

ROUGHLY EDITED TRANSCRIPT

APRIL

Role of CILs in Supporting People w/Psychiatric Disabilities

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[Please stand by for CART captioning.]

>> Hello. For those of you just joining us, we will be starting here in about five or six minutes. 1:00 Mountain time, 2:00 Central and 3:00 Eastern.

>> I want to let you know your mic is live now. I am looking forward to hearing you and Mike speak.

>> Thank you. Look forward to the opportunity.

>> MARY OLSON: Good afternoon, Mike. I just want to let you know that your mic also now is live.

>> MIKE BACHHUBER: Thank you.

>> MARY OLSON: Folks, we're going to go ahead and get started in about three minutes and let you guys get settled in. For those of you joining us, thanks again for you coming on to hear these great speakers, talk to us about the role of CILs and supporting people with psychiatric disabilities.

>> MARY OLSON: We still have a bunch of folks joining us. So we're going to wait a couple more minutes to let them beep in and then we'll get started.

>> MIKE BACHHUBER: All right.

>> MARY OLSON: All right. Good afternoon. Again, thank you, everyone -- they're still coming in. Thanks for joining us today's call on the role of CILs in supporting people with psychiatric disabilities. If you need to access our CART for today's call, please go to the APRIL Web site at www.APRIL-rural.org. Follow the link on the homepage. Or you can access it from any list of announcements for this call that you may have received from APRIL.

Our presenters also have handouts available that were attached to the announcement that went out on the web listserv. These are also available on our Web site homepage. If you have any difficulty accessing the CART or the handout, feel free to email me at Mary.Olson@MSO.UMT.EDU, and I can help you troubleshoot that while we're on the line.

Today's call is going to be recorded thanks to Bill Cochran at SKIL and the audio recording and transcript will be available online at our Web site under the IL Conversations tab following today's call. During today's conversation if you would like to add to the topic from your experience or ask any questions, please press star 2 on your phone and that raises your hand and I can make your line live. Then following your question, if you feel like it's been answered, if you could press star 2 again, that lowers your hand so I know not to keep calling on you. For those of you who are on the CART, please type in your questions, and I'm going to be my best to monitor those as well. Please remember to evaluate our conversation on our Web site following the call, and that also is under the IL Conversations tab. Your feedback is so important and it just makes us stronger as an organization. Support for this conversation is provided by the U.S. Department of Health and Human Services Administration for Community Living. No official endorsements should be inferred. Without further ado I would like to introduce your presenters, Mike Bachhuber is the Executive Director for Independent Living Council in Wisconsin, in Madison, Wisconsin, and he has worked in disability rights since 1997, including work at the state's protection and advocacy system and an IL center. As a consumer, Mike sat on and chaired the state's mental health planning and advisory council and served as a founding board member for mental health consumer networks. He currently devotes time to organizing the civil rights efforts of the National Council On Independent Living as the co-chair of its ADA and civil rights subcommittee. SeRonna is from Whitehall Arkansas and has been an advocate for over 25 years. SeRonna worked for eight years in the deaf community as an interpreter in the public school system as well as teaching sign language to K-8 and beginner classes for adults. She worked for the protection advocacy system, disability rights system of Arkansas for 17 years as director of external relations and worked for the Arkansas disability coalition working with parents who have children with disabilities in the public school system. She has been on the national alliance on mental illness of the Arkansas Board of Directors and currently is executive Board of Directors for Arkansas's Can Do. Joining us – SeRonna is also a parent with a disability and a parent and a grandparent of a person with disabilities. I'm glad to introduce these speakers and without further ado I'll let them take it away.

>> SeRONNA RODGERS: Thanks, Mary, I appreciate that.

>> MARY OLSON: You're welcome.

>> SeRONNA RODGERS: I didn't hear you, Mike.

>> MIKE BACHHUBER: I just said thanks for the introduction. Do you want to start

first or shall I in we probably should have --

>> SeRONNA RODGERS: I will let you go first.

>> MIKE BACHHUBER: All right. When we were planning this conversation, we tried to think what are some of the most common questions in our community about psychiatric disability and build a presentation around that. What we came up with is, starting with what is psychiatric disability, and then going into a little bit more about social supports and philosophical reasons for CILs getting involved.

We thought that the what is psychiatric disability is worthy of some discussion, and hopefully you've all had a chance to look at the sheet we prepared, and I think -- I want to make sure to give SERONNA for looking up some of the definitions people follow.

Psychiatric disability is different than a lot of disabilities we deal with like paralysis where either you know you have it or you don't. Experiencing depression and anxiety, and working with other people who experience psychiatric disability, I believe that it is very real for the people who are experiencing it, but there aren't the same kind of physical signs and symptoms that a lot of conditions are known by. And even within the scientific community, there is a fair amount of discussion. The whole idea of mental illness, for instance, is a construct that does not have universal acknowledgment. For instance, the director of the national institutes on mental health issued a formal opinion prior to release of the new diagnostic and statistic manual saying that they are not going to require its use for the projects that they fund because it does not have sufficient scientific reliability or accuracy. So it's worthy to look at what other communities use to define psychiatric disability for their purposes, and generally speaking, we're talking about people who experience high degrees of anxiety and fear and/or other emotional issues above and beyond what is common. It also includes people who have a sense of reality that differs from what most of us would describe. So, for instance, people who hear voices or see things or hold on to beliefs for which there's not a lot of objective purpose. And I think that the definitions that you see there do provide some information.

