ROUGHLY EDITED TRANSCRIPT

APRIL

"EXPANDING CIL CAPACITY THROUGH ENGAGEMENT OF CONSUMERS WITH MENTAL ILLNESS"

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P.O. Box 2780

Overgaard, AZ 85933

www.ccproductions.com

Phone: (602) 456‑0977

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>> KATHY HATCH: Okay. Well, you know what I think we can go ahead and get started if you want. I'm Kathy Hatch and I do apologize for the mix‑up in the phone numbers, but I'm really, really glad that *freeconferencecall.com* did their thing and told everybody as they called in that the number changed. Thanks, Bill, for getting it up on the website quickly too. I appreciate that. Anyway, this is an IL Conversation, and is presented by the IL Net, a national training and technical assistance program of Independent Living Research Utilization (ILRU), and was organized and facilitated by APRIL.

So, we're happy you could join us and are looking forward to a lively discussion. We have an hour and a half, so we'll start out with an introduction of our speakers, then they will each discuss "Expanding CIL Capacity through Engagement of Consumers with Mental Illness."

That's a new topic for the IL world and that's really, really important that we include this in the things that we do every day.

So we're going to try to keep it as conversational as possible, but I know questions will come up kind of throughout the presentations. So what I would like to do, I think Dee will speak first. As soon as she's finished, we can have a little short question and answer after her presentation and then Kathie will do the second thing and then we'll do some after hers.

A little housekeeping before we start.

First of all, on the APRIL website which is [*www.april‑rural.org*](http://www.aprilrural.org) print documents and links are up.

We are providing CART captioning services today and that can be accessed via our website too. You will see that highlighted on the invitation for today's call. You can ask questions via the chat line. I see several folks on the chat line. That's great. I will be monitoring that. So if you have a question, you know, just send it to me ‑‑ or send it to everyone, and that's fine and I will make sure it gets asked in the course of the conversation.

I'd like to ask everybody to put their phones on mute. I think everybody pretty much has already. Since this is a bridge line, it's really sensitive to any kind of background noise or cell phones ‑‑ (Phone ringing).

Uh‑oh. Someone has a phone ringing. Speaker phones and cell phones. Star six to mute their line and whoever has that phone ringing in there, could try to make that stop, we would appreciate it.

>> Hello.

>> KATHY HATCH: Yes, hello.

Okay. So once the Q&A starts, I will try to moderate the discussion a little bit. If we could all be courteous as possible and try not to talk over each other, that would be great and we'll try to go one question at a time.

So, I would like to introduce our presenters today and welcome them. I will begin by telling you a little bit about each one of them. First, we have Dee Barnard, who is the executive director at Access to Independence in Madison, Wisconsin. Is everybody hearing okay? I guess I should ask that before we start.

>> I'm getting some clicking feedback. I don't know where it's coming from, so ‑‑

>> KATHY HATCH: Yeah. Okay. Well, let's try that star six again and make sure everybody ‑‑ anybody that comes on ‑‑ you know what, I will remind folks every once in a while through the call and Kathie, if you hear it and you are trying to speak, say something, okay?

>> KATHIE KNOBLE-IVERSON: Will do.

>> KATHY HATCH: All right, thanks. So Dee has spent her entire career in the disability field, having worked in community mental health, educational occupational therapy, rehab, and for Independent Living Centers since 1988. While working in the IL field she's held several positions from youth transition coordinator, program director, and assistant director. And since 2008, has been executive director of access to independence in Madison, Wisconsin. Dee is also an active member of the Wisconsin Coalition of Independent Living Centers, and her primary interest areas have been program development and implementation, and staff development, and currently Dee has been focusing her energy on diversification of funding and the development of fee for service programs that will enhance and provide stability within the IL center.

Kathie Knoble‑Iverson is our other presenter and she's been director of independent living resources in LaCrosse, Wisconsin, for about 20 years. She's been an active member of Wisconsin's state Independent Living Council, and also the Wisconsin coalition for Independent Living Centers. ILR has developed exceptional skill in blending the IL philosophy with mental health recovery to be a provider of mental health services. ILR currently supports a mental health drop‑in center that serves over 450 people a year. They provide skills training, comprehensive community services, that is like Medicaid reimbursable services providing wellness and recovery planning, mental health first and peer specialist training and she will explain more about that as she speaks. ILR has two contracts to provide follow along services after crisis intervention, and education about county mental health services and consumer control.

So, again, they are here to talk today about expanding CIL capacity through engagement of consumers with mental illness and now I would like to turn it over to Dee Bernard. Dee?

>> DEE BARNARD: Thank you, Kathy. I will talk about some Wisconsin history in mental health services. I want people to know that change doesn't happen quickly when you hear what I've got to say. And in 1996, Governor Doyle formed the Blue Ribbon Commission on mental health and this body was charged with examining how Wisconsin mental health services could be improved and recommended that Wisconsin services focus on a recovery process.

So, again, it was changing the look of mental health services. In 2008, through Medicaid infrastructure grant, funding was made available to develop the peer specialist program as an employment initiative for individuals with psychiatric disabilities. ATI was contacted to work on this initiative, and work closely with the recovery implementation task force, peer specialist advisory committee.

These committees were asked to develop core competencies for peer specialists and looked at the training curriculums that would prepare individuals with knowledge and the skills needed to move towards employment as a certified peer specialist.

These committees also developed a code of conduct, sample job descriptions and reviewed a variety of training that could be utilized again to provide individuals for the Wisconsin peer specialist certification exam.

In Wisconsin, the Department of Health services Division of mental Health and substance Abuse chose to have certification for these individuals rather than licensure and I will go into that in a little bit. Certification just indicates that they have met the training competency, and were able to pass a certification exam. It is not licensure. If your state is going into licensure, it's a much more complicated process.

ATI did the work and hired statisticians and a variety of other individuals to work on the exam. It included people with lived experience with mental health. It included people running county mental health programs, as well as other areas that would employ potential peer specialists.

