

Strategies for the Implementation of Disability-Competent Care
Understanding the Lived Experience of Disability
May 13th, 2015 - Transcript

Kevin: Ladies and gentlemen, thank you for standing by and welcome to your conference call today, the discussion of Strategies for the Implementation of Disability-Competent Care. At this time, all participants are in a listen-only mode. Later, we will conduct a question-and-answer session. Instructions will be given at that time. If you should require offline assistance, you may depress * and then 0. Your hosting speaker, Chris Duff. Please go ahead, sir.

Chris Duff: On behalf of The Lewin Group, I would like to welcome everyone to this second webinar roundtable session of the 2015 series. The session is titled, The Lived Experience of Disability. As Kevin stated, my name is Chris Duff and I am a Disability Practice and Policy Consultant working with The Lewin Group.

The Medicare and Medicaid Coordination office, commonly known as the Duals Office, as the centers for Medicare and Medicaid Services has contracted with Lewin to develop technical assistance and actionable tools to support providers in their efforts to deliver more integrated, coordinated care to Medicare and Medicaid enrollees.

First, I'd like to introduce you to our platform for this presentation. If your slides are not advancing, please push F5 on your computer keyboard. Please note the icons at the bottom of the screen. The second icon from the right allows you to download the slides for the presentation. The Q&A window is open next to your slides. Please enter any questions you may have regarding the material and we look forward to discussing them during the Q&A portion of the presentation.

Beyond this Q&A feature, to which you can submit questions and comments any time, we will be using instant polling to ask specific questions to help guide our presentation. To demonstrate the process, here's the first question. In what context do you interface with persons of disabilities? First choice is as a healthcare provider. Second is health plan staff members, third is a navigator or consumer advocate or other. Please make a choice and submit. We'll all see the results shortly.

This series consists of eight webinars running on Wednesdays at this time through June 24. All the webinars will be recorded and are available, along with a PDF of the slides at this link on the slide. In the 2013 -- in 2013, we published a comprehensive disability-competent care self-assessment tool describing disability-competent care in three pillars, the first being individual care coordination provided by an interdisciplinary care team; the second being redesigned primary care delivery; and third, flexible, long-term services and support. We have since provided two webinar series focuses on specific components of disability-competent care. These are also available at the websites that I mentioned previously.

Our previous webinars were more content-laden with little time available for discussion and Q&A. For this series, we're switching that around with only summary content being provided to allow for discussion if the participants are interested. We would like to also solicit your opinion

on this series, as well as past webinars and supplemental resources. Please take the time to complete our survey at the end of this webinar and send us your ideas for future topics and content. Contact information is listed at the end of this presentation.

Now I'd like to go back and review the results of the first polling question. It's interesting. Last week, we asked a very similar question and most everyone was a care coordinator and this time, most are going with the health plan. My guess it's a fairly comparable population, but that your role within the health plan is probably in a care coordination role. I'm glad to see there's so many navigators and consumer advocates, who are also participating with us.

Today's webinar will be presented by June Isaacson Kailes and Dennis Heaphy. June has been a presenter for many of our webinars in the past and is one of the authors of the disability-competent assessment tool of which I just spoke. She brings over 30 years as a disability educator and policy advocate.

Dennis Heaphy became disabled shortly after completing college. Following rehabilitation, he set out in Boston and received both a master's of divinity and a master's of public health from Boston University. In the resulting years, he has worked in a variety of policy and advocacy roles and is co-chair of the Advisory Committee for the One Care program, which is Massachusetts' dual-eligible demonstration for adults with disabilities. That program carries with it both the honor, and the challenge, of being the first dual-eligible program to go live under ACA's new demonstration mandate.

I'd like to note that Dennis interfaces with his computer by voice prompt, so if he says, "Go to sleep," he does not mean the audience.

The overarching premise of today's webinar is that the first step in achieving the triple aim is to understand the population you are serving and listen to their individual experiences. Persons living with disabilities are highly diverse and experience a wide range of barriers to accessing necessary care. Throughout the disability-competent model and these webinars, we have reflected a view of disability that's the consequence of an impairment that may be physical, cognitive, mental, sensory, emotional, developmental or some combination thereof. It is not based on a diagnosis, but an impairment of function. It may be present from birth, or there could be an onset during the person's lifetime.