By the way, we will be pausing at several points in our presentation to allow for questions.

With that, I'm going to toss it back to SeRonna to have her add what she would like about the first question.

>> SeRONNA RODGERS: Okay. Thank you, Mike. I was staff liaison when I worked for disability rights Arkansas of the protection and advocacy for individuals with mental illness, and what I discovered along with what Mike is saying is that individuals who were members of that advisory council had different views and ideas on what they wanted to be referred to as, what their views were on -- we discussed medical models and recovery models, and I'd never heard of a recovery model. I'd only learned about the medical model, as it's called, which is, you know, you go to a psychiatrist, you get a diagnosis, and they give you medicine, and they may provide treatment, depending on

what your insurance allows for. But in discovering that there is a different view with the recovery model is more, I think, based on circumstances in life and things that happen to an individual as a result of a traumatic event. So I think it's important to be open-minded about any individual and to ask if someone -- what they want to be -- I just prefer to call people by their name, or I prefer to call them a person with, you know -- but consumer is a word that was kind of frowned upon. And so it really, to me, I'm a person with depression and anxiety. I know what it looks like and feels like. But it doesn't happen that way with everybody who has depression and anxiety. I mean, we're all unique individuals. So we have our own genetic make-up and our own history of health issues or not. And so we're all unique and we have to remember that when we're dealing with people with psychiatric disabilities that we have to keep an open mind about how we communicate with them. Everybody's got their own world views but everybody deserves to be able to live independent, and a lot of folks with psychiatric disabilities end up in our prison systems, and they end up without homes, and so there has to be more that we can do for those individuals regardless of whether they call themselves a person with a mental illness or whether they call themselves a patient or a survivor or an expatient or whatever they choose to call themselves. We have to figure out how to help every individual with a psychiatric disability.

So, with that, I'm going to toss it back to Mike.

>> MIKE BACHHUBER: All right. Thanks.

I have a line ringing in my ear.

So on the last page of the handout, we reproduced a chart sharing some of the different terminology, similarities and differences, kind of -- some of you may recognize part of it because the rehabilitation and Independent Living pieces came from a social science paper that has been shared fairly extensively within the IL movement comparing the IL and rehabilitation movement.

For a recent training, we added a column for recovery, and I think that what I wanted to do is just talk about some of the terminology is oftentimes different from organizations whose primary focus is of and by peers, people who experience psychiatric disability. So, for instance, the very concept of recovery is one that's relatively new to refer to the mental health area as opposed to the substance abuse area and may have a bit of a different meaning than some people are familiar with. Recovery does not mean that someone will no longer have psychiatric disability. It can mean that for some people, but, really, it's a very similar concept to Independent Living in that recovery is more of a process. It's something that the details which are left up to the consumer, and what it really means is being -- recovering your ability to function in society, recovering your freedom if you've had that taken away by a court can be part of it, and so, really, what folks in the recovery movement are looking for and trying to follow are very similar to folks in the independent living, using the support

of our peers to help us recover functioning.

>> SeRONNA RODGERS: To me, that's a very crucial component to getting through life, is if you have the right support system in place and you have those that understand what you experience on a regular basis, that's key in my opinion to how well someone will get -- recover from a situation that they might experience. So your social supports are invaluable, and I think we can pass along -- if people learn coping skills, that's going to help them get through to the next step. So social supports and coping strategies, I think, are very important to that aspect.

>> MIKE BACHHUBER: So, basically [INAUDIBLE] might come to [INAUDIBLE] every center in the country serves people with psychiatric disabilities. Sometimes people disclose them. Sometimes they don't. But from several different sources of information -- it's appropriate to estimate that about half of the people with other disabilities that we serve also have psychiatric disability. There's a very strong correlation between people who have had trauma in their lives as a child or as an adult and the experience of the kind of emotional distress that oftentimes gets labeled as mental illness or psychiatric disability.

Though, it's important to -- of course, centers, if you're aware that you have folks, then the idea is working with folks to make sure you're meeting their needs. If folks aren't disclosing psychiatric disability, then it may be appropriate to start looking at why that might be. And then, of course, in addition to people with other disabilities who experience psychiatric disability, there's also a substantial number of people whose primary disability is psychiatric disability.

So just to give you some idea, I've looked at data from Social Security, which primarily looks at primary diagnosis. We've looked at data for long-term care services. That shows substantial numbers of people with ongoing psychiatric issues. And one of the researchers up by Mary at the UMT Rural Institute actually did a study in conjunction with their consumers and found that half of the consumers with physical disabilities or sensory disabilities also experienced significant mental illness. And oftentimes the research uses the term "mental illness" even though to identify as consumers or peers or expatients would prefer not to use that term.

So maybe this is a good opportunity to pause and -- Mary, should we keep going or should we give people an opportunity to ask any questions as they come along?