The test was ‑‑ the exam was developed and the first exam was held in January of 2010. And that was done in partnership with UW Milwaukee who actually approved the test and provided it on an Internet base. It's a web‑based test and is basically proctored by the eight Independent Living Centers in Wisconsin.

And the reason for that is it would be easy access for people who wanted to take the exam and it also allowed people to become familiar with the Independent Living Centers in Wisconsin. The exam is based on core competencies that cover eight domains and objectives. Self‑knowledge and the role of Peer Specialist, ethics and boundaries, cultural awareness and access and ability to locate information, team work, service recipient choice and empowerment, crisis and safety and recovery.

Today in Wisconsin we have over 300 certified peer specialists with approximately 85% of them are employed. Peer specialists tend to be employed in a variety of settings. They can be in an outpatient setting, veterans hospital, supported living arrangements, prisons and forensics, homeless shelters, travel community healthcare, drop‑in centers, community support programs, comprehensive community service programs, Aging and Disability Resource Centers, Independent Living Centers, crisis stabilization and respite programs, long‑term care programs, and we also have seen in Wisconsin where the division of rehabilitation services will often contract for those services as well.

Certified peer specialists engage the peers towards recovery. Peer specialist provides a sense of belonging, supportive relationships, valued roles in community. The goal is to promote recovery focused wellness, independent living and self‑direction which enhance the skills and the ability of the peer to meet their chosen goals. Peer specialists work from a strength base perspective and embody the belief that recovery is possible.

Certified peer specialists use their unique set of recovery experience in combination with solid skills training to support peers that experience the psychiatric disability.

Independent Living Centers have a long utilized peer mentors to assist individuals in gaining the knowledge and the skills they need to increase their independence, to enter employment, and to be active members of the community. Peer specialists also provide these along with hope to the individual with a psychiatric disability.

Today, ILCs see many individuals with disabilities and are working to increase the capacity to work with all types of disabilities. Ways to increase services and capacity. Find out what your state is doing to move to recovery based system. Get involved on committees and increase your agency's capacity to serve individuals with psychiatric disabilities. Developing a healthy organizational culture and mental health recovery is a crucial component in the success of a new organization or program.

Some of the known successes are organizations or agencies that often become better places to work. The programs show continued improved outcomes, employee retention grows and there's a greater ownership in the workplace. Synergy is created and the staff work more effectively. Consumers receive a higher quality of services and community collaboration and partnerships improve.

I'm going to reference the ‑‑ the employer toolkit that I believe Kathy has put up on the APRIL website for you. On page 23 there is an **employer toolkit,** and that was designed for counties to provide to peer specialists within their organization but this tool can be modified to kind of look at your independent living center and assess its readiness for recovery‑based services.

The assessment tool can be used to begin to evaluate an existing program. It can look at overall agency readiness, and your readiness to incorporate peer specialists as a staff member and the supervision of peer specialists.

As you can tell, I have been very involved on the systemic level, and I do employ peer specialists as well, but Kathie will talk more about how her independent living center actually responded to the need for peer specialists through what her community was telling her. So that's all I'm going to say for now. So if you have questions, did I more of the systemic change.

>> KATHY HATCH: Okay. Any questions from anybody? And what you talked about was pretty much Wisconsin oriented but I think it's transferable to other states. Does anybody have any questions?

>> PARTICIPANT: Where is this tool that she was talking about? Because I saw the email reminding us about the call but I'm not quite sure where the tool is.

>> KATHY HATCH: Right. If you go to the APRIL website which is [www.April‑rural.org](http://www.Aprilrural.org), okay, in the very front of that, right at the top of the website is the information about today's call. And there should be a link in there of ‑‑ either a link or it's actually a ‑‑ the document itself is up there.

>> DEE BARNARD: It's actually listed there.

>> KATHY HATCH: It's listed. It's actually the document itself then.

>> DEE BARNARD: Mm‑hmm.

>> KATHY HATCH: Okay? So whoever was asking about that. Any other questions for Dee at this point? No? Okay.

Don't forget you have to take your phone off mute and that's star six again. It toggles on and off.

All right. Well, now we'll go ahead and I think Kathie Knoble‑Iverson will go ahead and speak about some things from her side of the issue. Go ahead, Kathie.

>> KATHIE KNOBLE-IVERSON: I want to reiterate that what we are talking about, some of it is really specific to Wisconsin, but a lot of the big picture things are certainly things you can start at your center at any time. I wanted to let you know, we do have 14 certified peer specialists on staff. And they do a lot of different things at our agency. And we're going to hire another one. We are going to hire an IL staff person in a couple of weeks, and we hire folks who are living with a mental illness who are in recovery so that they can become a certified peer specialist sometime in the next year.

We opened our doors in 1994. So we are a fairly newer center but when we did, we were really committed to serving cross disability and we thought we were doing a fine job serving people living with mental illness. And then in 2002, we were approached by a local county because they knew we did advocacy. They wanted to know if we could help get mental health consumers more involved in the system.

There was a movement in LaCrosse County that really wanted to change the mental health system. And so we jumped on board and said, okay, we can do this. We will help you get consumers involved and we really did. I think at our high point we had 35 or 40 consumers involved, showing up for meetings and system change and work groups and all sorts of things. And one of the things that we were just sort of hit over the head with. Our involvement with this process had a huge impact on our organization. And it made us realize, number one, that we weren't doing a very good job serving people living with mental illness. And that we were ignoring a mental health system that really was many, many, times doing more harm than good to people, that the traditional mental health system was taking care of people, was making decisions for the folks that they were serving, but people had absolutely no say in the types of services that they got, and it really upset us. So we really even got into this and decided, okay, we need to ask people what they want. We did a couple huge meetings in LaCrosse and I only invited people living with mental illness, nobody else and they had to have some experience in the service system, which it would be private or public.

And, you know, we got incredible response from them. And they had no problem telling us what they wanted to see change in the system, and they wanted ‑‑ and you are going to really see the **connection to IL here when I list** **the six things or the eight things that came out of this survey**. It was that:

* They wanted involvement in the change process.
* They wanted control input in the services they receive.
* They want to be integrated into their community.
* They wanted to experience hope and to have the people around them have hope for them, that they could have a good life, despite their diagnosis.
* They wanted good, solid information about whatever they needed, whether it was housing, advocacy, Social Security, so they could make good, informed choices.
* They wanted employment.
* And they wanted alternatives to hospitalization. They just ‑‑ this group in this community really felt that ‑‑ and data shows that, that we have one of the highest rates of hospitalization in the state of Wisconsin, in this particular county.

