcare services or there is low quality healthcare services.

Care deserts are typically the result of lack of providers, whether it is direct service personnel, doctors, specialists, or other goal practitioners. Next slide, please. -- Or other medical practitioners....

Lack of facilities or cavities, for instance lack of (indiscernible) companies or hospitals or medical offices, health clinics, also there can be long wait times or waiting lists before our current self-direction program it was in Wisconsin and it was a 10 year waiting list for waiver services and self-directed services.

People could only move up on the waiting list when someone passed away or when someone moved out of the state. They probably would have the state to move to a state without a waiting list obviously. Other reasons for care deserts are the high demand and cost and or low supply or availability.

We have all had that special is that they are waiting to see. It took me over a year to see a neurologist, which is a specialist for muscular dystrophy. It can take a long time. Next slide, please.

And then some additional challenges for rural communities on helping with consumer transition is there is little to no affordable or assessable public transportation. I am from a super small town also, and a rural town, and just because my mom has no access to it she calls Huber because she does not even know what it is she has never used it and she has no idea, (indiscernible).

There is also that significant lack of affordable and assessable integrated housing including year-long waiting list for the housing choice cultures. In some states like Wisconsin for example, preference is given to people who are transitioning out of an institution.

And also in rural areas people and places are just really spread out. You might not see another house for miles. You might drop drive miles to a grocery store. In my town the closest door was 25 miles away so you really better hope that you did not forget an ingredient for dinner for that recipe because you were not going back.

I now live about two minutes from a grocery store. Next slide, please. And then some additional challenges for rural communities are just, I think we have got to go back one more slide. There we go. Thank you so much.

There are power outages or sometimes unplanned emergencies are more common because you are further from the power source, but also there is just other things that can happen. I am not lying to you when I say that when I was a kid, a deer ran into our electric box at our house and knocked out the power for quite some time.

When I got up that morning we did not have any power and I can tell you that my teenage self was mortified that I could not curl and wrap my bangs up before he went back to school. Do not judge me, it was in the 80s.

There was also a lack of providers with cultural competence or any cultural humility at all because there is just less providers. There is a more likelihood that people who are not culturally competent. There is a more likelihood to have people with a disability buyer roast -- disability biased or ablest.

I was really person in my school that used a wheeled chore -- wheelchair for mobility or person that had a disability. When I entered high school, my principal saw that I had a physical disability and took me out of my classes and place me into special ed classes because he thought that I would be better off in one classroom than having to switch classes to go to my high school classes.

I reminded him that I was in a power wheelchair so it took less energy for me to walk around then it would take anyone to walk around. I just zoomed around. Also in many rural committees have diverse populations such as Native Americans, so from finding providers that understand or respect the varying cultures of individuals can be really difficult in rural communities.

Next slide, please. Now, as promised we will switch years a little and give you that definition of self-direction I talked about. Self-direction is a model of service delivery where the consumer that is receiving the services has a high level of choice and control.

The consumer decides when, how and from whom their services are delivered. Self-direction is based on the independent living principle that people with disabilities know their own needs best, and should lead the planning and managing of those services.

Next slide, please. Consumers are really empowered to hire, train and fire their own staff, in addition to that, manage a flexible budget to spend on what they need.

Next slide, please. A few hallmarks of self-direction include a choice of goods and services, so there's no more cookie-cutter, one-size-fits-all, everyone gets the same service. It's really tailored to the person. There are many freedoms in self-direction, including the freedom to develop the worker schedules and have people come and go as the participant would like.

There is also the use of community members and resources and you are really reaching out into the community to find those caregivers. I currently have 1/3 shift machine operator and she would never walk into a home care agency for a part-time job, but because she saw my ad on Facebook and thought it would be cool, I could hang out with her.

It also really honors the dignity of risk and everything in life has risks. Walking out your front door gives you risks, but self-direction really lets you take those risks for those two rewards to be able to live a full life.

It honors the flexibility and creativity to be able to be flexible and creative to get your needs met. Especially in rural areas, using devices when people are not available. Next slide, please.

So kind to put things into perspective, I generally like to talk about self-direction in real life and real persons. We will go through a few examples versus Self-Directed Services.

In agency services or Traditional Services, the agency sets the worker schedule. As a college student I had to go to bed by nine or 10 PM even on the weekends. This was not a scheduled that any college student wanted. There was no flexibility to stay -- up all night and there was no time to go out with my friends. I was going to bed as they were going out and I was getting up when they were coming in from a wild night of partying.

Now, I set my worker schedules. I go to bed when I'm tired and I get up when I want. Now I'm old and I go to bed at nine or 10 PM anyways, so doesn't matter. Next slide, please.

Other examples of traditional versus self directed services. With traditional services, I ate meals on a schedule and now we get to eat when I'm hungry. I had to leave a social event and be home and in bed by midnight because there's no care available after midnight. It also meant once I was in bed, I stayed in the exact same position until my caregiver came the next morning. I'm not able to get out of bed, rollover or move myself, or even scratch my own head in the middle of the night. So I cannot move without the assistance of another person.

Really think about that. How many of you end up sideways in the bed when you wake up and you have no idea how you got there? Unfortunately, I don't have that luxury. I had to hope and pray that nothing happened and I didn't need to evacuate. I lived in a dorm that was primarily for freshman and sophomores and the fire â€“ Mike alarm went off at least every weekend. Likely, they were false alarms and I just had to lay there praying I wasn't going to burn up until someone came and told me otherwise.