To provide further context, I'd like to ask one more additional polling question at this point. Regarding your familiarity with disability, please choose one of the four below and feel free to actually choose more than one. This will give us the sense of kind of your experience with disability as a whole. While you're choosing that, I'm going to go ahead and turn this over to June and Dennis for their presentation.

June Isaacson Kailes: Okay, well, hello. I'm June Kailes and I'm going to approach understanding the lived disability experience by highlighting four practice competencies. One, being aware of and controlling your disability-related biases. Two, recognizing the complexities of living with disability and three, listening, learning and using information from participants and four, attend to details.

We will also share some personal stories and stories from the Disability Rights Education and Defense Fund healthcare video collection, which really eloquently illustrates the lived experience in healthcare. And by the way, we recommend that you consider using them as discussion facilitators in your staff meetings focusing on issues like what can be done to remove barriers and increase successful access to care.

Do we have the poll results ready regarding the familiarity with disability? Okay, here it is. So, interesting results. Almost 9%, they have a disability; 35-36% have a family member or close friend living with a disability; 73% have experienced working with people with disabilities and 14% have had minimal or no experience interacting with people with disabilities. So, thank you.

Let's continue and we'll try and get that important video to work. So, the first competency, like they talk about here in slide 8, is being aware of and controlling your disability-related biases. And this competency includes understanding the importance of engaging in self-reflection in order to heighten awareness of your disability-related beliefs, biases, prejudices, stereotypes and fears. Where do they come from and how can they affect your working effectively with people and how can you contain them so they don't interfere with your providing effective care?

Some examples. It's common for people to equate speech disability with intellectual disability and to equate a disability with a lesser quality of life. Denise Jacobson tells in one of the video stories, "A letter that accompanying the lab results that went to my doctor from the specialist of endocrinology and metabolism said, 'We saw this unfortunate 57-year-old woman in our office and my impression is she is far more intelligent than she looks to be.'" Fred [Nissan] in another video says, "That because of my speech disability, they assume they won't understand me, so they don't try and some people don't think I'm intelligent enough to communicate with just because of the way I talk."

And Larry Voss tells about, "The first surgeon I saw recommended a procedure which involves removing part of my pelvis and my entire leg because of the location of a tumor and when I expressed lots of concern about this, the doctor expressed his opinion that he didn't see why that would make a big deal to me since I wasn't walking anyway and was a wheelchair user. And you know, it just amazed me that he couldn't see all the other aspects of losing a major part of your body, all the effects that might have, even though you couldn't walk."

So, Dennis, I know you also have two stories. Want to go ahead and tell your stories?

Dennis Heaphy: Yes. The first story is a story -- I should let folks know that I've got a reputation for doing things that a lot of folks won't do and that includes in the area of dignity of risk. I'm a C4 quadriplegic and I grudgingly allowed myself to be admitted into the hospital emergency room one night. After a horrible night's sleep in an uncomfortable bed and being not positioned properly so that my bottom actually had pressure on it from being improperly turned, I told the nurse that I was going to be leaving the hospital AMA. I had already spoke to my personal care attendant and had my personal care attendant getting me dressed and ready to leave the hospital because as I told my doctor, if I stayed in the hospital, they would kill me and that I needed to go

home to people who knew how to care for me and how to actually directly serve me and I actually did end up leaving the hospital.

The second story is of my friend, Gail. As folks know, people with disabilities are often seen as asexual or nonsexual beings and my friend, Gail, went to the doctor and told the doctor that she wanted birth control and the doctor responded, "Why would you need birth control? You're blind." Hand this back to you, June.

June Isaacson Kailes: Yes, thanks, Dennis. I'm going to ask you to jump over to slide 14 for a moment and also, prompt you to be aware of how your communication messages relate to disability in terms of what you have to say and the kind of unintended messages that might get delivered. For example, a message like, "You'll never walk again," or, "You'll never work again. You'll never work again," versus, "You have to explore some alternatives that will allow you to continue to work." Or, another message, "You will always be an invalid," versus, "We will have to explore ways to use your strengths and skills to meet your goals."