So this got us and the folks we were serving or supporting in the involvement to get even more involved. Right now we have a contract for a peer one drop‑in center and we have been asked to develop two more of those. We are a CCS, comprehensive community services provider and that is basic skill training with a real tilt towards mental health, coping, understanding, you know, your triggers, developing a wellness plan, those sorts of things but it is skill training and we have a consumer affairs coordinator which provides advocacy and support for folks who receive CCS and we have a crisis ‑‑ a follow‑up crisis case manager who is also a certified peer specialist and she has her master's degree and she still feels that the whole mental health ‑‑ the peer specialist certification added so much to how she's practicing now and what she's learned in school.

So we have three staff who are trained, certified peer specialists. We have a RAP facilitator, which is a wellness action trainer and staff trained in mental health first aid.

And like Dee said, none of this happened fast. Part of this process started 12 years ago by getting involved in an advocacy issue and really we are building up to what we are doing now but we learned so much about how to make this happen, that that's why I wanted to share this with you folks.

I think when you start talking about building capacity in your center, there's some real basic things that you have to do. And one is you have to take a really good look at who you are as an agency. You have to look at the agency's culture, and you need to understand the difference between your culture and the activities that you do when you respond to a consumer's request for services.

And I'm going to give you some examples of that. So your agency culture and I don't want anybody to take offense here, but I'm going to use examples of how a culture might not be very ‑‑ a very healthy environment for someone who is living with a mental illness, is that maybe most of your staff have a physical or a sensory disability, and no one on staff, at least tells anybody, that they have a mental illness or live with a diagnosis.

Poor language is really used in your office. You would never use language that was offensive to someone with a physical disability, but the words "crazy," "insane," "nuts" are used all the time and sometimes in really offensive ways.

There's always condemnation about the lack of self‑help from someone who doesn't look ill, but might have some behavioral issues or related to their diagnosis or ‑‑ and one that's in the newspapers all the time is this connection when something ‑‑ when a horrible act of violence happens in the community, that it's really connected to mental illness. And in a lot of centers ‑‑ well, not just centers…

In a lot of businesses. I happened to walk into a business that we're a collaborator with a couple of years ago when there was that horrific shooting on a military base, and what I heard when I walked in the door was, “some crazy bastard just killed a whole bunch of people.” And I got very sad and tried to talk to them a little bit about, you know, maybe he's mentally ill. But there was this definite connection that they made, which it was on purpose, because he believed differently, or that he was mentally ill and the result of that violence was because of his illness.

And so I ‑‑ you know, I think we need to be careful how we talk about people who live with mental illness. There's also a real ‑‑ and I hear this from consumers from people we serve all the time, that people talk around them or talk to them as if they have an intellectual incapacity. That they are stupid or that they are developmentally delayed versus simply having a mental health diagnosis.

So that's an example of what the culture in your organization might be like. Then there's the example of taking a look at how you respond to requests for services from people when they come to you or when they call you, or when they walk in the door. And this can take on a whole variety of issues that I have heard from people who feel like they have walked into an independent living center and they have not been treated the same as if they had walked in and they were an amputee or if they were blind or deaf, that they don't feel that they were treated with the same level of respect. So when you talk about a request for services, you know, are you referring people back to a system that's already failed them and they are coming to you because it has failed them and you simply go, well, you need to go back to the county, to the mental health system because we can't help you?

Your social worker should keep ‑‑ you know, you should go back and have them help you apply for SSI or help you deal with work‑related Social Security, or that, you know, you talk about the fact that, you know, I'm really sorry that you got raped while you were on a psychiatric unit. Maybe you need to go back to the hospital and file a report.

You know, those are the kinds of things that happen to people living with a mental health diagnosis every day and unfortunately, lots of time that happens when they walk into an independent living center.

I think the first thing that people really need to do is take a look at how your organization talks about and deals with mental health internally, and then how you deal with it when a consumer walks in and wants services. And to me, one of the best tools you can use ‑‑ and you can tweak this tool. It's the tool that Dee talked about, it's the organizational self‑assessment that's part of the tool kit. And there're other assessments out there. You might find something that's maybe more appropriate for your state that might deal a little more effectively with your own mental health system in your state, but I think it's really important that you take a look at yourself first because you can't change if you are in denial about how you deal with people. There's no way you are going to make enough change in order to do a good job responding to people who need our services.

The other thing that I would suggest is that once you have really taken a hard look at yourself, and, you know, you don't necessarily need an assessment tool to take a hard look at yourself. Our agency always does that through our strategic planning process, and so, you know, somehow you need to really take a look, are we doing the best we can do? And our organization is constantly working to try to improve how we serve people, whether it's a person living with mental illness or another disability. So we are always sort of evaluating what we can do better.

Once you have done a self‑assessment, you really need to develop some sort of plan, and, you know, a plan is in the eye of the beholder. You know, I don't care if it's something that, you know is bullet points that you put up on a wall, as long as everybody in the organization understands what your plan is, and what you are shooting for, what your outcome is.

A couple of different times we have published our plan to get better at something in our newsletter. That way people sort of hold us accountable, along with holding ourselves accountable. It's out there.

And we really feel like you have to figure out what you need to change in your organization, in order for it to be a really safe place for employees who want to identify themselves living with a mental health diagnosis so that a consumer gets dealt with as fairly and, you know, with as high quality of service as anybody that comes to your center.

So there's a whole list of things that you could identify and I will just identify a few that got us really on track when we decided we wanted to do a better job serving folks, and the first thing was we realized we knew so little about the mental health system in our state. We really thought we knew a lot, and we did not. We knew a little bit about local ‑‑ about some of the local mental health systems but we didn't know much about what was going on statewide.