I decided when I'm ready to leave a social gathering and go home because I also have 24/7 care. I can help hope whenever I need it, including Whitten in any emergency.

Some final examples â€“ can we switch the slide please? In Traditional Services, I use the bathroom and shower on a schedule and I was not able to shower every day because of time constraints. Now I use the bathroom when I need to and I shower every day unless I say otherwise.

And finally, in Traditional Services I did not meet my caregivers until they showed up for their first shift. I had to train them on all that I needed them to do in those first two hours. There were four different people I had to train. If I didn't mesh with someone I could tell the agency and they could try to find someone else, but it wasn't always possible.

Imagine having to rely on someone that you don't like to provide you with intimate cares, like bathing and going to the bathrooms. In self-direction, I recruit, interview, hire and manage and train all of my workers. I get people I like and want to spend time. I also have people I love and already know on my payroll.

My mom is on my payroll and is mostly a backup. I tell her that she's on there only so I can tell her what to do because it's a nice payback from when I was a kid. Next slide please.

Now we will transition into talking the self-direction and Independent Living and how they go together. As you probably all know by definition, consumer control with respect to the Center for Independent Living, means that the -- CIL puts the power and authority in individuals with disabilities hands. Including individuals who are or have received Independent Living services and when it comes to management, staffing, decision-making, operation and provision of services. Next slide please.

And also consumer control with respect to an individual, means that the individual with a disability asserts control over their personal life choices, and has control over their Independent Living Plan, making informed choices about content, goals and implementation. Next slide, please.

So, self-direction and consumer control, self-direction is a really valuable service delivery model that gives individual consumers control of the services they receive for implementation of their Independent Living Plan.

I really hope you can see how similar Independent Living Center's and services are to self-direction. Just like self-direction helps people control what, where and how services are delivered... Next slide, please.

So now I will talk a little bit about the history of the Center for Independent Living and self-direction just so you can see why they go so well together. The reason they are similar is because the history of self-direction is deeply rooted in the independent movement and philosophy.

Early concepts of self-direction were developed and advanced by Independent Living leaders. Including Ed Roberts and other disability activists, launching a self-direction attendant program at the University of California at Berkeley. Next slide, please.

Self-direction then became available to the broader Disability Community with the formation of the first CIL. It was often within and supported by CILs, as more CILs came into being and expanded across the country, so did self-direction.

Next slide, please. Now on to what you all probably really want to know about, why self-direction for CIL consumer rural transitions? Rural transition has many complex and unique layers. There are so many parts that have to go right.

Self-direction gives an individual consumer more choice and control and the choice of who will provide the services, what services will be utilized, when the services will be delivered, and how the services will be delivered. Next slide, please.

So, the answer to why self-direction is addressing individual needs when there are limited resources available, especially in rural areas. With self-direction consumers specifies the tasks that are completed, so they can get help with exactly what is needed. Not a checklist that some agency said should be done. Consumers can also choose a family member or friend already providing a service, or somebody that lives close by that can be a concern in rural areas.

Services can be delivered in different ways. Instead of having a transportation provider if there is not one in that small town or rural area, maybe a friend can drive the consumer around. Or, if there is not a day program available or if they don't want to go, there can be a staff hired to provide one-on-one support during the day, with the person. Next slide, please.

Now that you have the basic information, let's connect the dots on how CILs can use self-direction to support rural transition. CIL staff education and training on self-direction. Self-direction is so tied to CILs and it can be helpful in transitioning that CILs staff should be expert on self-direction. They should know and understand what self-direction is, how self-direction works in their state, that there are over 200 self-direction programs and there are about 200 ways that -- things can be done and self direction.

So, if you know one self-direction program, you probably know one self-direction program. Also to understand how to access Medicaid waiver services and how to use and access them. And also how to leverage Medicaid waiver funding for home mods that might be needed for transition out of the home.

Many programs -- will offer ramps and those can be super helpful when transitioning. Next slide, please. So, CILs should designate and train their staff as self-direction subject matters to assist with transition. And do you know who should be the subject matter experts? The people utilizing self-direction. They have the inside scoop. The people using the program are the experts and know how the programs run, so CILs really need to use that peer support.

They also need to empower CIL staff to empower their consumers to use self-direction for transition or just have a full life in their own community. Self-direction can seem scary and daunting at times, but it truly is a great resource and something that I am so happy that I did.

Now, I'm sure you all are sick of hearing me talk so I will turn it over to Jen.

JENNIFER KUCERA:
Thank you so much, Erica. Welcome everybody! I'm so glad you are here today. I'm Jennifer Kucera and I will give a brief description of myself. I was actually born with a disability much like Erica said, I have the same disability, spinal muscular atrophy. Mine is actually type II if you know anything about spinal muscular atrophy.

I started out younger. I had the ability to walk for a while, but it is slowly progressed to the point where I do use a wheelchair and I'm really only able to control my left hand from the elbow down, and control of my head as you can see here.

I actually have been able to live by myself for the last, I think it's going on 11 years now, I did live in an institution for a couple of years and was able to use money to move into my own apartment. I live in the state of Ohio and I do have a Managed Care Organization waiver called my care Ohio and I really love living in my own apartment, really under my own control.