Now on this slide 14, there's an array of other negative messages that were really said to people, believe it or not, people with disabilities. I also urge you to go back and listen to the Sandra Jensen and Tom [Strax] story that we covered in the September 10, 2013, webinar of the Lived Experience.

So, back to slide 9 now. Another competency is recognizing the complexity of living with disabilities. People with disabilities, of course, are a diverse group, varying in age, gender, sex, race, ethnicity, socioeconomic position, sexual orientation and type of functional limitation. There are very high numbers of people with disabilities in Medicaid and Medicare and dual pilot programs, but they're all well-represented by people enrolled in all other health plan product lines, as well.

To slide 10, this competency includes understanding that the lived experience is not about an exercise which artificially tries to simulate a disability experience for an hour by, for example, wearing a blindfold or using ear plugs or using a wheelchair. The lived experience in diversity and complexity of living with a disability is not easily duplicated or understood by those without a disability, so learning from participants is key.

So, on slide 11, makes the point the barriers need to be recognized, as does understanding that some individuals, when it comes to healthcare, may have experienced years of -- next slide -- frustration, fatigue, failure and fear and some of this, for some, has been translated into lack of care, delayed diagnosis and deteriorating health.

Skip on to slide 15, the next competency is really about listening, learning and using information from participants. This competency includes effective listening. Always ask and explore with people what has worked for them. Make no assumptions. Ask questions. Listen to, respect and incorporate their answers into your work. Appreciate and incorporate individuals' expertise that comes from the user experience. Many have sophisticated knowledge about their bodies and the most successful approaches and options for successful health management. Honor their specific insights and expertise.

So, a few examples. I urge you to go onto the DREDF healthcare stories site and listen to Alice Wong's story. She has a level of sophistication that many don't have, plus her story underscores the competency of listening to, and exploring options with participants that include appreciating their quality-of-life and dignity-of-risk issues.

Elizabeth [Grixby] is another video on that site and she reports, "that her hospital stay ended up to be five months in a hospital. They had to transfer me several times because I needed to go to x-ray, but then, nobody would listen to me about how you have to hold my legs. They came in and just pulled back the covers and started lifting. They were like, 'Oh, we do this every day. We know what we're doing. Oh, just relax and let us do our jobs,' and when they went to lift me, you heard this loud pop, my knee, and it's like my knee, which went one way, and the rest of my body spread over onto the gurney and I was in such excruciating pain, I felt so like I was being treated less than a human being."

So, Dennis, over to you, one more story?

Dennis Heaphy: Sure. I should tell folks before I tell this story -- it's actually about dental care -- that I'm a mouth stick user, which means I use a stick in my mouth to maneuver buttons on elevators, with a keyboard for my computer, light switches and things like that, so my teeth are extremely important to me and I received, for many years, my dental care from a dental school.

And a number of years ago, I was told by two dentists, actually professors, that I needed periodontal work, but unfortunately at that time, the student who was providing my dental care was graduating and so, I was being assigned another student. The student who I was assigned to was very open in providing the periodontal work, but his professor, in looking at me and looking at the wheelchair, said that it would not be worth doing the periodontal work because of the hassle of working on me in the wheelchair and so that because of my disability, it would be worth -- we should just wait until the periodontal condition became infected and got to the point where it became an urgent need and so, for me as a healthcare -- as a public health person -- I was horrified by that.

But also as a person with a disability, I became so alienated from the idea that they would not provide me with the periodontal work, that I did not go back to the dentist for years and as a result, I incurred even more problems with my teeth and now, I actually have a good dental program that I'm a part of, but now before I can get the periodontal work, I have several cavities that need to be dealt with first. And so, it could have been dealt with several years ago, have now been exacerbated because this professor did not want to treat me because of the hassle working on me because of the wheelchair.