And, you know, one of the first things we got our hands on when we started this was the **Blue Ribbon Commission Report** and then we used the information and the feedback we got from the **consumer listening sessions** that helped us really start to focus on the kinds of things that we could change internally, so that the **outcome** was that a consumer felt that they had total control over their services that they are treated with respect when they walk in the door of whatever organization that is providing them services.

You need to learn about **mental health recovery philosophy** and how that fits with IL philosophy. There is a ‑‑ a long list of toolkit and self‑assessment on the APRIL website there. Is a mental health 101 and it's a little thing we did. A little article we did for ourselves so that all staff understood why we were taking a look at mental health recovery. It's called **Mental Health Recovery 101** and how it sort of blends and to us, it was like a perfect fit. Mental health recovery and IL philosophy. We just use a little different terminology. They are so compatible that when consumers do come to you, and they are served well, they go, wow! Why didn't I know about you people? How come, you know ‑‑ where were you ten years ago when I was hospitalized for first time, and people told me I was never going to be able to do anything ever again?

You know, it's things like that, that we hear from people all the time.

You need to learn how to reduce stigma in your own center first and then to help people ‑‑ we train people how to tell their stories so that they can go out and they sort of consider themselves stigma busters and so they can go out and help people understand why certain terminology and other things, you know, hurt them, make them feel bad and don't help the community understand what they have to offer. It's always in a real negative tilt.

You also need to **learn about trauma**. There's more and more coming out about how so much of the mental health issues are from the base of some trauma, that someone has experienced or ongoing trauma and, you know, trauma, again, one person can handle a trauma where the next person can't, and it causes some changes in their ‑‑ in how they respond to life in general.

So I think it's really important. There's some really good information out there around trauma and I don't know, Kathy, did we post anything about trauma on the website?

>> DEE BARNARD: I did not.

>> KATHY HATCH: I had posted what you guys sent me. If you have something else you want to put up there, we can definitely put it up and people can still access it.

Yes, I think we will find some stuff, and ‑‑

>> DEE BARNARD: You will make a list.

>> KATHY HATCH: Either send it to Billy, or send it to me. I will take care of it. It's not a problem.

>> KATHIE KNOBLE-IVERSON: What we realized and with feedback from some of our staff, that sometimes we were retraumatizing our own staff at work. And part of it was our fault as an agency, and the other was that the staff person didn't share with us. For example, I'm a real touchy, feely hugger person and when I talk with people, I like to connect with them physically. And we had somebody on staff who had been physically abused on a long‑term basis and that was a trigger for her. And I did not know that and I could not figure out why there was this huge issue between us. And we finally figured that out.

And you have to talk about this kind of stuff real openly. It has to happen with everybody in your organization in the room, and the administration of your organization really has to buy into these changes. It can't happen in a little program area, or in the hall outside the finance office, you know? It has to be a system‑wide.

And then you need to keep updating your plan. Your plan needs to be flexible. You need to take a look and when you think you have accomplished something, you need to take an in‑depth look. Okay, have we done everything we can in this area?

We have changed some training curriculum. We have changed ‑‑ not many, but a few policies and procedures that we felt maybe didn't have very good language or that we might indirectly be discriminating against someone with a psychiatric disability.

Next you need ‑‑ and Dee talked about. This you need to get involved in the mental health system so that your CIL staff really understand what's going on locally, statewide and nationally. And I think if you are a center, and you start to learn about this stuff, you should get really upset because folks ‑‑ the mental health system is light years behind other systems, as far as providing up to date services, not having wait lists. I mean, here in LaCrosse right now, if you have a child with a mental health issue, they can wait for two years to get in to see a psychiatrist. What good is that for a family when they are in crisis and when the kid is in crisis?

So I think there's lots of advocacy issues that as an organization, that really should be part of everything we do every day.

You need to develop and utilize maybe a certified peer specialist as an IL staff person as your first staff person. You know, I don't know what you call them. Here we call our IL staff independent living specialists, and three of those staff were our first peer specialists. And there wasn't a certification process then, but we trained them. We got them trained from an organization in Arizona. I think you have that wonderful combination of the skill set that an IL staff person has and then you add the knowledge about the mental health issues and you have this amazing employee. Then it changes how you deal with everybody. Not just how you deal with folks living with mental illness.

And we have certified peer specialists in middle management. They do IL. They run their drop‑in center. We do skill training. There are trainers who go out in the community and train and we have three certified peer specialists we just secured a year ago a grant to provide technical assistance to other peer‑run organizations statewide. And so it's really been a wonderful thing for us. Dee said this earlier.

It changes the organization. I don't care if you are an Independent Living Center or a mental health counseling center or a homeless center. Hiring people that have the experience and the training, and are healthy and in recovery really, really will change your outcome and it will change your work environment. It will be a better place, a better place to work.

And that's all I have. Does anybody have any questions?

Sorry, I'm feeling like this will be short and sweet.

(Chuckles).

>> PARTICIPANT: I have one.

>> DEE BARNARD: Yes.

>> PARTICIPANT: My name is Dorthia Box. I'm from the Oakland and Macomb Center for Independent Living. Disability Network is what we call ourselves now in Michigan. Did you develop an alliance with your local NAMI? National Alliance for Mental Illness?

>> DEE BARNARD: No, we did not.

>> PARTICIPANT: Do you use them as your resource?

>> KATHIE KNOBLE-IVERSON: A couple of our staff go to the meetings but our NAMI were all parents over the age of 70 or 75. It's changed now. Now we have a very different relationship. You have to remember this is 12 years ago. And it was ‑‑ they wanted to keep their children in the church basement and have someone take care of them because they were never, ever going to be able to do anything. And so we have worked with them and lots of people in our community over the last 12 years to help them understand, you know, that we have a different philosophy. We do believe their children can be successful and have very fulfilling lives despite the fact that they have a mental illness. And that took some ‑‑ some political maneuvering on our part to just be part of their organization and sit there and listen and then take opportunities to talk about, you know, the changes in philosophy and what was coming.