Even though I do not use self-direction at the moment, because it was really not a good program in the state of Ohio, but we are working with our departments and agencies to make it a much better program and I literally cannot wait until I am able to use self-direction. So, I'm currently using the agency model, but they actually treat me as if I am self-directed because there would be no other way if I just had people coming and going that I did not know to care for me.

I've had the same two caregivers and I've been very fortunate, the same two caregivers for the last 11 years. It's been pretty amazing. I currently work at one of the centers in Columbus Ohio mama called the Center for it is the empowerment and I am their healthcare -- outreach coordinator. And I also chair the Ohio Olmstead Task Force, so please feel free to Google anyone and look me up on LinkedIn.

I use the pronoun she her. I am a white woman in my mid-50s. I have purple hair that's pulled up. I have a pink shirt on and I have a blurred purple background and you can see some certificates on the wall behind me. I use the pronoun she her. Next slide please.

There we go. Some of the things I will be talking but today are actually just transitioning in general. As I mentioned earlier, I actually did use Money follows the person to get out of an institution and I absolutely love that program and I wish more CILs were able to do the work of transitioning, because if I had it, everyone who did not want to live in an institution would not be living in an institution. I'm a big proponent of Money follows the person.

For several years I did transition people out of nursing homes back into the community. It was one of the best jobs I have ever had. It's just so exciting to get somebody out of an institution and back into the community again with the writ supports.

So some of the things I will say today are just general things. That ace center should be doing in general when you transition people. But then some of them will apply directly to self-direction, so I will give you a mix with an emphasis on self direction.

One of things about living in overall County resource as Erica mentioned are tough, so you really have to get creative with your planning and your solutions. Going outside of the box is encouraged. Really in any situation, but especially in out rural situations.

Like I said, you have to get really creative, and they may not be traditional models of solutions. But I know one thing, I know that I have been very creative in my solutions for living on my own in certain circumstances.

The only other thing if you do work in a CIL or help people transition out of institutions is you really have to get to know your consumer or your fellow peers with disabilities that you are assisting. A lot of this comes down to open-ended questions.

It is not a check the box kind of survey that you can give to one because as Erica mentioned, if you have seen oneself direction program, you have seen oneself direction program. To be able to transition somebody, you really have to get to know your consumer.

A lot of open-ended questions because you may think of something that they have not, and vice versa. Drawing information out of them is very, very helpful. I also suggest that consumers and the peers have realistic expectations.

You have to help them to develop a must-have list that they cannot live without. As an example, I was talking to a person with a disability and their family member. And they attended a college where they had everything available to them.

The caregivers lived right next door in a room so that they could get up in the middle of the night, and they could go to the local wherever, a movie, bar, wherever they want to hang out because there caregivers lived next door.

He wants to move out on his own and I said that may not be possible. What things do you absolutely have to have? He also has a lawyer lift that lifts onto the ceiling it is attracted to him and I said do you really need that or would you get a floor model? A lot of places like Apartments will not accommodate the ceiling lifts for one reason or another.

You really have to develop a list of must have. What is necessary for person survival, and what are other things that they could live without? I know, because of my situation, I do not have around-the-clock care. I only have X amount of hours. It is a split shift.

There are many hours in the afternoon when I am by myself. For me, a compromise was to go without hot food. My caregivers help set meals up in the morning, and by the time I get around to eating them, they are pretty much room temperature.

That to me was a fine compromise. I do not mind that. I get to be alone here in the afternoon, and I really value my alone time, so to me, I was fine with that decision. So, there are things that you have to put on your wish list, but I always suggest just trying to have a must-have list.

Community losing is also not right -- community living is not great for everyone. There are people that did not mind living in an apartment was up like I said I do not mind being by myself, but that might not be possible for all people. Making a pros and cons kind of document is also very helpful.

This is just in general, but it also pertains to self-direction because going back to that must-have list, you know, like I said I have an agency model which is not always going to work for people.

I would much rather have self-direction, which I am going to go to. But what if you cannot find anybody from the self-direction space? You might have to choose an alternative until you can train and have your own caregiver.

Again, it is kind of developing that Wishlist with realism used on what is available. Next slide. Alright, you have to leave -- lien into limited resources so that you can maximize transition. You want to help the person build a transition support team to be used as a resource.

So, this is another, or I am talking about open-ended questions, you want the person to feel completely supported before they get out of an institutional setting.

It is a combination, again, of utilizing self-direction and brainstorming, really, about the caregivers. Who do they know in their space? Who maybe do they not know, but they could know?

Like for example, what I'm able, right now, my caregiving agency, they drive me around as I am not able to drive anymore. But once I am able to use self-direction, I will advertise for a driver of the vehicle so that that person just has the ability to drive me from point a to point B, and that frees up the caregivers to do what they do with personal care.

And I do not know that driver yet, so I would be finding them, and advertising for that position. So, it is brainstorming those kind of things that the person may or may not need, but might be thinking about in the future as their situation changes.

It is also about finding those caregivers, and teaching the person how to train and find those caregivers. So, the centers for independent living really have to be versatile in their knowledge that they know. So, you know, even though the person that self directs is responsible for finding and training their caregivers, not everybody is born knowing how to do that.

I know I had a happier support when I first did that, and even fighting locations where it is advertised to get a caregiver. -- Finding locations where it is advertised to get a caregiver.... As the teachers or the instructors, if they can talk to the students to maybe even find a caregiver within the classroom setting.