June Isaacson Kailes: Thanks, Dennis. That really illustrates the issues of attitudes and biases, as well as lack of care, delayed diagnosis --

Dennis Heaphy: Right.

June Isaacson Kailes: -- and really deteriorating conditions, all making things much worse in the end. Well, one of my other stories that I tell is that I went for an annual mammogram to a place I've been going to for a long time and I was greeted by a new technician that I didn't know and so, I said to her, "You know, I'm not sure if you're aware of this, but we need two people to do this because I need help to get into those contorted positions and stay still long enough for you to get quality pictures," and the new technician said, "Oh, honey, I've been doing it for years. Let's do it my way," and I said, "Oh, honey, let's not. I've been doing it for years, too." Well, I know it's a real sophisticated response that probably years ago I wouldn't have had the guts to say, but in the end, the technician said, "You know, you were right. I'm glad you really kept to your guns and spoke up."

So, again, listening to the person, incorporating their expertise. Or similar to Elizabeth's story, you know, the common transfer battle stories, that go like this. "I know you're taught to transfer people that way, but trust me. For me, this is what is safe and effective." It's all about listening and respecting people's knowledge that comes from years of living with, and knowing what works.

So, lastly, attending to details is the last competency -- stay on slide 15 -- attending to details. Planning prevents poor performance and the competencies are knowing how to document accommodation needs, to really document what works, like for me, documenting what's the best way to accomplish a successful mammogram.

It's important to know these so they are accurately reflected what the individual's needs get equal and successful care and to document this so that the accommodations will be seen, understood and attended to by all those working with the individual and to also ensure that the notes are current and updated frequently by checking for changing needs with the participants. So, attention to detail is all about incorporating accessibility in the processes, procedures, protocols, policies, training, practice and of course, experience.

Accessibility is all about attention to the details. It's not just about installation. It's not just having the elements, flows and services in-place, like physical equipment and communication and navigational and coordination access. It's knowing when and how to use them and how to get them.

I was once in a clinic that complained that they didn't have a height-adjustable table, so I looked over there and guess what? They did have one. They just had never plugged it into the wall, so the equipment isn't helpful if you don't know how to use it, you know, where it is, and how to get the patient who need it to the right exam room. Attending to the details also means when you make referrals, anticipating needs and checking out that the needs can be met, such as participants being able to communicate, understand and use the information when needed, having access to interpreters and other auxiliary aid and services, including materials in alternate formats like large print, disk or audio and -- next slides, 16 and 17 -- and if the memory has mobility issues, it's about can they get to the site from public transportation, from a drop-off area, or from a parking lot which includes the ability to access accessible parking spaces and then, to get to and into the building and the clinic or office using an accessible path and to get to and use an accessible bathroom.

And slide 18, to get into an exam room and get on and off an exam table, sometimes with the needed transfer assistance and getting weighed. These are all some of the details that can be so critical to successful care.

So, in summary, to end, adopt a can-do, a can-do attitude and approach that incorporates working with participants of partners, flexibility and creative problem-solving and include these four competencies in your practice. Recognize the complexities of living with disability. Two, be aware of and control your disability-related biases. Three, listen, learn and use information from participants. And four, attend to the details. So, I'm going to stop here. Chris, back over to you.

Chris Duff: Thank you, June and Dennis. I appreciate your comments here. I've learned, behind the scenes, that actually the video of Alice Wong was working fine for everyone except for the few of us presenters, so we're going to go back. I'm going to ask the AT&T operator, Kevin, to go ahead and line that up again and we're going to actually show that video for the presenters. Just know that we're not going to be able to hear it and maybe not even be able to see it and then, we'll pick up with questions after we're done seeing the video.

[Video]

Speaker: DREPF healthcare stories. Alice Wong was interviewed at the Ed Roberts campus in Berkeley, California.

Alice Wong: My name is Alice Wong and I live in San Francisco and I'm a researcher. I guess my official medical diagnosis is spinal muscular atrophy type 2, which is a type of muscular dystrophy. When I was around 18, I started feeling really ill and what I didn't realize was that I had really severe sleep apnea, but I didn't realize it. And I got to the point where I was really, really sick and basically had respiratory failure.

