

The Lewin Group
Disability-Competent Access
February 22, 2017
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Christopher Duff: I appreciate the introduction. Thanks for joining today's presentation. Virginia referenced the chat function for questions. Technical questions will be addressed as they come in, and content questions will be addressed at the end of the presentation. If you would like to download the slides, please use the icon on the top right of the screen. Additionally, live closed captioning is available at the bottom of the screen.

My name is Chris Duff, and I am a Disability Practice and Policy Consultant who has been working with The Lewin Group to come up with the Disability-Competent Care webinars and materials. I will be joined today by another coauthor of the Disability-Competent Care model, June Kailes. June consults on the integration of inclusive procedure and protocols for many health plans and medical centers. June is also the Associate Director for the Harris Family Center for Disability and Health Policy at Western University of Health Sciences, California. Most of June's work has focused on building critical, actionable, disability-practice competencies in healthcare and emergency management in order to deliver equally effective services to people with disabilities and others with access and functional needs.

On behalf of The Lewin Group, I would like to welcome you to our Disability-Competent Care webinar series. The Medicare and Medicaid Coordination Office at the Centers for Medicare and Medicaid Services has contracted with Lewin to develop technical assistance and actionable tools to support providers in their effort to deliver more integrated, coordinated care to Medicare and Medicaid enrollees. This series will consist of seven webinars running on Wednesdays at this time through March 22nd. All of the webinars are recorded and available along with slides at the Resources for Integrated Care website.

In 2013, we published a comprehensive Disability-Competent Care Self-Assessment tool describing Disability-Competent Care and has since produced 25 webinars on the topic along with numerous supporting tools and documents. These are also available on the RIC website. The DCC material has recently been revised to be more accessible to users and reflect the further development of the field. It is now structured into seven pillars of disability-competent care. In this series, we are introducing the seven pillars with a webinar dedicated to each. We will be allowing at least 15 minutes at the end of each presentation for discussion and questions. As you can see on this slide, today's presentation is on the third pillar: access. We would like to solicit your opinion on this series as well as past webinars and supplemental resources. Please take the time to complete our survey at end of this webinar and send us your ideas for future topics and content. Contact information is listed at the end of this presentation.

Today, we will focus on access from multiple perspectives. The Disability-Competent Care model focuses not on the disability, per se, but on the functional limitations that result from the disability with the goal of maintaining or achieving health and obtaining healthcare services necessary to address access to a barrier to care. The DCC model describes access barriers in five groups: internalize attitudes and biases, accommodation, physical accessibility, communication access and programmatic access. Some of them are fairly concrete such as physical and communicational accessibility. Some require personal reflection such as attitudes and biases, and others require an understanding of the health and social services in your community such as programmatic access. Access in the broader sense is perhaps the

greatest problem faced by people with disabilities in their attempt to achieve health and healthcare services.

Research has repeatedly shown that persons with disabilities experience a range of health disparity and most all of them are related to issues of access. The result is adequate care and poor outcomes. For example, persons with disabilities commonly experience difficulties or delays in receiving necessary care and they fall short in targets for rates of important screening tests.

Due to difficulties obtaining primary care services and their reliance on specialists, their preventive care is often neglected. Many have not had dental care and do not routinely receive relevant sexual health information. Even something as basic as hypertension is not identified at the same rate as the broader population.

There is also a variety of social factors impacting health status and outcomes. Many people with disabilities rely on Medicare and Medicaid for their healthcare services. For example, Medicaid is income-tested meaning the recipients are living on a very limited income, and thus, are financially challenged. These programs are going through extensive research moving from fee-for-service to value-based purchasing. As the payers are beginning to focus on outcome measures such as cancer screenings, vaccinations, and diabetes management, the clinical interventions are straightforward. However, communications and service delivery stretch the disability competence of most providers. Of course, many of these are directly related to access issues June will discuss shortly. Add to that the financial eligibility, transportation, and other challenges, it is no wonder they experience poor outcomes. For many providers and plans, improving outcomes for people with disabilities will have a direct impact on revenue. At this point, I will hand the presentation over to June.

June Kailes: Thank you, Chris. I'm sitting here in Southern California and the sun actually came out! It's typically been raining here nonstop, so it's nice to see the sun.

First I want to give you the visual since you won't have it. I dressed up on your behalf today; no Friday casual. I am not sitting here wearing my sweats. Before I cover slide 10, I want to sum up the content of the webinar today by saying I'm going to talk about attitudes, about asking, and about attending to physical equipment, programmatic, and communication access. I abbreviate that; it's three A's to PEPC. PEPC standing for physical equipment, programmatic, and communication access.

I will cover the three competencies of being aware of and controlling your disability related biases. That's attitudes. Second, is asking, listening, learning, and respecting and using information from participants, and thirdly, attention to detail.