So, you have to use all of those tools. Even responding, especially in rural areas, you really need to plan for health crisis. Hopefully it will not happen here consumer, but you have to be ready. From taking wheelchair chargers, having backup wheelchairs perhaps.

Knowing where to go if you have to evacuate your house, and that all out planning, you really want to build a really detailed transition plan, and living plan for the person. Next slide. Thank you.

Along with that, there is some basic knowledge that I feel throughout my experiences, with (indiscernible) and being a transition coordinator is that the CIL staff should really have fundamental knowledge of how their state Medicaid and Medicaid waiver programs work. Including the self-direction.

I know a lot of times like I am an advocate through and through. I was a math teacher for a while, what I've always gone back to advocacy. It is in my blood. And so, your CIL, if you work at a CIL, you really want to know the system in your state. Every state is different. You also want to know if you have managed-care companies within your state and in the my care program for me is a managed care organization waiver.

So you also want to get to know each of the managed-care companies, how they operate, what they do and what they don't do, because every managed-care company is different. You want to know about your waiver programs, you want to know what is offered, you want to know about the self-direction program in your state.

And get to know your state Medicaid folks and your aging folks. It is so important to build relationships with those organizations and agencies. You also have to know other things about the housing landscape that is in your area.

That is one of the top things that is not available that we, you know, hopefully will have more of one day and I know that we are advocating for in Ohio. But that is affordable, accessible, integrated housing. Know about all the options available. Make sure not only that you have a list of possible housing options for people, but that you know that housing.

It is one thing to send somebody to an apartment complex and say go check them out, but if you've actually visited that housing resource then you know firsthand what it is like and you can better suggest things to people or explain things to people.

Along with knowing what your public housing programs are, and how they operate, and what kind of dollars that they have, all of this is also advocacy work to, because not only do you need to know this, but you need to make sure that these things are included in their budgetary plans for the state.

Next slide. Alright, and this, again, this is a systems wide level. Thank you. Along with the housing, and the Medicaid programs, you want to know about the transportation options. And again, every area is different, what they offer. You have to be really, really knowledgeable about all the transportation options that are available, and also the public transportation pilots.

There may be some things happening in your area or maybe you can even develop one of your own, and you can get some funding for it. With self-direction comes even more than that because people now, if there are Uber wars transport services in your area -- Huber... Under self-direction, it can increase the transportation options available for people. So you really need to know, again, of all those options that are available that people can tap into. If they need to.

And the same thing goes with Internet, technology, you know, is there workable Internet in the areas. That you are in. Where is the workable Internet? Hopefully it is connected to the areas that have housing. How is the assistive technology?

We are getting into a world that someone has some kind of smart phone feature. Know how to tap into that because the inter-self-direction, we have the goods and services piece that can cover some of this assistive tech.

A lot of this is getting even more and more affordable like the ring doorbells. Things used to be all under durable medical equipment, so the cats were astronomical. A lot of that is changing. I'm not good to say that the smart speakers may, because they will talk, but I cannot live with one of those now. It SA me. There's a time I got stuck in the doorway of my house, and I did not have my cell phone with me.

So I yelled it's name and told it to make a phone call for me and they came right away and I was able to get out of the doorway. Things like that really increase the independence of people, and it is not as expensive as it once was.

I have other devices. We can now get smart devices to open and close your shades and your curtain. All of that can be covered under self directed goods and services, and of course we have the home modification portions under the waiver.

If your state does not have those or even if you do, there could be other organizations that will provide assistive technology. Developing like a resource list of ways to get technology into a person's home is fabulous.

And individual advocacy, I keep coming back to adversely work because along with LOC -- knowing all the services, you have to advocate for more. It is the individuals, we all have to advocate for ourselves, disability or not.

But we have to advocate for changes in our system. If you see something that is lacking in your area, and there may be something to do with that, reach out. Talk to your legislators, talk to your representatives.

Go to other organizations that might be willing to partner with you, or others to fix some of these gaps that we have in our service models. Next slide. So this is kind of what I was just talking about. You may now have a deep knowledge of your state's waiver system. But you want to even go beyond that and I realize some of our centers are small and you do not have a lot of people power. But every little step is a step closer services.

And so, if you know what your state looks like, try to research other states that might be somewhere. I just got back from the community based services conference and I love it because it brings a lot of states together and I learned so much when I'm at that conference.

We have the internet and so if you have internet access, you can learn about what other states are doing and take little pieces of other states that might not be summer, but you can take little pieces and it's so important. Like I said, it's very important to stay engaged and actively involved with your state Medicaid and Aging offices.

I know in Ohio, we've developed partnerships with both our office of aging and office of Medicaid because who knows best? We know the best about the Disability Services. We are the users of the services. We are the disability experts, so we must be involved in the change. And in teaching them how to best serve people with disabilities. Next slide.

So, the access rule. I am sure some of you have heard about the Medicaid access rule but it is so important â€“ I know our state has not even switched over to the two, the MAC, and the BAC, the Medicaid Advisory Committee, and the Beneficiary Advisory Committee full top

The Medicaid Advisory Committee are for those people that are involved in organizations and the Beneficiary Advisory Committee is those that receive services. You may be able to be on both in your state if you work in an organization, you also receive services.