So, I went into the ER really, really sick, really out of it and totally disoriented. Didn't know who I am, respiratory failure. And basically I was hospitalized and they absolutely wanted to intubate me and put me on a ventilator. Luckily I had the presence of mind to say, "No, I don't want that. I want to know what are my options and I want something non-invasive," and I'm really proud of myself for standing up for myself and saying that because I'm sure most patients would have been like, "This is an emergency situation. Do what you need to do."

So, they did say, "Well, you can use a BiPAP and let's see if we can stabilize you," and a BiPAP is just a kind of a non-invasive, ventilator support, it's like a mask they put to help you breathe instead of a tube. So, luckily that worked. I had to be in the ICU for about two weeks. I got better and stabilized and began to use the BiPAP at night to treat my sleep apnea and that's when I first started seeing a specialist, a pulmonologist, and what was really interesting is that in my appointments with him, he would say, "Well, you know, as you know, now you need the support at night. You might want to think about in the future, you know, your condition will progress. One day you probably will need 24-hour support," and I go, "Yeah." It dawned on me that this is obviously a sign that I'm getting weaker. This has never happened to me before, but this is a signifier that things are getting worse, yeah, okay.

So, then, he said, "You know, you should really think about getting a trach, a tracheotomy, and using a ventilator." He says, "I have many patients who use it. They are doing really well on it." And I was like, "Well, you know, I don't really need it now. I feel like I like using the BiPAP. I don't want to get too invasive," and this is what he said. He said, "Oh, is it an issue of vanity?" And I was like, "Vanity?" He's like, "Oh, yeah, I understand. You're a young woman. You might be concerned about how you look," and I was like, "That is the least thing I really cared about." I mean, I was concerned about infections. I was concerned about being dependent on a machine. I mean, what if the battery dies and to me, that's really frightening.

And I was trying to, you know, convey that these are my wishes; that in our conversations, in our long-range plan, I want him to know I'm the kind of patient that wants non-invasive measures as much as possible until I really need it and I feel like it didn't really reach him because, I guess, you know, why wouldn't a patient want an intervention, why wouldn't -- if he has other patients that do well on it, it may be hard for him to understand why a patient wouldn't want that.

So, that, to me, was interesting that there's intersection of gender where he thought it was a vanity issue and to me, that was totally like not on my mind at all and it really annoyed me and it got me really angry to think that he was kind of condescending and patronizing that way and not really hearing my valid concerns.

Chris Duff: Okay, I think we are finished now with the video. I hope people enjoyed it. What I'm going to do is push one more polling question and that is, having heard this presentation, what level of appreciation and competency do you think you and your organization have in terms of understanding the lived experience of disability? The reason we're asking this is so that it can guide us in development of future material or webinars or whatever format we hear from you would be best.

And would the operator please introduce and open up the phone lines for questions?

Kevin: Thank you and if you wish to ask a question, please press *, then, 0, on your touchtone phone at this time; * then 0.

Chris Duff: As a starting point, what we're going to do is go to some questions that were submitted on the Q&A. First one is actually one that I struggled with personally for many years and that is they stated, this is an awkward question, but what do I do if I simply can't understand what the individual is saying to me? I think I'd be interested in hearing both June and Dennis respond to that question.

June Isaacson Kailes: Okay, Chris. Well, I'll go first. You know, it's a common issue. There's a lot of anxiety that develops when you can't understand somebody. Sometimes we try to use humor and say that a CP accent, it's hard to understand. That's somebody with cerebral palsy. But there a lot of techniques that can be deployed. You know, one is just to be calm and get used to their speech. Be in a quiet area. The second one is to get another person in there to kind of help you understand. A third strategy is to just frankly say to the person, "You know, I'm having a lot

of difficulty understanding you and I know I need to and it's important. Is there anything, you know, we can do?"

And thirdly would be to, "Tell me, show me how you say yes." You know? "Can you wink or have fingers. Show me how you'll say no," just to develop some techniques or being able to point to pictures, all are things that, you know, in a pinch, can begin to help a bit, but also to make sure that, you know, a second appointment, or another appointment, that you allow for longer time and that you really use some problem-solving about what's going to facilitate the communication. Dennis, anything to add?