So it took a whole bunch ‑‑

>> DEE BARNARD: Kathie, some of the NAMI affiliates in Wisconsin are very active. Some of them actually provide peer specialist services through the comprehensive community support services, and a variety of other things. I think it really depends on the culture of your local NAMI too about your ‑‑

>> KATHIE KNOBLE-IVERSON: Well, the local NAMI is very different than it was 12 years ago. It's one of our partners now.

>> PARTICIPANT: Our local NAMI provides classes. They call them Family in Action classes that they have allowed us to attend even though we are not parents, adults or children with mental illness and everything that you have been talking about, they teach. So it ‑‑ if your local NAMI is offering classes, I highly recommend it.

>> KATHIE KNOBLE‑IVERSON: Yeah, they trained several of our staff at our drop‑in center. They also offer great classes on how to be a facilitator, a group facilitator. You know, I think that's part of what people need to do is seek out, you know, resources and partners in the community to see what you have in common and what you can do for each other because one of the things that has paid off for us, the parents and the participants now in NAMI really know a lot about who we are and what we do, where 12 years ago they did not.

>> PARTICIPANT: Thank you.

>> KATHIE KNOBLE‑IVERSON: Mm‑hmm.

>> KATHY HATCH: It took a long time to develop that partnership, right, Kathie.

>> KATHIE KNOBLE-IVERSON: Oh, my goodness 12 years.

>> DEE BARNARD: But I think that's in the focus of NAMI, it was a parent‑driven organization and I think as more people became aware of recovery principles and recovery practices, they also had to look at things a little differently.

>> KATHIE KNOBLE-IVERSON: They did because the curriculum that that lady ‑‑ the person that just asked the question was talking about is now a national curriculum.

>> DEE BARNARD: Correct.

>> PARTICIPANT: It's called something else.

>> KATHIE KNOBLE-IVERSON: It's Parent to Parent and sometimes other things.

>> PARTICIPANT: Yeah, Parent to Parent.

>> KATHIE KNOBLE-IVERSON: Yep and we have a wonderful teacher here in LaCrosse who is a mom who teaches that class once every six weeks.

So it has changed a lot. So ‑‑

>> PARTICIPANT: Good.

>> KATHY HATCH: Well, we seem to have lost our CART here again for a little bit. So ‑‑ yeah. So just, you know, keep ‑‑ if you've got more to talk about, we can do that. But I just wanted to let you know ‑‑ oh, she's getting reestablished. So hopefully it will be in a minute.

>> KATHIE KNOBLE-IVERSON: Backup?

>> KATHY HATCH: What?

>> KATHIE KNOBLE-IVERSON: She says she's getting reestablished. We said earlier when it happened. I said we must be doomed today and she says, oh, no, now the Internet went down. So she says I'm getting reestablished. So hopefully we will be okay in a minute.

So anyway, so are there other questions for Kathie and Dee at this point?

>> PARTICIPANT: Kathy, can you hear me?

>> PARTICIPANT: I have a question.

>> KATHY HATCH: I have two people. One person said, Kathy, can you hear me. If you want to go first, that will be fine and the person who said I have a question, we'll get you next. Star six to come off mute.

>> PARTICIPANT: This is Shelly, I'm from Oregon, and I have ‑‑

>> KATHY HATCH: Hi, Shelly.

>> PARTICIPANT: Hi there! In our experience, we have some real active mental health peer groups and one thing we have noticed is it's sort of difficult sometimes to partner because folks in the IL program are not always seen as peers. And that terminology sometimes creates some interesting barriers. I don't know if you have experienced anything around that, but I was also wondering if ‑‑ if there has been ‑‑ when you talked about having specialized training for mental health peers, how does that impact your organization as a whole, your center as a whole, because my brain is just going to the place of saying, well, then would other groups, other types of disabilities say, well, we want to have somebody specially trained to work with us and there are so many disability types. How would you do that?

And, you know, maybe could you speak to that a little bit.

>> KATHIE KNOBLE-IVERSON: Sure.

>> DEE BARNARD: Do you want to go first, Kathie, I will make a comment after.

>> KATHIE KNOBLE-IVERSON: I think the request for all disability. Personally, I think we already do that. We use interpreters. We use all sorts of things, but it's too accommodate somebody and I really think that every disability we serve ‑‑ that we served probably in the last eight years, if you ask, you will find that majority of those folks also have a multiple diagnosis of mental health or drug or substance abuse.

And we decided that this just makes us a better center. It's not ‑‑ we're not doing it so that we can just serve people living with mental illness. It's made us better at serving everybody. And so you learn how to do better interviewing. You learn how to help people with coping skills and how to develop a wellness plan. It doesn't matter what your disability is, but that you can use as a tool in your job.

So I personally don't feel like it's doing something special for one disability group. I think it's bringing on a better skill set, doing a better job of serving people. How well do you think you do serving people with a mental illness?

>> PARTICIPANT: Well, I work for the State Council (SILC). We are not providing direct services. But we have done some work with the peer support organizations, and at the state level we have connections and we're trying to improve the collaboration between the IL program and the mental health program and we have some centers with fantastic programs serving consumers that have ‑‑

>> Okay. Because, you know, we ran into the issue of not being accepted as ‑‑ as a ‑‑ because we were an Independent Living Center. First, we were being criticized. All the centers in Wisconsin were being criticized because the mental health system, some consumer groups felt we weren't doing a good job serving people with mental illness. So as a group, we ‑‑ you know, you can see that there are several centers that are really stepping up and trying to do a better job, and then we got a little bit of resistance.

I will say ‑‑ and Dee, you can comment on that. Do you think that's going by the wayside now, that we're sort of being accepted just because ‑‑

>> DEE BARNARD: Well, I think, you know, the common image of an Independent Living Center, unfortunately is that you only serve people with physical disabilities or sensory disabilities even though we know that we are serving people with mental health disabilities as well.

Again, I think ‑‑ it depends on the comfort of your center, as far as how well you serve that population. Again, I think the training to become a peer specialist, the core curriculums that are available really do give what I want to say, value added training to any IL staff because, again, a lot of it ‑‑ a lot of just the things that you learn to become a peer specialist are all things that you transfer over to anybody else that you work with, and, again, to talk about, well, you know, when I drilled down on, you know, who are we serving and we serve a lot of people, obviously, with multiple disabilities. When I drill down on that, 65% of the people that we serve also have a mental health disability. Again, I think it's higher than that and people just aren't talking about it.