>> MARY OLSON: You know, why don't you go ahead, and if you don't mind, I'll just kind of pop in and stop you when I see a hand raised. So, again, if folks would like to ask a question, participate in the conversation, if you would press star 2, that raises your hand and I can make your line live. Or you can type in a question using the CART. Actually, it looks like there is one question from Mechelle in the CART and she says: What would be the proper terminology?

>> MIKE BACHHUBER: Do you want to start on that?

>> MARY OLSON: Versus mental illness.

>> SeRONNA RODGERS: Right. I don't like the term "mental illness" because of the biases that people form with that term. To me it's a very negative term. But if you -- I don't have a problem with telling anybody that I have -- I experience depression and anxiety. So that's a good way to coin it, is by what it is that you actually have. It's a psychiatric disability that you have to -- people have to learn how to deal with on a daily basis, and so I don't have a problem with just calling it exactly what it is... depression, anxiety. You know, people -- they think of mental illness, and they automatically think that -- jump to -- because I think the media really hurts more than they help because they enjoy the sensationalism of using the terms "mentally ill," and "this person had a mental illness." Well, I like to break it down and find out more about it than just a mental illness. So that's what my answer would be, is call it what it is.

Do you have something you want to add to that, Mike?

>> MIKE BACHHUBER: Sure. I generally prefer to be called Mike.

>> SeRONNA RODGERS: Yes, there you go!

>> MIKE BACHHUBER: And I also -- if you read about Abe Lincoln and other people in past ages before the medical system had taken over, you hear a lot of different terms. Like Abe Lincoln was also called a melancholy.

>> MAN:, and I kind of like that term. I think it describes that part of my personality in a way that it's separate and apart from how a doctor may describe my ability.

Sometimes melancholy isn't adequate. There may be other terms like anxious. And I think it really depends quite a bit from person to person.

Having been involved with a number of organizations where people with primary disability are in charge, I have been involved in some debates more than I would care to remember where people go on and on that consumer -- I want to be called a consumer because of this and this and this, and don't ever call me a patient. And someone else will say, don't call me a consumer, because I don't use psychiatric services. I'm not a consumer. And other people will say, "I was locked up in a psychiatric institution and I survived and that's how I want to be known." So it gets to be a very individualistic kind of thing for how people like to be called. I mean, generally, when I am involved with organizations of people with psychiatric disabilities, I call myself a consumer because in IL that's what we call people with disabilities that we work with. Although, I think it's becoming more common among organizations of people with psychiatric disabilities to call each other peers. That's a term that I'm not particularly comfortable with because everybody is everybody's peer. So, again, there are different terms, and you really kind of need to start with who you're working with at the moment and what they're most comfortable with.

Does that answer the question that we started off with, then?

>> MARY OLSON: While she is answering, I'll email that Kathy Baker in the CART says that one of her consumers said "just call me by my name."

>> MIKE BACHHUBER: And that's why I started out with the "You can call me Mike."

>> SeRONNA RODGERS: Exactly. That's how I should have started it, too. Call me by my name.

>> MARY OLSON: She says that did answer her question. People-first language versus a label.

>> SeRONNA RODGERS: It's not about political correctness. It's about respecting the individual as a human being first and foremost before we place a label or categorize individuals. You got to get to know that person and then, you know, then you'll know their name and you'll know what to call them.

>> MARY OLSON: I don't see any more questions -- oh, go ahead.

>> MIKE BACHHUBER: So that does kick off for me something else that we should add, and pretty much everywhere in this country they have some system to take away the rights of people because of mental illness, and that is one of the reasons why term mental illness is one that often is not given much respect among people with psychiatric disabilities. According to case law that has arisen since the late 1960s, not enough that someone just has a mental illness in order to take away their rights. They also have to be considered dangerous based on some recent acts. However, courts have been very loose about what -- how they consider -- what they consider to be dangerous based on recent acts. For instance, oftentimes if a social worker thinks that you aren't following an adequate diet, you aren't eating the way that they think would be healthy, that they have gone to court and gotten court orders to take away someone's rights because, well, if they don't eat right, they could get sick or die, and, therefore, they're dangerous to themselves. And that whole way that the medical establishment and the use of mental illness as a condition to take away people's rights has an interplay over an awful lot of the interaction between people as a person with a psychiatric disability and other aspects of society. Once someone has had a court order taking away their rights, and sometimes those court orders require a person to go to a so-called hospital, which is essentially a jail with a nurse instead of a regular jailer, locked doors, bullet-proof glass, same kind of features that you find in many other jails. Some court orders when they take away people's rights don't require a person to be hospitalized but merely take away their authority to decide what kind of treatment they will undergo for their so-called mental illness. And some court orders are essentially guardianship orders that most of us are probably familiar with. But that role, that tie between the medical system and the legal system is kind of ever present and a deterrent to people getting treatment, and it's something that I think if we're going to be working with people with psychiatric disabilities, it's something for us to be aware of, it's one of the reasons why some people won't disclose a psychiatric disability, and it's probably one to consider working on as a systems advocacy issue if we are working with people with psychiatric disabilities.