My state, even though I think the deadline has either passed or up-and-coming, they have not switched over to these yet. And so, we are pushing our state to have the formation of these made, but make sure that you include yourself in at least one of these committees.

And then also, the -- MCOs, you want to get to know them and how they operate. Set up meetings and let them know who you are. Let them know what you offer. A lot of times people do not know what the CILs do and what we are. "How many people do you house there?" "We don't house anybody here. It's not an institution, it's an information giving system and we are the disability experts."

Make sure you let people know that you exist. Work with the MCOs. If something is not working and you hear about a consumer that's having difficulty, help them advocate but you can also help out with that.

Next slide, please. And this goes again to speak on systems change. And getting to know your person. You've already gotten to know the person that wants to self direct, you know what their needs and wants are, but maybe something is not available. This is where system change, as I have been talking about, comes into play.

You can start a mobility Advisory Committee â€“ again, you know your list of possible transportation but reach out because maybe there is funding for something to be started or you know of an organization that you can say, "hey, what did you think about this?" And increase the transportation that is in your area.

Not only is it transportation advocacy, but it's built environment advocacy. There are other ways to get around the city. I know I roll around in my wheelchair all the time and there was a one time, and the curb cut was not there. I reached out to my mayors office and within a couple of months, they have put a curb cut in there. I know that's an exception and I live in a small town. I was thankful they got it done so quickly, and it may not happen in your area, but be aware of these things when you go out.

Rely on your consumers to tell you about these areas that might not be great. Curb cuts, ramps â€“ I went to a restaurant in Baltimore and the restaurant still â€“ I cannot get into the restaurant. Things like that are still happening. If we don't shut out that awareness, it will never change.

Same thing goes with housing advocacy. Look at your city plans, look at your state plans for housing. You have to get involved in systems advocacy. A person can self-correct all they want, but if these things are not put into place, they still cannot get them no matter if that service is available. So, we must all do systems change. Next slide.

All right, these are a couple ways that CILs actually could be involved directly with self-direction. And one of them is information and assistance services. So, there's a lot of outside agencies that sometimes do information assistance and it's a service that could be added to a person's waiver plan.

This is the type of service that helps oneself direct. They are also called support brokerages and you might've heard that before, but this is where you would offer, and we are doing this anyway: we are doing this work but not getting paid for it so why not get paid for it? It's the information assistance service. It's a little different than information referral because this is where you actually talk with the consumer and to all of the things that Eric and I have said.

You help a person find a caregiver, you help teach them how to train an interview their caregivers, and everything that we talked about that you should be doing or helping a person who is self-correcting do, asking those open-ended questions, helping them set up a plan, you actually could get paid for that if they added this information assistance services to the plan.

So some CILs across the country are already doing this. The other services that some souls provide is the FMS, or the Financial Management Services. That's a little bit more complicated and you need to have a really defined plan for this, but this is the Financial Management Services, they are the ones that send out the Paychecks. They take out the money and they help the self-correcting consumer set up there budget. CILs can also do that and we've seen some do this portion of the self-directed piece as well.

And I just wanted to ask my co-presenter, Erica, if there's anything that she would like to add that I may have missed about either one of these two services?

ERICA ANDRES:
No, I think you did a really good job explain. Information and assistance is kind of the case management role, it's what it's usually referred to as. Or care coordinator. You are the person who is getting the person started and self-direction, figuring out what services want to be self-directed, getting the budget set up and services in place. And then really just make sure things go smoothly if you need your plan change, or if you need corrections made, additions or new services added, all of those things.

It's there to help you along the self-direction -- journey. They pay the bills and they have monthly statements to make sure you are staying on track, but otherwise they are there to help to get your employee set up and get you going. Thanks.

JENNIFER KUCERA:
Thank you so much, Erica for that in-depth overview. Thank you. The setting up a budget part can be difficult for a lot of people and it's very, it could be very complex. Obviously, in self-direction you can pay your caregivers different rates based on what you decide the person that is self-direction, and you set up agreement between you and the caregiver on the amount that everybody is happy with.

So, the FMS helps guide that along, like Erica said, and CILs have done either one of those jobs across our country. I don't really have the data on which states do this, but if your CIL does not, they can always ask for more information and maybe they can offer one of these two services.

Next slide. All right, so a few final important points. Everyone can self direct with the right supports. I've heard from some case managers that say, "my consumer cannot self direct." And this is completely false.

With the right supports, everybody can self direct. We have to be the advocates of understanding on this and in telling others that they can self direct and offer those supports to the person so that they can self direct.

Self-direction opens up a world of possibilities for people with disabilities. It is an amazing program if it is done right and I would fight until the death or self-direction. If I could. And we need proponents that are working to make self-direction work for everyone.

You want to keep an open mind and ask many open ended questions when dealing with consumers and your peers that want to self-correct. In supporting them with their transition. I mentioned many of them today, but it's those open ended questions that are going to get the job done and a lot of people do not want to take the time to do that anymore. They want a easy fix, a one-size-fits-all, and it's not. Self-direction, as Erica and I said, you see one self-directed program, everyone is different. Everyone wants different things.

So, you have to ask those open ended, time-consuming questions and bounce ideas â€“ your consumer will bounce ideas off of you, you bounce ideas off of your consumer, but together with that support everyone consult direct.