>> KATHIE KNOBLE-IVERSON: Yep.

>> DEE BARNARD: I think it's a value added training that just supports more of what you do.

>> KATHIE KNOBLE-IVERSON: Mm‑hmm.

>> PARTICIPANT: So what I hear you saying is that you stepped up your quality in your centers to ‑‑ or your center to serve people with mental health disabilities and that just gave you more credibility with the mental health peer groups?

>> KATHIE KNOBLE-IVERSON: Absolutely.

>> DEE BARNARD: This is Dee and I think Kathie also talked about it, I think there was probably some discomfort among center staff as far as, you know, sharing that they did have a mental health disability. You know, how were they going to be perceived or treated as some of the things that she talked about earlier, and, again, we have to make our environments open to everyone, you know, and feel comfortable to share that information.

Again, you know, sometimes employing people with psychiatric disabilities, sometimes they work different schedules, sometime they have other accommodation issues that you need to address, and, again, some of that learning about, you know, maybe somebody needs to come in later because of, you know, their medications, you know, they have a lag in the morning. So again, being open to some accommodations which people could perceive as just, “well, they don't want to get up and get to work on time.”

So the whole attitude of the people you work with and the consumers that you serve, that's why it's got to be a whole center thing.

The other comment I want to say, in Wisconsin, some of the other things that we did for all of the centers to make us stronger, we have what's called a mental ‑‑ we are not doing it right now, but for a long time, we had what was called a **mental health best practice committee**. So we would look at self‑assessment tools. We would look at what kind of trainings did we feel every center needed to have for their staff, and Kathie listed some of those. We worked hard to get that training across the whole state so that people could feel more comfortable and access services across the state.

>> KATHIE KNOBLE-IVERSON: Yeah, and we found out some of this training is free. We found at the state level, there was a person who educated the world about trauma and all of us were able to have that person come to our center and do a training. In fact, we had her back three times but, you know, I think it's really important that, again, start to think about the kind of things that you think will help people be more open and accepting and to make your staff more comfortable.

>> PARTICIPANT: This is Shirley with the Disability Resource Center in Charleston, South Carolina. What is the length of the training and is there a recertification process in addition to the initial training?

>> DEE BARNARD: In Wisconsin, we have three approved core curriculums that someone can participate in, and I'm not going to remember what they are. The National Association of ‑‑ NAPS, DBSA which is ‑‑ oh, what is it? I can't think of it, what the acronym means. I'm trying to think about the other one. Anyway, the state approves which curriculums we can use. We actually do a curriculum review as to what meets the standard for Wisconsin.

So people go through the training. They have to take a test at the end of the training to see that, you know, they passed their curriculum training. And then they can take the certification exam which is an online based tool exam that's proctored in the eight centers. The requirement for recertification is that every two years individuals must get at least 20 hours of continuing education and we actually have categories that they must get certain hours in and then others ones can be related kinds of context to what a peer specialist might do. The other thing we are working on right now is really trying to integrate some of the substance abuse ‑‑ the substance abuse disorder things within it, because we know oftentimes a person with a psychiatric disability also has a substance abuse disorder.

We are kind of working on how can we get that more entrenched in the core training of a peer specialist as well.

>> KATHIE KNOBLE-IVERSON: Yes, the core training for a peer specialist is six days. 48 hours of training.

>> DEE BARNARD: It depends on your curriculum.

>> KATHIE KNOBLE-IVERSON: Oh, okay. That's what ours is.

>> DEE BARNARD: I mean, it's ‑‑

>> PARTICIPANT: This is Kathy from Missouri. Can I ask a question about the training and also funding? I think someone mentioned a grant. I'm curious to know if you all have received grant dollars to get people certified as peer specialists and then if the service is Medicaid billable in your state.

>> KATHIE KNOBLE-IVERSON: I can answer that.

>> DEE BARNARD: Do you want me to take that.

>> KATHIE KNOBLE-IVERSON: You can talk about writing grants.

>> KATHY HATCH: One at a time, guys. Go ahead, Kathie.

>> KATHIE KNOBLE-IVERSON: The state had lots of money out there to do training but before that, we did our own training. I wrote a $25,000 grant and brought somebody up and they spend two weeks at our center. Then the state started funding peer specialist training and now they don't fund it at all, and it's sort of ‑‑

>> DEE BARNARD: Well, let me talk to that.

>> KATHIE KNOBLE-IVERSON: And so we have continued as an agency because I have three trainers that we went ‑‑ we write grants and we're ‑‑ what we're doing is training people in our service region so that there is an opportunity for people to work, and so that people will develop the opportunities, the employers will also develop the opportunities because they know that there's people out there that are trained.

>> KATHY HATCH: I think Dee had something else ‑‑ I think Dee had more to say about that real quick.

>> DEE BARNARD: Yes, I mentioned what was called the Medicaid Infrastructure Grant which the state received, in 2008. One goal of that was to develop the peer specialist ‑‑ the certified peer specialist as an initiative program and during that five years, there was a lot of training that was paid for through the Medicaid Infrastructure Grant. They did recovery, trauma, informed care training, motivational interviewing, oh, I'm trying to think ‑‑ there was just a whole array over that five years to really start getting things in place for when we wanted to actually roll out the certification process. And, yes ‑‑

>> KATHY HATCH: Are those kinds of trainings ‑‑ Dee, are those trainings still available?

>> DEE BARNARD: Not as much.

>> KATHY HATCH: Are they still available somewhere?

>> DEE BARNARD: But as far as the trainings available for becoming a peer specialist, the state has decided that it was free enterprise. So we have Kathie Knoble‑Iverson, she has a curriculum the NAPS curriculum and we have IROC. I will get that stuff for you. And there are trainers on that particular curriculum and then there's the DBSA curriculum that people are taking right now. But, again, we also find for individuals who want to do that training, we have also worked with DVR, Vocational Rehabilitation. We feel it's a great employment path. So they will pay for the training. They will support people if they need to be living in a hotel during that training and their meals, their travel. And they will also support them in the fee to take the test.