>> SeRONNA RODGERS: I agree. Mike, I know we didn't discuss this, but you brought

up something that reminded me, and I don't know -- I'm pretty sure it differs from state to state, but one of the things that centers could do is learn about advanced directives and talk to your -- the folks that come into your centers about whether they have an advance directive. An advance directive is a -- it's like a -- kind of I would refer to it as a living will. It is a set of instructions that a person who experiences a psychiatric disability provides, this is if I have an episode, depression episode, and I get to a point where my ability to make decisions is compromised, I've got a sheet of paper here that's been authorized and approved that says here's what types of treatment that you can provide. This is the person in charge who I -- who I want to be in charge for this period of time. And it's just a go-by sheet of what your wishes are for your own personal recovery. So that may be one of the things that if states -- if your states abide by an advance directive that we could work on helping individuals obtain as an advance directive.

>> MIKE BACHHUBER: and that kind of leads into the resources that were distributed with the notice of this conversation. There were links to a number of links on coping. One of the things that, to the extent we can make broadbrush propositions, that prove helpful for a lot of people with psychiatric disability is something as simple as coping skills. In the IL model we would talk about it as part of an IL skills training. So, for instance, one of the issues that I have dealt with is anger, and I have learned skills that help me control my anger. And so SeRonna found these sheets online. It seems like they're very much within the IL model as far as something that people with disabilities can share with each other to improve our ability to function in society. So there were sheets on a whole number of issues, and from what I saw they looked to be very helpful. I don't know if there is anything else you would like to say about that.

>> SeRONNA RODGERS: Well, there was just the vicious cycle of depression, vicious cycle of anxiety, progressive, muscle relaxation, problem solving. Some of the obstacles that we face as individuals experiencing some type of psychiatric disability is not having a resource. So if we can -- you know, I have -- I've developed coping skills myself. I think that my anxiety is probably worse -- or greater than when I'm dealing with depression. So I have to -- I have to make sure that I pick a time to travel to work in the morning. I pick a path less traveled. Because I know if I'm in traffic, I don't want to start my day with anxiety. I want to start it as peaceful as possible. So even just strategizing how to plan a day without setting off triggers is helpful for me. So I think the more that we're able to share what our coping skills are with each other, and, you know, help them see how these coping skills can get them through a situation and kind of enhance their day, I think that these are good tools for CILs to have on hand. The more that we can learn about what a person is dealing with, the less guesswork that we have to do, the better for the individual that's coming to us. The more that we can educate ourselves, the better we'll be able to help figure out what help looks like to them.

>> MARY OLSON: I might pop in just a minute here and let folks know that again those links that they're talking about in those handouts are on the APRIL homepage. You can find all the links there. And then also it went out in any of the emails from the listserv you received. If you have any trouble finding those, again, you can email me. And with that -- is it okay, there's a couple of questions. Would you mind if I let them ask?

>> MIKE BACHHUBER: Absolutely. Go ahead.

>> MARY OLSON: Great. So I'm going to go ahead and make your line live. Hello?

>> PARTICIPANT: This is Teresa from Spokane.

>> SeRONNA RODGERS: Hi, Teresa.

>> PARTICIPANT: I have a question about the patient directives. Can a psychiatrist in the event of a patient becoming ill to the point of not being able to make safe choices for themselves, can a psychiatrist override the directive, if there is a directive in place, a legal directive, or is it that up to the state to determine?

>> SeRONNA RODGERS: I think that's going to differ from state to state.

>> MIKE BACHHUBER: I think that's correct.

>> PARTICIPANT: Is that something that the advocates on a federal level can address? Because it seems like with the Independent Living philosophy it would be a very important decision, I think, if that was to make that a federal mandate, that a patient's directive should be allowed to be taken into consideration and followed and not overridden by a psychiatrist. For example, if a person has a mental breakdown and having severe depression and the psychiatrist has been told that they absolutely -- the patient absolutely did not want ECT treatments, however, the psychiatrist feels that that's the only option for treating at that time, if the patient did absolutely not want the ECT treatments, it seems like that should be followed, and I would hope that the advocates on a federal level would fight for that.

>> MIKE BACHHUBER: Right now the advocates at the federal level for the last few years have been focused on the real basics, which is that a number of us feel that the EDE should actually restrict -- ADA should actually restrict the way state programs work with respect to people with psychiatric disability and not allow rights to be taken away in circumstances when others have rights unless the person shows themselves to be a direct threat to himself or others based on objective facts. And that is something that is not followed much of anywhere, and the dominant forces in Washington, both in the administration and in Congress, have been working on further eroding rights with psychiatric disabilities rather than adding new rights. So that's one that has not risen to the top of lists. Personally, I don't think it's a bad idea and something that if there's a strong base of support within APRIL or NCIL that maybe our organizations could be working on.

>> SeRONNA RODGERS: I agree. It is a very important legislation. It's very important that we fight for that. I agree.