And remember that person centered planning is not the same as self-direction. I will say that again: person centered planning is not the same as self-direction. It plays a role in self-direction and at the beginning Erica described and give you definition of person centered planning and we want people that self-direction to have that person centered planning because it is about the person. But it's not somebody dictating to them what that plan is. It's the opposite.

They are dictating to everybody else what they want. They can pick from services, just like Erica said, she can now stay up until midnight, 1 o'clock in the morning, 2 o'clock in the morning â€“ she was never able to do that before but now she can because she is choosing to run her life. Like people with no disability gets to do. It should be the same for us with disabilities. We dictate our lives and not everybody else.

It takes person-centered planning one step further. We are the deciders of our deaf fate and nobody else. Next slide.

So, I already talked about that and one last thought. I know there's a lot of work all across our country with Charting the LifeCourse and if you're not familiar, of course you could do a Google search and bring it up, but I just want to give you some things to think about if you're considering using Charting the LifeCourse as far as self-direction goes.

You want to remember that this is person-centered and Charting the LifeCourse can be an all-encompassing model and with self-direction, you are really working for care. You are looking to control your own life. It should always, my feeling is that it should always, it should never be mandatory.

If you are going to use it, it should always be a tool. But not mandatory for everybody to fill out, because again, everybody's situation is different. And it also could be very overwhelming to individuals. Self-direction, I'm asking for care. I don't necessarily need an entire thought spelled out in front of me when using self direction. And so, just be careful and think about using it if you are going to use it, and one other food for thought is that a lot of times self-direction can change â€“ I'm going to say minute by minute, I know it won't change minute by minute, but we change.

Every day we are little bit different and Charting the LifeCourse, it kinds of puts out an even playing, it might have some hopeful ideas but it involves a lot of thinking and planning and it can be overwhelming to consumers. So, I just throw this in there so that you are mindful if you are going to be using the Charting the LifeCourse, that it may or may not work for everybody.

So, I will end with that and I think we are going to go to a Q&A period but I will turn it back over to Mary-Kate.

MARY-KATE WELLS:
Thank you so much Erica and Jennifer. You can stay on camera Jennifer because I think some of the questions are going to be for you. Before we jump into questions, just a reminder that we will be putting the evaluation survey in the chat.

And then on the slide is also a link to the QR code to the IL Summit in September. I know when I was listening to both of you I also went to the HCBS conference last week, and just I was taking notes seriously because I am always learning something about self-direction in independent living.

There are a few great questions in the chat that I will read out loud, and if folks have other questions, please put them in the chat. The first question is for you, Jennifer.

Kathyrn asks "the information assistance services, I may have missed it. Is that a fee for service that CILs can perform?" Yeah, if you could explain yeah, I do not know if you can just answer that?

JENNIFER KUCERA:
I am going to defer to Erica for that one if that is OK, Mary Kate.? Yeah, definitely.

ERICA ANDRES:
(indiscernible) is generally built into a self correction program so it is generally something that an RFP or a request for proposals would be going out when a new self-direction program starts or when a contract is being renewed.

And it goes out to depending on the program, statewide, countywide, wherever. And you can kind of bid to take that job. And so, you would look at the request for proposals and you would say yes, I think we can do this. And then you would put in your application.

The applications range. They are usually about 2000 pages. I am exaggerating a little bit, but they are quite long. But yeah, you can position yourself to be able to be a information assistance provider just by filling out an RFP, and filling out their application.

And also I can come back on video but it says that I am not allowed. Just saying. (Laughs)

MARY-KATE WELLS:
I just sent a prompt. There we go. OK. Yeah, so I think to Sound that might be helpful for folks. -- Something that might be helpful for soaks. When we say a new self-direction program sometimes your state will call them waiver program. Dozers have the keywords you are listening out for, right?

The language is going to be a bit different in every state. And I want to come back to that process, but at first, I will have Jen's question. Jen asks if self-direction can work for everyone would we still want to discuss the pros and cons of institutions? Obviously the choices on the consumer, but aren't institutions the opposite of the IL movement?

JENNIFER KUCERA:
I will take that. And then Erica, please jump in. When I said self-direction can work for everyone, everyone can self-correct. Meaning that you cannot -- everyone can self-direct.... No, if you explain the self-direction program to them, and break it down and help them kind of navigate it through step-by-step, everybody can understand self-direction, and with the right supports.

This may mean that someone else helps them with the interviewing or the potential caregiver. But self-direction should not be forced on anyone. Pros and cons to discuss the institutions, yes. If you are transitioning someone out of an institution, it is not your job to decide if an institution is better for them or not.

It is up to the consumer to choose that. There are some situations that people want to live in institutions. I know of a gentleman that does not want to get out. He feels very secure, he feel safe, he feels secure, and he said that he does not want to leave the institution. Even if he had all the support in the world.

That is his right to make. To help the consumer think through this, I think is very important if you are trying to get them out. But at the end of the day, it is their decision what they want to do.

And I do not know if institutions are actually the opposite of the independent living movement. Independent living movement is more about a person's right to decide and choose. If they say that an institution is better for them, and they have thought this through, and they know the pros and cons, then it is their right to live where they want to live whatever that looks like for them.

Hope that helps a little bit. Erica, do you want to add anything into that comment?

ERICA ANDRES:
No, I think you answered it well. Just that it should be anybody's choice when given all the supports that are available in self-direction and the extra help that can be added there. If the person still then does not she would, that is OK, it just should be offered, and should be, the belief should be out there that anyone can do it with the right support.