So, again, I think its developing relationships all the way around. We did a lot of work with DVR, as far as potential for employment outcome, you know the state did a lot about the initiative of, you know, getting training out there and setting standards.

I think you really have to look at how your state is looking at doing that.

>> PARTICIPANT: And then my second question about it being a Medicaid billable service. Is it not?

>> DEE BARNARD: Yes, it is.

>> KATHIE KNOBLE-IVERSON: Well, it depends on ‑‑

>> PARTICIPANT: It depends on your state?

>> DEE BARNARD: Yes. But that's another place for you to advocate. If it's not happening ‑‑ like, in Wisconsin, the only program where it's truly laid out is Comprehensive Community Services, what we call, and that's kind of like an in between community support program, and like no services. It's kind of like a step up. But we do know that there are peer specialists paid for within a community support program maybe. They may be working under a different title, you know, as far as I'm trying to think what the title is under CSP, but, again, it's a value added skill that we're finding in Wisconsin that most community mental health programs want to hire peer mental health specialists even if they can bill under Medicaid.

We also had backlash when we started rolling out the peer specialist program, they are going to do this and they are going to do that. No, it's very finite what the role of a peer specialist is within a county system.

>> KATHY HATCH: Can you maybe explain ‑‑

>> KATHIE KNOBLE-IVERSON: The employer toolkit that was developed, Dee, I believe you were on that work group, weren't you? Or not?

>> DEE BARNARD: Yep.

>> KATHIE KNOBLE-IVERSON: Yeah. It really helps you take a look at how to integrate that position into your position, because there're some things happening and this is going to happen anywhere, not just in Wisconsin. Is that counties wrote into contracts, for example, in our area, that you had to have certified peer specialists providing this service. So they hired ‑‑ they let ‑‑ the community support program in Wisconsin which is the intense Medicaid reimbursed service for folks who really need intensive services. They were told in their contract that they had to have peer specialists on staff. So they went out and hired a peer specialist and that person is treated more like a person who participates in CSP than they are like a staff person. And so it's really important that if you are going to bring folks on, that ‑‑ that they are treated with ‑‑ you know, they are treated like every other staff person. They are treated with respect and that people understand their skill set and what they are supposed to be doing. Not ask them to do things that are out of their realm. Have a good job description so that they know what the expectations are. Have a strong supervisor connected to that person -- probably a real seasoned supervisor -- so they can get the support they need to be successful in their job.

That's really important ‑‑ it doesn't matter how skilled the person is coming into an environment. If that environment isn't healthy, and isn't accepting of that position the way it was meant to be, it may not be a successful match.

>> DEE BARNARD: And this is Dee again. In the back of that **Toolkit**, there's a section called **attachment four**, and it's the fees for mental health and substance abuse services and the community for adults and it lists a whole bunch of different things. You might be able to find something comparative within your state. If not, it's a frame of reference. Maybe if you are going to be doing some advocacy with your state, about do we just need to have it written into the rule or do we need to, you know, submit something to CMS to get that approved for payment. But there are ways to do that.

Again, the other part of the Toolkit, especially if you are working within a county system or contracting with a county system, some of the things that we also tried to address is oftentimes, the certified peer specialist that you may hire to work in a county system may have also gotten services through that county system.

And so we have really recommended that if that's the case, their records are locked and nobody has access to them because we know there are always curious people. There are a lot of different people in there and working with your community and doing just some education about the benefit of certified peer specialists.

>> KATHY HATCH: Okay. Well, I have a question. Can I ‑‑ would you guys be okay with my putting your email addresses up on the website in case somebody wants to get in touch with you, I'm talking about Kathie and Dee. Is that okay with you?

>> DEE BARNARD: Yes.

>> KATHIE KNOBLE-IVERSON: Yes.

>> KATHY HATCH: And some of the things you are talking about, I'm not sure exactly what's up there right now but if there were things about that list of the curriculums for one thing, the different curriculums that you were talking about, or that kind of thing, we could put those up there as well and then people can access them.

>> DEE BARNARD: Yes, I'm writing my list of what I need to get to you.

>> KATHY HATCH: Okay. Okay. That's great. Great. Any other questions?

>> PARTICIPANT: Yes. (Overlapping speakers).

>> KATHY HATCH: Hang on. Hang on. We have two people. The gentleman spoke first, I believe. Go ahead.

>> PARTICIPANT: Thank you. Vito in St. Charles, Missouri. We are a center for independent living and we are very familiar with peer support as we understand it here and we have a very good center called Kreiter Center that does a lot of work with mental health. We are trying to understand when you are referring to a peer and then you also refer to differentiate that from a social worker. Can you explain that?

>> DEE BARNARD: The peer as a certified peer specialist, I will talk about within the county system, the county mental health system. They have ‑‑ that is ‑‑ in order to be a certified peer specialist you must have the lived experience with a psychiatric disability. You must have gone through the training and passed the certification. The role of that peer specialist, depending on what type of program you work in, may change.

We have peer specialists here ‑‑ certified peer specialists here in Wisconsin that can do some case management, and some are doing skills trainings, helping people develop recovery action plans, helping them understand their psychiatric diagnosis. They are doing life skills training, some pre-employment kinds of things. So it's pretty varied.

Now, I do know we also have some social workers within Wisconsin who are also people with lived experience who have also gotten trained under a certified peer specialist curriculum and passed the test. We are finding in those areas that they really believe that that's, again, an value added training for them in working with the individuals that they are working with. So I don't know if that answered your question or not.

>> KATHIE KNOBLE-IVERSON: And this is Kathie. We have a social worker who is a certified peer specialist and she has her master's degree. The work she does as a certified peer specialist is what the county is asking. They are not asking for a master's degree social worker. They are asking for someone with lived experience, who can act as a peer to support people after they have been in crisis. So, you know, it ‑‑ it's one of the things we have to work at here at our agency, because we have different folks doing different things that are certified is that we just have to make sure that we are constantly clarifying with staff what role they are playing and what outcome we are getting paid to do for people.