Dennis Heaphy: Sure. One of my best friends was completely nonverbal and communicated, actually, using his tongue, so it was an alphabet system when he would A, B, C or D, he would stick out his tongue. One of the persons speaking to him would provide the alphabet and I think for my friend, Jim, one of the biggest issues was that the person who was communicating with him felt that ease and comfortable with being imperfect and making Jim as comfortable as possible in the situation because as frustrating and uncomfortable as it is for the provider, it's also the same thing for the person who experiences, you know, the inability of having people understand him or her on a regular basis.

So, I think as much as you can feel comfortable and have a sense of humor about the situation, the easier it is for you to interact with the person who may be nonverbal, who you have difficulty communicating with. And again, as June said, it's really if you can't understand the question, invite somebody else in the conversation, but make sure that you're not speaking to the person who's helping in the communication process, but that you're speaking to the person who you're communicating with directly because the other person that matters the most and who you need to hear from. June?

Chris Duff: I actually agree with all those comments. Two kind of comparable. Dennis mentioned the tongue issue about pointing to the letters. I've, at times, created a letter board that's handwritten out letter boards and move my finger around and the person will acknowledge when I get to the right letter. So that's a kind of down-and-dirty thing, but it works.

Another thing -- and Dennis kind of referenced it also -- is there is one person who we work with who really had an attendant who really was the ticket to communicating with him and that was really important that we not communicate just through the attendant, but that attendant had been with this gentleman for 20-some years and they had it worked out and they were clear and that attendant would never allow us to communicate just with her.

But she, we actually would have her go into the hospital with him when he was in the hospital in order to communicate with the staff because he was just unable to get them to take the time to engage. So, I'm not trying to encourage people to avoid interaction with the person with the disability, but be creative and making sure that the communication does happen, I think is the important thing.

We now have a question from Victoria [Holcum.] Are there specific hospitals or healthcare facilities that specialize in providing special accommodations for people with disabilities? June, do you want to start with that?

June Isaacson Kailes: Sure. Can you repeat the first part of the question, Chris?

Chris Duff: Are there specific hospitals or health facilities that specialize --?

June Isaacson Kailes: You know, that probably depends on, you know, where you live. I think that the most important piece, since we're talking about a very diverse group here, is to really check out and be clear about what the individual's needs are and then, do the homework and the footwork to make sure that those needs can be accommodated. For example, in Dennis' story, you know, it's imperative that he have a certain kind of bed if he has to be in the hospital, and that he be turned a certain kind of way to avoid, you know, pressure sores that can make for awful complications.

So, to really check that out in multiple ways and keep reinforcing it before the appointment or the hospitalization, as well as during, so I guess it's all about, you know, planning is key and never assume, even a hospital that may say, "We specialize in this or that," you know. When you're seeing a person with a disability, whether it's -- no matter what the diagnostic label is, you've seen one. Everybody is different and so, we can never assume that two needs would be the same.

Chris Duff: You want to add to that, Dennis?

Dennis Heaphy: Yes. I guess I would ask if anyone knows a hospital that's got all these competencies, please let me know because I'd like to go there.

Chris Duff: Yeah.

Dennis Heaphy: But what I would say is that if there are doctors or other providers whom you trust that have best practices and they work at a hospital, that you ally with them in providing care to the person with the disability who's going to be hospitalized because there are best practices out there and learning what those best practices are, I think is one way to go, but also to work with providers who actually have the skills and background is another way.

Chris Duff: What I would add to what Dennis and June said is when I was building a health plan for people with disabilities, first thing we did is we asked the participants, "Where would you go? Where have you -- what providers do you believe best meet your needs?" Healthcare is to context-based that you really need -- you know, one urologist is one urologist. One hospital is one hospital. And so, our first step was always the consumers, peers of that person and what they said.

Another step was the staff who worked with those individuals. What was their observations and experience? What providers had the right beds? What providers respect the individual and so on?