MARY-KATE WELLS:
And I think, too, another rule that IL movement has is to advocate at the system level to make sure that there are those resources outside of institutions so there are options, right?

Everyone has the right to choose, and the dignity at risk, and what you are talking about, Jennifer, that CILs can provide that peer support. And we also do that advocacy piece ensuring healthcare access and all of that.

I know that is especially challenging in rural communities. So, folks, please, if you have any more questions for Jennifer and Erica, please put them in the chat. I have a few, and just when people are thinking.

Erica, so do regular part of the presentation, you are saying how CIL staff should be subject matter experts in this process, in system. I know that this is one training resource, but would you have any other training resources or suggestions on how CIL staff can get that type of training.

ERICA ANDRES:
Shameless plug for pride self-direction. The company I work does have different levels of membership for people that would like to, and a lot of times, I am sorry, there is a fly in my house, and it is flying on my face.

But yeah, so we do have different levels of membership, and just today we planned our self-direction 101 it is called. It is a very basic guide to self-direction, and what self-direction is, and how it can be.

Currently I work it was CILs and a couple of states to set up self-direction programs, and what self-direction can mean. We also can be hired on for technical assistance to discuss programs and what it is and how you would need to get up set up to be in our position to do information and assistance or learn about self-direction.

Just even as simple as signing up to do technical assistance with you to do are really intensive what is self-direction, what does it mean, what does it mean for your CIL? Things like that. I also used to work at a CIL, so I am very familiar with what the philosophies and things like that.

We can definitely do a very intensive thing, but also if you are a member we have tons of member only resources on our website of different things involving all self-direction.

MARY-KATE WELLS:
Thank you. And it looks like we have another question in the chat from Elizabeth. Elizabeth asks "how do you navigate when a consumer wants to self-direct and make their own choices, but a family or parent, a parent or family member has power of attorney or guardianship, and they want to stay institution based?"

(Multiple speakers)

ERICA ANDRES:
You can go ahead and then I can add.

JENNIFER KUCERA:
It is a very tough situation. I think, if I'm not mistaken, you can also talk with your PND system, protection and apathy system like disability rights in Ohio it is disability rights Ohio, so I would also talk with them. To see with some of the options that they would even suggest.

I know that is a very sticky situation, and I do not want to say something that might be incorrect. So I would rather you talk with your disability rights organization in your state.

ERICA ANDRES:
When I was a case manager in self-direction, I had a lot of situations where the participant wanted one thing and the guardian or power of attorney or whoever wanted something. First of all, remember that power of attorney does not take rights away.

It is just a person that is there to help. If it is just a power of attorney, that can be easily switched. Well, not easily, but that can be changed, and the person, based on power of attorney, does have very many rights in their own life and livelihood.

If it is power of attorney for that if it is guardian, that is a separate story. But really, also just maybe trying to do a lot of compromising or trying to figure out a common ground.

Maybe you do not live in an institution anymore. Maybe you could be a transition to a group home or an adult family home or something like that to get into the community a little bit more. And then pass that, maybe you do move into self-direction.

Really just trying to find that common ground. For example, I worked with a participant whose family was very into college, and he needed to go to college and that was where he was going. And the gentleman wanted to stay home and play video gains all day, and that was really all he cared about.

The father was the Guardian and he said you were going to college. I do not care. So we found a program at the local community college that was literally videogame writing. That is what he did so he went to college and he designed videogame.

Really try to get that common ground or that area where you can maybe make baby steps, but again, remembering that a power of attorney is very different than a guardian and those can change.

MARY-KATE WELLS:
Anything, too, that is where some of CILs community outreach and education training are not only their partners, but community members on some of these different models or supported decision-making and self-direction so that that is a more common kind of use versus automatically saying going to guardianship or something.

I could see that as another place work centers could provide support. And this actually kind of leads into what you were saying, Erica, about compromise and the advocacy. Kathyrn asks do you find that there is a need to build once advocacy competence before you introduce the idea of self-direction model? So looking at it as a set up, awareness, and education.

ERICA ANDRES:
(indiscernible)

MARY-KATE WELLS:
Either.

JENNIFER KUCERA:
I do not think I would see it as something that needs to be done before. I think all of us could build our advocacy skills. I have been doing this for a long time, but there is something new I learn every day.

I do not know if it is something that can be done before. I think it could be built alongside. Self directing would build somebody's advocacy competence, so I think it could be done in parallel or side-by-side. So I do not think that it needs to be done before.

I definitely think, again, the person might need a lot more hands-on assistance in self directing if they have never spoken up for themselves before, but I feel that it can still be done, and it does not need to be one or the other or one before the other.

ERICA ANDRES:
Nobody comes into self-direction knowing. I happen to have a degree in human resources, but generally I do not come into self-direction knowing how to be a boss or recruit, hire, get your own workers.

You will learn all of that stuff, and by learning that, you are also learning advocacy. Because I am learning how to speak up for myself, and have caregivers that do the things I want as opposed to doing what they want. And learning how to be a boss and how to be a good employer and how to have those difficult conversations, things like that.

You are learning them along the way. I think advocacy and self-direction are like go hand-in-hand because you are learning how to be your own best advocate in a self-direction program, and also learning how to be in a self-direction program and being an employer.