>> DEE BARNARD: Yeah, and it's driven by what program or service you are providing.

>> KATHY HATCH: Somebody had another question a second ago.

>> PARTICIPANT: Yes.

>> KATHY HATCH: A lady out there.

>> PARTICIPANT: My name is Alexa. I'm from the independent center of northern Virginia. I did want to say to the presenters that I don't know if anybody else is, but you guys are breaking up a little bit. So I don't know ‑‑

>> KATHIE KNOBLE-IVERSON: I don't hear anything. It's all broken up.

>> KATHY HATCH: Yeah.

>> PARTICIPANT: But the question that I had was I heard you guys talking a little bit about action plans and wellness plans. Is that stuff the sort of stuff that is in the training for the certification?

>> KATHY HATCH: Let me say something real quick before you answer that question, okay? If anybody is not on mute, make sure that you use star six to be on mute if you are not speaking because like I said, cell phones and speaker phones sometimes make a problem. So star six. Make sure you are on mute. Thanks.

Okay, go ahead, Kathie or Dee. I'm not sure.

>> KATHIE KNOBLE-IVERSON: Can you repeat the question? I'm sorry, it was ‑‑

>> DEE BARNARD: It was about ‑‑ (Overlapping speakers).

>> PARTICIPANT: We are talking a lot about ‑‑

>> KATHIE KNOBLE-IVERSON: Yeah, wellness plans and action plans.

I think they touch on some of that and Dee can reaffirm this, but in the training we do, we touch on some of that, and it's bigger concepts that you can deal with. You can get trained. We have a staff member who does wellness and action and recovery plans. You have to get certified in that and you are not supposed to be doing those plans with people. You can develop a WRAP plan. There's a difference. You can educate a person about how to do and give them feedback but you can't sign off on the plan. It's Mary Ellen Copeland. I don't know how many of you are aware of her. She has a WRAP plan and we have to be careful about how we use that information.

>> DEE BARNARD: Let me speak to that. There are several forms of Recovery Action Plans that, you know, people can start learning about their triggers or what is helpful to them when they have symptomology. It's taking control of their illness and kind of being mindful of what's going on and what do they want to have happen and know what helps them to relax or whatever the trigger might be. The Wellness and Recovery Action Plans (WRAP) are done by the Copeland Center and you can look her up on the website. You need to be trained to do the wellness recovery action plans Mary Ellen is good about that. We have six or seven people who are able to do those trainings.

How they work at least in my shop, you know, we will hold wellness recovery action plan trainings and we usually do them over three evenings, two hours a night with a core group of individuals. It might be eight people or up to 12 or 13, and I don't think you can do more than that in that type of a situation. That's become a fee for service for us. DVR will pay for those kinds of things. Other types of service providers will pay too. It works on a great action recovery plan and talk about what are their triggers. What works to reduce their stressors or their symptomology, or what do they want to have happen when things aren't going so well. Do they want to go to some place safe or what do they want to have happen? It's always being revised with individuals because their situation changes about you it's a great tool and it's kind of a ‑‑ if you are really practicing recovery. That is one of the big tools that really instills hope and control over one's psychiatric disability.

Would you agree with that, Kathie?

>> KATHIE KNOBLE-IVERSON: Yes.

>> KATHY HATCH: Sounds like a good thing to have. So any other questions?

No?

It's about quarter after 4:00. So we are coming up on the half hour where we will be finished.

If any ‑‑ I will ask one more time? Any other questions from anybody? Anything you would like to ask these ladies?

No? Okay. Well, I think we'll go ahead and chose it up then. I want to thank you all for being here today and for being patient with us. This has been a little tough one.

Thanks to our CART folks and our friends at SKIL in Kansas who are recording this.

Just so everyone knows, the recording of this will be up on the APRIL website in just a couple of days or something like that, and also a transcript from the CART ‑‑ now it's going to be a little bit sketchy but the audio should catch everything.

And I would like to say thank you so much to our presenters, Kathie Knoble‑Iverson and Dee Barnard. You have a lot of great information and I hope a lot of folks out there learned a lot today. Did somebody have a question?

>> PARTICIPANT: Can you hear me?

>> KATHY HATCH: Yes.

>> PARTICIPANT: This is Barb from Red Rock center in St. George, Utah.

>> KATHY HATCH: Okay.

>> PARTICIPANT: And I know you talk a lot about the certification, but is that state by state or county by county? I understand the wellness action recovery plan that you have to get certified but just to have the peer support, I mean, I don't know if there's any regulations in our state that would require that.

>> DEE BARNARD: And it is different by state. There're several states that have certification for peer specialists so that they can build Medicaid, but like Kathie started before the certification even existed. So, again, I think it's state by state.

>> PARTICIPANT: Okay. Thank you.

>> KATHY HATCH: Okay. I'm sorry, I didn't ‑‑ I didn't catch you quick enough there. So is there anybody else who has got a question? You have to use star six to come off mute. Maybe that was the problem.

Anything else?

Okay. All right. Well, so anyway, I would like to invite you to visit the APRIL website, where you will find the documents that were discussed today. A few of them are up there already and a few we will be adding over the next day or so. So we'll make sure that those are there and that website is www.April ‑‑ like the month ‑‑ [www.April‑rural.org](http://www.Aprilrural.org) and look for IL Conversations and it will be archived. Look for training and IL Conversations.

If you have questions about today's discussion, you can reach me at [kathatch@charter.net](mailto:kathatch@charter.net). Even though I will be gone in a few days, I will still answer questions. Don't hesitate. Thank you all so much for being here today.

This IL Conversation is presented by the IL‑NET, which is operated by the Independent Living Research Utilization program at TIRR Memorial Hermann in partnership with the NCIL and the APRIL. Support for the presentation was provided by the U.S. Department of Education, Rehabilitation Services Administration. No official endorsement of the Department of Education should be inferred.

So, again, thanks, everybody, and take care. Bye‑bye.

(End of meeting)