That's also a very important piece. But I must remind you that it's really contextually-based within the community in which you live, so there is no one answer by any sense.

The other thing you need to look at is what is the unique needs of the individual. Is it an urgent care situation? Is it a skin surgery? Is it respiratory? Just as the rest of us, we need to have the right facility that's skilled in meeting those needs.

I can go onto another question, from Kimberly [Warset]. She asked, are there laws about having advocates available in the emergency rooms for people with disabilities? I'll take a first shot at that and that is that consumers can choose who they want in the emergency room with them. So, that's the first line that you need to start with. June or Dennis, have you had any experiences, or have heard of any experiences that have been inconsistent with that?

June Isaacson Kailes: I have not, but it relates to what we were just talking about. I mean, whenever you can, it's really good to have a support person with you who you've briefed in how to work with you as an advocate, either with you or on your behalf if you're unable to do so, who knows enough about you to communicate your needs, what's going on, you know, both in an emergency situation, as well as in a situation where you just talked about in a hospital. Things can go wrong and it's always good to have some support there with you. Dennis, want to add?

Dennis Heaphy: Yeah. I think sometimes in emergency departments, the question will be asked, "Are you a family member?" And in situations where we really need somebody to be an advocate for us, you know, it doesn't matter who that person is, as June and Chris have been saying. It's a matter that that's a person who can advocate, you know, with us and they don't need to be a family member. So, I think regulations like family members only can really be harmful to the therapeutic process or whatever the person's needs are.

I think also, to Kimberly's question, something we've not talked about in this presentation, is the needs of folks with behavioral health conditions who may have needs that go beyond just physical access. And we've not gone into that in this presentation and I think that's another topic we can talk about at another time, but it's also particularly important that folks, you know, with any sort of disability behavioral health need have access to the advocates they need to get the care, the appropriate care, there at the hospital or emergency department they need to get.

Chris Duff: Kevin, are there any questions on the phone line?

Kevin: Let's try Michelle [Netchen's] line and see if she has a question. Please go ahead, Michelle Netchen? Do you have a question? All right, no response from that line. Just a reminder --

Chris Duff: We might have waited too long, sorry.

Kevin: Just to remind other participants, if you do have a question, you can press *, then 0 at any time on your touchtone phone, *, then 0.

Chris Duff: Great. Why don't we just -- if you could put up the polls of the last question, the last polling question, for the responses while we are waiting?

Dennis Heaphy: Chris, can I interject something?

Chris Duff: Yes, please. Go ahead.

Dennis Heaphy: I think when we're talking about disability competency of care, it's also important to bring into this competency in providing -- bring ethnic and racial competency into this, as well, because not all people with disabilities are white, male or white female folks and there are folks in different ethnic populations that you need to have competency in Spanish and French Creole and other things, as well. And so, bring all those competencies together and provision services for all sorts of people with disabilities is really critical.

Chris Duff: Thanks, Dennis. I do want to acknowledge the results of the polling questions that I think is pretty phenomenal, actually, that a full third of the audience here feels that the organization you work in has a great deal of competency in understanding the lived experiences of disability and a full 50% feel you need a little more, but that it's adequate. I'm absolutely thrilled. I'm convinced that five years ago, it would be a totally different story, so I'm actually heartened to see that response.

I'm going to go do another question that was submitted and this is from the -- I know people who have dealt with for years. There are times when -- and I believe this is coming from someone who works with a health plan. There are times when the individual is asking for something that is not in the benefits that we provide, but that could be beneficial to the participant. For example, for somebody living with MS asking for an air conditioner. What can I do in these situations? June, do you thoughts first?

June Isaacson Kailes: Dennis, I'm going to let you go first this time.

Chris Duff: Dennis?

Dennis Heaphy: Yeah. Long-term service and supports should be seen as opportunities to provide healthcare to folks that goes beyond medical care and if we limit LTSS to just a laundry list of helping folks with their activities of daily living and don't realize that people live in a larger context, then we're actually going to increase hospital costs and emergency department visits. I can tell you for myself, that I don't have control over my own internal thermostat and that without an air conditioner, I overheat and so I need that.