>> MIKE BACHHUBER: Traditionally issues of legal capacity have been defined under state law, and so the limits on that have been the area where the federal government either through the ADA or constitutional decisions by courts have gotten involved. There are a number of states where courts have looked at advance directives and specifically and said that they are valid within the mental health context. There are other states that have refused to follow advance directives. And then there are still a number of states where that issue has not been expressly decided one way or the other. I think I also wanted to respond to the point to ECT, which is a very good illustrative of a lot of what goes on in -- as medical treatment for people with psychiatric disabilities. When you look at anecdotal evidence, there are plenty of people, both doctors and consumers, who feel that ECT, and for those who don't know, that's an abbreviation for electroconvulsive therapy, or what used to be called electroshock treatment, where a person usually gets tied down to a gurney, has a rubber tube put in their mouth and electrodes attached to their heads and a large jolt of electricity is forced through their brain. There's been a study committee at the Food and Drug Administration that looked at whether ECT devices were a safe and effective treatment for a number of specific types of mental illness, and this was back in 2011, I believe, and made recommendations that the FDA require presale clearance. In other words, they would be forced to prove the safety and effectiveness of their machines. That recommendation has never been acted on by the FDA, but basically their panel of experts, a majority of their panel of experts voted that after looking at all of the research on both safety of the machines and effectiveness of the treatment that it was not -- it was neither safe nor effective, there are many side effects from ECT, including loss of memory, which is almost certain, and that the only area that they got a majority to say was not -- the majority said it was effective but it required a super majority in order to actually have a recommendation other than the presale clearance. So they got a majority of their panel to say that it was -- it was effective as a treatment for depression that was so severe no other treatment was effective. But for most use, for 90% of what ECT is used, the panel said it's not effective. And even in that one area, it didn't get the super majority it would have needed to find it safe and effective. But ECT is not only used across the country despite the lack of evidence on safety and effectiveness, but oftentimes it's used as a court-ordered treatment where courts will order someone to have ECT despite the fact that it is not safe and not effective.

>> MARY OLSON: Thanks, Mike. I have one more question for you guys if you don't mind. I'll go ahead and your mic should be live. Do you have a question, caller?

>> PARTICIPANT: This is Maya. Hello?

>> MIKE BACHHUBER: Hey.

>> PARTICIPANT: We are a rural area in Georgia, recently, couple years ago, our state closed the mental hospital. It was closed with really no supports in the community in place to speak of. So we are -- we're dealing with a very increased number of people

with severe psychiatric disorders and I use that term not lightly. I'm trying to figure out what we can do, because we have people with paranoid schizophrenia, you name it, and I realize these are the types of disorders that are not as common as panic attacks and anxiety attacks, et cetera, but they're very real and very tough to deal with, and we are not professionally equipped to deal with that, but there's nowhere for us to really refer people to go to. So what kind of support can we offer to this population?

>> MIKE BACHHUBER: I think one thing that's important to recognize is that there has been a lot of deinstitutionalization in the last half century. Usually states have not taken the money that they used to keep people in so-called hospitals and put it into a community treatment system. Usually the money goes back into the state coffers and is used for highways and whatever else they need. Therein lies the problem, is people who are used to not making decisions about their life and having to live in an institutionalized manner are put out on the streets, and there's not really access to treatment. That being said, one of the most promising things we can do is based on peer support, and oftentimes we're dealing with people who can become agitated and do experience reality differently than you or I might. One answer is a program called ECPR. It's emotional connection empowerment, and I can't remember the R. It's recovery or something like that. This, like a lot of peer support is based heavily on listening to and connecting to, engaging with a person, and it does tend to defuse a lot of the media issues so that we can have a real conversation with people about housing, transportation, kind of getting into some kind of treatment. And so despite the negative words I've said about ECT, or hospitalization, I do believe that different kinds of treatment can be effective for different people, but it tends to have to get outside of the medical framework because a lot of times people have had very negative experiences in hospitals or with psychiatrists and engaging, and just kind of as an aside, once a person has lived with -- has lived through more than one episode that gets diagnosed -- they have to have more than one episode to get diagnosed with schizophrenia, and -- however, the studies do show that people who do get some social support and recover to the point of functioning in everyday life -- so some of you may have seen the movie "A Beautiful Mind" about -- I can't remember the name of the mathematician.

>> SERONNA RODGERS: John Nash.

>> MIKE BACHHUBER: There you go. One of the things that didn't -- was kind of glossed over and misrepresented in that movie is he was not able to recover his life and functioning until after he stopped taking medication, and there is a substantial body of research showing that people who are not on medication are more likely to recover functioning than people who are taking medication, or schizophrenia, specifically, but also for other conditions.

So you may have something to say that may or may not be different than what I just said.

>> SeRONNA RODGERS: No, I agree. The thing that I keep going back to is media -- first off, the mental health system that I know in Arkansas, mental health systems are not great. Every county should have a community mental health center that you can refer someone to, but it's hard to refer someone to a place where you know that they're going to be treated less than. So our system -- maybe other states have better mental health systems than this state, but what we've been talking about is how people with mental health issues are portrayed, like Mike was talking about the movie "a Beautiful Mind," and even as -- even as -- it was a movie that was -- had a better portrayal and more accuracy to it than, you know, the "One Flew Over the Cuckoo's Nest" the way our society is educated, unfortunately on mental health issues is the media, and it is things you see on TV, which are so off what life really is like. I mean, it's hard to tell someone that they should disclose that they have a mental health issue when society as a whole looks at you like, "Oh, this person could go postal at any time." Using that term -- the world views people with mental health issues a lot differently than they view other people because of the lack of scientific evidence and because of all these different factors. So it's hard to -- you want to do -- you want to do whatever you can, and our systems are so broken that there's not a lot of -- that's why our jails are filled up with people who haven't committed a crime but they have some type of psychiatric disability, but like Mike said, rights are being taken away. You know, if you think this person is a danger to themselves or someone else and you know how to prove it, you can have them involuntarily committed. I mean, it's just a broken system that we need to fix, and I don't know what CILs can do other than provide peer support and, you know -- I know mental health parity has come and gone but -- I don't know -- there is a lack of services. There's a lack of understanding. So it's a big problem. I -- it goes beyond CILs, but what we can do is talk to the individual and find out what they need. I think just listening is sometimes something that not everybody has support systems, don't require a hospital or a psychiatrist's office. So listening to individuals. Sometimes people just need to be heard, and allowing a person to say whatever they need to say is a very valuable thing to be heard.