JENNIFER KUCERA:
I would like that up one more thing to that. I know that I've been advocating for myself for so very long, but there are still things that I cannot ask for. And my caregivers are like you need to speak up. So even though I have been doing this a long time, because there were situations in my life where my opinion and needs were very repressed, I still had that trauma where I do not ask for myself.

And I don't think like oh, like go into work. I had this job once where I did everything myself. My coworkers like Jen, why don't you get a caregiver to help you with some of the stuff? And I never even thought of that.

Even somebody that has been advocating for themselves for so long does not think of all things. That is why we need each other to bounce ideas off of.

MARY-KATE WELLS:
I think that's where some of the peer support is really key here too. Awesome. We have two more questions. One more question in the chat. From Carol. Carol, I just want to have you clarify, when you see PA, are you meaning personal assistants? The question is, do you have any strategies for accessing, I will assume it's personal assistance services in rural communities where there's limited people and agencies available to provide the personal assistance services. OK, thank you.

JENNIFER KUCERA:
That's the beauty of self-direction. You can hire anyone to be trained as your caregiver. Anyone. I use the example of Bill down the street. He's never even thought of being a caregiver but he likes to come over and help me with my garden. An outside type of things. I could hire Bill once I get him connected, and he can help me with gardening and other things. That's the beauty of it.

It doesn't happen to be a person who would work in an agency or be a provider, they just get along with you and you get along with them.

ERICA ANDRES:
I'm addicted to shopping and I found caregivers, "I love the Dollar Tree." Who doesn't? It's a dollar. I carry little business cards with me, "want to have a fun job?" I can literally hand a business card to someone. I literally was a woman sitting next to me at the bar one day and she asked me what my drink was and we started talking. Like Jennifer said, you don't have to go to an agency or things like that, just live your life and find people and make up cute little business cards.

Mine are cute because I love pink. Just make them fun. When you meet someone who is really cool when you're at that restaurant and the waitress actually put your drink in front of you, instead of across the table, and maybe say, "I'd love for you to work with me."

Even in small towns, maybe there's a library or there is always a bar in a small town. We have three. Maybe you go in and you have that drink and meet that neighbor that you just had a drink with and you are a little more loosened up, but also word-of-mouth and putting signs up. I've been known to sit outside poll dancing classes because if you can hold yourself on a poll, you can probably take care of and lift me. Go to the local gym and things like that. Just really getting out into your community and living life. Going to community events.

I know that a lot of small towns, my small town has a local rummage sale and I have been â€“ I don't live there anymore but I have been tempted to put a booth up and say, "I'm not selling anything except myself and a job." Just really being creative with what you like or if you like music, if there's a music store, but a flyer up there. I don't know, other interests, reading, put one up at the bookstore and things like that.

MARY-KATE WELLS:
Thank you for sharing some of those personal experiences as well, Erica. It sounds like that community connection piece is really going to be key in some of those rural areas.

ERICA ANDRES:
If you cannot find people in rural areas, like I mentioned in the presentation, there is also technology. There is monitoring services and things like that. If you cannot have an actual human there 24 seven, I've worked with participants who had a monitoring service overnight, so there was an alarm on his door if he wanted in and out. There were alarms on the windows. There was a thermometer, temperature gauge, so when that went above, it would automatically take it back to a set temperature. Using technology to help with things as well.

MARY-KATE WELLS:
That's part of understanding your state Medicaid and waiver systems on what you can use your waiver dollars for and the goods and services piece, which allows folks to make some of those purchases. I think that's a good resource to tap into as well.

And I just see comment in the box. Catherine, I'm curious about building a training or awareness event to present statewide to consumers. This has been a great training. Thank you. (Reads chat) There is never too many questions, Catherine.

I know we are coming up to around the end of time. But I did just want to give a couple, just a little bit of space if anyone has any more questions, or Erica and Jennifer, if you have any final thoughts. No worries if not.

ERICA ANDRES:
Obviously, I'm a huge proponent of self-direction and I've been using it for a really long time but I just think that CILs are the perfect set up for self-direction and for people to know, as I said, I started out with my first big girl job at a CIL, hiring for the personal assistance services.

It's crazy to me how many people in our Wisconsin CIL don't understand what it is. But it's so rooted in the self philosophy that it really should be something that is explored and dove into because, as we talked about quite a bit in this presentation, peer mentoring and peer support is the way to go. The only way we will get that is with CIL getting involved.

For people who are using the programs and involved in the program, they are the ones with the inside scoop and those of the people you are getting your real knowledge from. And I just think that more CILs should really get involved in self-direction and know about it, and encourage it, and spread the word to other consumers.

MARY-KATE WELLS:
Thank you. We want to hear from you as well on what other trainings would be helpful in this area. So, if any feedback that you have, "I think we need this more specific training or this was helpful in this format," please let us know because we want this conversation to continue, even though our webinar will be ending.

Jennifer, any final thoughts? No worries if not but I just want to leave some space. No? OK, great. Awesome! Ryan in the Q&A just said thank you for sharing. Thank you everyone, Jennifer and Erica, for sharing this information today. I definitely think it's just the start of summer conversations the community is going to have.

And with that, as a reminder, to fill out the evaluation form if you are able to and check out our IL Philosophy and Practice Summit. We hope to see you there! Thank you, everyone.

(Webinar ends)(Recording stopped)
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