And so, I think it is critically important that healthcare plans, when they look at benefits, that they actually provide person-centered care and allow the individual and the provider to define what the person needs, rather than the plan benefit package. And so, it's really about person-centered care and I can tell you for myself, as well, that I needed a coughing machine because I'd been in bed for awhile to enable to assist me with coughing. The benefit package did not allow for a coughing machine within it because I didn't meet the criteria. However, the plan I'm a member of enabled me to get that coughing machine because the provider indicated that it was

important for me and my health. And so, I think it's a matter of being flexible with what the benefit packages look like and thinking more about what the person needs, rather than what the plan deems as just within a defined set of parameters.

Chris Duff: June, any comments?

June Isaacson Kailes: I would just add that often when you look at the big picture, there is an overall direct connect, you know, with health and with independence and with quality-of-life, but also with one's emotional and mental health, which can again, is a direct connect to someone's health. So, I think whether it's, you know, an air conditioner or whether it's something that allows the independent use of a leg pad or whether it allows for greater mobility, both inside the home and outside in the community, there are multiple direct connects to one's health that go far beyond what might be listed in a definitive list of benefits. So, again, creativity and the flexibility and the investment and the return on the investment and looking at that more broadly, again, in terms of the return, I think is critical.

Dennis Heaphy: A good example of that, June, would be non-medical transportation and that there are many folks who are isolated and because of that isolation, are experiencing secondary depression and other conditions that could be actually reduced if a plan would provide non-medical transportation for the person, let's say, to go their faith community once a week, or to see their family if the family is not able to see them, like an elderly parent or other relative or someone else with a disability. The impact of the ability to be no longer isolated itself would be of tremendous benefit and so, the opportunity to have that non-medical transportation is something, as you said, might return a lot for the plan, as well as the individual.

June Isaacson Kailes: Absolutely, thanks.

Chris Duff: Great point. Great point. I'm going to take one more question, but first I'm going to call your attention to the link to the webinar participants survey. We would very much appreciate everyone taking a minute to answer the few questions in that survey.

I'm going to ask one last question and it's again, from Victoria Holcum. Excuse me if I mispronounced your name. Are there support groups that healthcare people can attend to learn and actually observe techniques for how to work with people who have extreme disabilities or hear their health challenges first-hand? I'll give two answers and I'll ask the others to give their thoughts.

One is the DREDF website that we mentioned earlier. I believe that's in the resources at the end of the slide set. They have health stories that probably 15 or 20 of them, which are basically people like Alice Wong who are sitting there talking about their experience. They're all really interesting and I think they address a lot of what you're looking for.

The other thing I would consider -- yes, on this slide, the DREDF one is the last bullet point there. Another idea would be to call your local center for independent living. Not every community has one and not every community has been able to do this, but that would be a good starting point to ask them about what resources would be available because again, you need to

listen locally because things change so much from one community to another. Dennis or June, any responses?

Dennis Heaphy: Yeah, I think recovery learning communities, as well, for folks from the mental health community is really important.

June Isaacson Kailes: And a quick thought from here. In training, I've been with a lot of health plans. There are seasoned staff people, seasoned people within plans that are great at some of this and just using some of your in-staff resources can sometimes be quite helpful and sometimes they're overlooked as really subject-matter experts because I've been around doing this a long time. Back to you, Chris.

Chris Duff: Thank you both. I'm afraid I'm going to have to wrap this up now. We've reached the end of our time today. There are few questions we received that we were unable to answer and we will make sure that they are answered offline by the presenters.

Next week at this time, we will be discussing the integration of behavioral health competency within primary care. Everyone who signed up for this webinar will receive notice of all future webinars, tools and other resources we are able to provide. I would like to again thank our speakers, Dennis and June, for their presentation today and we look forward to continuing of these presentations over the coming year in order to support the demonstrations that are going live across the country. Thank you very much.

Kevin: Thank you. Ladies and gentlemen, that does conclude your conference. We thank you for joining while using AT&T Executive Teleconference. You may now disconnect.