>> MIKE BACHHUBER: And I think this is one of the areas where the coping skills do come into play, that there are coping skills that can be taught, even to help people with schizophrenia or other similar types of severe psychiatric disability. What I have found is helpful is built around three things. One is listening, because I have found that almost everyone, even when they're agitated, if you actually listen to them to the point where they feel they're being heard, will calm down and you can have a decent conversation with them. The second is trust. So if someone thinks that if they start talking to you about so-called mental illness you're going to refer them to the local community health -- community mental health center that will take away their rights, they aren't going to trust you, if they find that to be a bad thing. So referrals can be appropriate but they should always be made with the consent of the consumer. And

the third issue that I find to be helpful, the third thing, is honesty, you know, that if someone's way of keeping their home, letting garbage build up or hoarding things or whatever, is interfering with their right to keep that home, you need to be honest with them, and you need to help them negotiate to find middle ground where they can be more answerable to social norms but still feel that they're in control of their own life and their own stuff.

>> MARY OLSON: Great. I have one more kind of follow-up. First off, I just wanted to say that Kathy Baker in Georgia wanted to let you know that she used to work at the hospital that Maya was talking about and that there aren't any community supports in place there.

Joe wants to let you know that part of the problem he thinks is that no one truly knows the chemistry and how to effectively and positively respect people that experience psychiatric issues. And then Joe followed up with a question. He's wondering, how do you know if you are negatively affecting the person if they tend to not fully communicate? I guess more, how do you make sure that you can fully open lines of communication?

>> MIKE BACHHUBER: So are you specifically talking about people who can't communicate because of psychiatric sim temps or just kind of more generally, I guess, would be the question, trying to figure out what the intent was. If you have an answer, great. If not, you know, communication as in so many areas of life is important, and if someone has difficulty communicating, either because of psychiatric issues or physical issues, you're obviously going to have -- and I should add in other mental issues -- or cognitive issues might be a better term, because people with disabilities like autism might have difficulty communicating for nonphysical, nonmental health reasons. Obviously that gets much more difficult. Some of the things that I've been talking about that are based on interaction aren't going to work if there isn't good communication. Frankly, having worked with people with various developmental disabilities who have been institutionalized at several points in my life, I know that issues that the healthcare practitioners have trouble with as well. I think that what I would tend to do is go back to the experts on that, which is people with disabilities that are impairing communication but who may be at a point where they can talk about it and try to work with some strategies, try to work out some strategies that way. SeRonna, do you ever any better ideas?

>> SeRONNA RODGERS: No, I think you pretty much touched on it when you were saying the three things that people are needing, is to be listened to, to be honest, and to gain that trust, and so with that, I mean, you know, I don't know a better answer than that, so I think you've already given a good one.

>> MARY OLSON: I'll stop interrupting you guys and let you go on. I know we could probably go on all day with just questions.

>> MIKE BACHHUBER: Yeah, they are great questions, and we know that these

questions and a lot more are common because we are dealing with people with a range of disabilities, and as we know, people with more severe disabilities oftentimes have more trouble living independently and need more supports, including social supports. The middle Section of the conversation that we wanted to go through was dealing with coping strategies. Do you have anything you want to add?

>> SeRONNA RODGERS: No, I think it's important for centers to understand psychiatric mental health issues and psychiatric disabilities and learn about those. But other than that, I think that we've pretty much touched on that.

>> MIKE BACHHUBER: So then we can probably move on to the last section, which is talking about more of the philosophical reasons for centers to be involved. Do you want to kick that one off?

>> SeRONNA RODGERS: Sure. I think we've already even touched on that as the lack of services for people with psychiatric disabilities is -- I mean, it's just little to nothing, and so we have to become involved because, you know, it strikes me funny that people think that mental health issues are separate and apart from any physical health issues in and you can't remove the head and just work with the body, or you can't just work with the head. It's all connected, and usually when there's -- not in all cases, but oftentimes a person with a physical disability is going to have some kind of mental health issue to deal with as a result of an accident or something to that nature or losing the ability to do something that they were able to do before. So it's everywhere that you look. I mean, mental health is -- you know, the statistics say one in four, but I think that it's probably higher than that. So if centers don't become involved, you know, then we're missing an entire population of individuals that are in the jail systems and in -- living under bridges, and to me that's unacceptable. You know, we have to do a better job at getting folks integrated into the community and try and advocate for a better system that will allow you to live independently without having your rights stripped away. And so I think that the more we can advocate on a systems level, that's a great thing, but at the same time, we also have to look at a one-on-one peer support level. So there's a lot of different reasons to -- for CILs to become involved, because you don't know -- like Mike was saying earlier, if someone doesn't disclose that to you, you may not know that the person sitting in your office with the physical disability is also dealing with some type of mental health issue. So it's very important for CILs to become involved because, you know, everywhere you turn you're going to find someone.

>> MIKE BACHHUBER: For me, I come back to, you look at people on Social Security disability or SSID, in the neighborhood of 30% have a primary diagnostic category related to mental illness. When you look at other data, people with severe disabilities of other type, physical or developmental disabilities, in the neighborhood of 50% also have significant emotional views that they're dealing with. So when we're talking about psychiatric disability -- when we're talking about a cross-disability community as

Centers for Independent Living, we have to include our brothers and sisters with psychiatric disabilities. If not, we are excluding a very significant part of our family. And then when you look at the kind of issues that people deal with, many, probably the overwhelming majority of the issues are the same kind of issues that we deal with other people with disabilities, people who can't get around and don't drive, people who are having trouble with housing, either finding appropriate housing or keeping their current housing situation. We also have very significant issues about access to appropriate care and services, and I think it's important to think about services for people with psychiatric disabilities, supportive services, just like we think about supportive services for people with other kinds of disabilities, having access to regular and ongoing peer support and skills training and various other people-to-people services have shown to be very effective for people even with the most significant psychiatric disabilities. And oftentimes that's requiring a level of support above and beyond that which a CIL has resources to offer unless they can find grants or governmental support to provide those level of services. So those are, I think, the most significant philosophical reasons. I think that there's also a growing realization on behalf of public mental health systems that there is a very significant role for peer support and for IL skills training and those kinds of things as an ongoing support service for people with psychiatric disabilities and so it may be an opportunity, depending upon what state you are in, to provide services on a fee-for-service basis, and I think it's important not to forget that, too. It's a reason above and beyond basic philosophical reasons, but something that is oftentimes very important, CILs getting money in so we can keep the door open and serve our brothers and sisters.

>> MARY OLSON: A couple questions, if you have time. Is that alright?

>> SeRONNA RODGERS: Sure.

>> MARY OLSON: So one question, what is your opinion on the clubhouse movement? I know there are about 300 worldwide.

>> SeRONNA RODGERS: The clubhouse movement? Mike, have you heard of that?

>> MIKE BACHHUBER: Sure. Clubhouses are organizations, sometimes consumer controlled and sometimes not consumer controlled, or less consumer controlled, that tend to focus on peer support and are very vocationally oriented. They're really looking at a measure of success that people can get and hold jobs. I think consumer control is an important factor. There's a clubhouse in Madison where I'm living that is controlled by our local mental health system, a giant nonprofit that is not consumer controlled, but some people still like to go to services. So I think that they can be a good addition to a spectrum of supportive services that should be available to people with psychiatric disabilities. They're not going to be for everybody, but they certainly can help some folks.

>> MARY OLSON: All right. We're coming up on the end here. We have about nine minutes left. Again, you know, if folks have questions, you can push star 2 to raise

your hand. I'll let you -- I'm sorry, I said I wasn't going to interrupt anymore, and then I did.

>> SeRONNA RODGERS: That's okay. I think we have time for questions. Go ahead.

>> MARY OLSON: Great. So we have one more -- or a couple more questions here. Go ahead. Your line should be live.

>> PARTICIPANT: I have a question, too.

>> MARY OLSON: Go for it.

>> PARTICIPANT: Okay. My name is Dolores Mason and I'm the Executive Director at an Independent Living center called Disabled Resource Center in Long Beach, California, and I know you had a long discussion on terminology for people with psychiatric disabilities and what to call them, and I got that, you know, that people like to have their name used or maybe the name of their particular disability rather than mental health, but you also said that you don't like the word "consumer" or you said someone said because you're not using a product for psychiatric disability, and I just wanted to add, and maybe you folks already know this, but department of rehabilitation, which we're under, they use the terminology "consumer." They used to use "client," and now it's "consumer," and therefore we have to use it. So I don't really like it either. It seems like nobody likes it, but we just -- we have to use it.

>> MIKE BACHHUBER: It's one of the disadvantages at times needing other people's money to do the work we want to do.

>> PARTICIPANT: I get that, too!

>> MIKE BACHHUBER: They sometimes impose conditions that we're not entirely comfortable with, and you have to decide how you can live with that.

>> PARTICIPANT: We just -- we have to, you know, but I just wanted to make that note -- let you know that some people are required to use terminology that they don't like, but I really appreciate the fact that we're getting so much more sensitive to using politically correct words for -- we have a course even here on right terminology for -- using for people with disabilities. It's a training course. And part of the material that we teach is disability etiquette right off the bat.

>> SeRONNA RODGERS: That's very important, I think, in any center, especially this center here, disability resource and advocacy center, is a brand-new center. So getting folks in that maybe people with disabilities or may not still being brand-new in working with others who have disabilities, it was important for me to make sure that everyone understood about different types of disabilities and how they come about so that when someone comes through the door they're not wondering, "How am I going to interact with this person, what do I say, what do I do?" The more that we educate ourselves on what types of disabilities people have that are going to come through our door, the better we're able to understand how to help them and understand some of the problems that they might have. So how to interact with people is very crucial. Disability etiquette is very important in our centers. So -- so that we're not offending

somebody. I mean, we're not going -- we're not going to have our doors open if we don't know how to interact. So disability etiquette is crucial. To me it's not so much about being politically correct, but as using common sense and making that person feel like they're valued just as much as anybody else.

>> PARTICIPANT: I was at an American public transportation association conference this month, which I am a member of, and we put on a workshop, and I wasn't one of the speakers, and it was part of it, and it was on the ADA, and one of the main speakers was a person, a wheelchair user, and they were talking about how to reach people, and says, "Ever since I've been in this chair and making these kinds of comments," and it just bothers you so much when you hear that now when you know the difference. But I thought how are people going to take us seriously when we don't take ourselves seriously. Like we're not putting -- we're thinking of ourselves as this person with a disability first instead of us as a person.

>> MIKE BACHHUBER: In this area the most common terminology uses mental illness, and mental illness describes a broad range of emotional distress, some of which is long term and severe enough to be considered a disability, some of which is merely episodic or mild in nature, and more so from the disability standpoint the entire term comes out of the medical model. So for this conversation, we've tried to use psychiatric disability to be here that we're talking about people with disabilities of a mental or emotional nature, but even "psychiatric disability" is a term that I think some of us not entirely comfortable with either.

>> PARTICIPANT: Right, right, because it sounds medical to me, too. But what else do we use? If you can think of something else, let me know because that's what I work with, that population every day, and I'm always looking at better ways to approach people and reach them. So...

>> SeRONNA RODGERS: I have -- if it has to be coined as -- with a label, I prefer to speak of mental health rather than mental illness mental health is taking care of all of -- we all have mental health that we have to take care of.

>> PARTICIPANT: That's good. I like that.

>> SeRONNA RODGERS: I generally refer to them as mental health issues or mental health experiences. Thank you so much for that.

>> PARTICIPANT: Thank you.

>> MARY OLSON: So we have --

>> MIKE BACHHUBER: How are we doing, Mary?

>> MARY OLSON: We have only like two more minutes left and I have two questions. Hopefully we can get through them quick. How does that sound?

>> SeRONNA RODGERS: Sounds great.

>> MARY OLSON: Caller, your line should be open if you have a question.

Oops, nope?

>> MIKE BACHHUBER: We lost someone.

>> MARY OLSON: Okay. I do have another back-up question. Kathy was asking -- let's see. A couple of things. First that I know IL and residential have been separate for a long time, and so there would be no shadow of a doubt that a person could live on their own. -- there would be no shadow of a doubt that a person could live on their own. Can the clubhouse movement be an effective IL tool?

>> MIKE BACHHUBER: Can you repeat that last part?

>> MARY OLSON: Yeah, she just says that IL and residential have been separate for a long time, so that there would be no shadow of a doubt that a person could live on their own. Can the clubhouse movement be an effective IL tool?

>> MIKE BACHHUBER: And again, most of the clubhouses in my experience are organized more along vocational supports. I suppose that a particular clubhouse might get involved with residential supports, and I think the answer is pretty much the same as what I gave earlier, which is some people might find that helpful, and if they do, I hope it's available to them. Not everyone -- it's not for everybody.

>> MARY OLSON: Well, I think, gosh, we're already out of time. Can you believe how fast that went?

>> SeRONNA RODGERS: Faster than I thought.

>> MARY OLSON: Yes. So I just want to let folks know that, again, this call is going -- is being recorded and will be available on our website probably by tomorrow. As well the transcripts will be available on our Web site. I don't know if -- if you have any parting words, Mike and SeRonna, or if folks have further questions or do you have resources you would like to send them to?

>> SeRONNA RODGERS: Ah --

>> MIKE BACHHUBER: This is a large area, and I think that there is -- there are a lot of negative attitudes in society about mental illness, or psychiatric disability, and the best weapon that we have to make lives better for people with disabilities who experience those kinds of emotions and related issues, the best thing we can do is talking to the consumers that come in, talking to each other, and providing a National Network of support, and I really hope that the information we shared today is helpful to the folks who got on the call.

>> SeRONNA RODGERS: I just want to say that I appreciate the opportunity to be involved in this, and anybody that would like to contact me or email me, please feel free to. I'm sure that that information is on your Web site as well, Mary, contact information, or do I need --

>> MARY OLSON: It's not, but I will go ahead and I can get it up there if you don't mind?

>> SeRONNA RODGERS: I don't mind a bit, and I would welcome anybody that has questions. I'd be happy to answer if folks have questions afterwards.

>> MIKE BACHHUBER: And I'd be happy to answer any inquiries that come my way as well.

>> MARY OLSON: Great, thank you both. I'll make sure your email addresses are up

on our Web site so folks can reach out to you. And as well, what organizations you work for. So thank you again for agreeing to give this great conversation, and thanks to everybody else who was able to join us.

>> SeRONNA RODGERS: And thank you, Mary, for all the hard work you did to put this on.

>> MARY OLSON: Thank you! Please don't forget to evaluate us on our Web site. Thanks, everyone. Thanks, Mike.

>> MIKE BACHHUBER: Thank you.