Building and making these AAA competencies into your culture and systems takes strong and sustained attention to apply practices, programs, procedures, protocols, trainings, and audits. The goal is hard-wiring these actionable practice competencies to reduce the disparities that Chris talked about. People with disabilities have higher incidents of obesity, smoking, and physical inactivity. They are three times more likely to have heart disease, stroke, diabetes, and cancer than adults without disabilities. Nearly half of all adults with disabilities get no aerobic activity. Adults who do not get aerobic activity are 50% more likely to have these chronic conditions.

Taking in these competencies reduces other costly barriers as well. These barriers include appointment failures and sub-standard and unequal treatment as well as adverse events. On a more positive note, making these competencies actionable achieves equitable and effective care and includes offering any of the needed services and accommodations. That results in improved health. Folks tell me: “Hey, June, this content is just common sense.” I say: “You know, yes, it is, but there is a gap between common sense and implementation.” Moving that needle is wide and deep.

I know it can be hard to not see us speakers. I am going to try to keep you busy, so you do not get sucked in by that unanswered e-mail. Start a running list of your next actions based on what you hear, and how it relates to what works, what doesn't work, and what needs work in your area of practice. Take a moment to list some of the compliance drivers behind PEPC (physical equipment, programmatic, and communication access). I've got six items on my list. How many did you get?

First is the American with Disabilities Act. Despite over a quarter of a century since its passage and also over a half century since the passage of Section 504 of the Rehabilitation Act of 1973, compliance is far from achieved. Additional compliance drivers include aid in federal contracts, CMS regulations, performance and quality measures, and increasing illegal activity focused on PEPC. I don't use disability etiquette, sensitivity, or awareness since it is rather soft as far as weight when we talk about the actionable disability-practice access competencies.

Attitudes are the most silent and impactful barrier in terms of the first competency. Take a moment to think about your experience with customer service with an attitude. List the words that describe that experience. When I ask people to do this, people give me words like maddening, frustrating, condescending, dismissive, defeat, being exhausted by a nonresponsive system. That's what it is like for some people with disabilities to encounter attitudinal barriers in healthcare. It might be more nuance and it might be more subtle. On slide 11, this attitude competency involves engaging in your own self-reflection regarding your beliefs of stereotypes and fears. Where do they come from? Are their messages you get from your culture or messages you got growing up about disability? How do you contain the negative ones, so they do not leak out and interfere with you providing effective care?

On slide 12 are examples of real people stories. I did not make any of them up. The attitudes are that if you can't stand, walk, stay still or hear, then we can not do this or we can just skip the test or the exercise or nutrition class. We assume you are not a sexual person, so we can skip the birth control, HIV and STD discussion.

We get attitudes such as you smoke, you eat too much, drink, you are depressed, but if I were you, I would do that too. Another example, “this is an ambulatory clinic. You can't walk, so we cannot help you here.” It is common to equate disability with a lesser quality of life.

I need to remind you that if you are on the phone, you need to turn on your computer to hear the video that we are going to play. If you are not able to do that, you can catch it on the RIC website because all of these webinars will be archived. Go ahead, Chris, with the video.

Denise Sherer Jacobson (video): I have had cerebral palsy, and I've had it all my life. I am a writer and

disability educator and I am married and have an adult son who's 25.

June Kailes: Denise is another interesting story. She saw a specialist, and the specialist gave her a letter to take back to her primary care provider. She opened and read the letter before giving it to her PCP. It read like this: "We saw this unfortunate 57-year-old woman in our office. My impression is she is far more intelligent than she looks to be." You can hear a lot more of Denise's interview if you go to <https://dredf.org/healthcare-stories/2013/02/19/denise-sherer-jacobson/>. There are a lot of great stories on that website done by DREDF, and they are excellent glimpses into her experience and the real life experience of others with disabilities.

Fred also said because of his speech disability, they always assume they will not understand me, so they do not even try. Some people do not think I am intelligent enough to communicate with just because of the way I talk. It's all about attitude. Gayle went to her doctors and explained that she needed birth control, and the doctors said to her: "Why would you need birth control? You're blind."

To keep you busy here, create a list with two columns. In the first column, write the words that describe the message, and in the second column, write down the words that describe the second message. The first message: you will never be able to walk again. The second message: you will have to explore alternatives that will allow you to continue to work. Another message: you will always be an invalid versus you will have to explore new ways to use your strength and skills to meet your goals. The last message for those talking to a parent about your partner or child: you will have to take care of them versus together you can explore new ways to maximize their independence.

The first set communicates no hope, it's over, you're washed up, there are no options and you're unable. The second set indicates hope, encouragement, options and does not assume a lesser quality of life because of a disability.

As slide nine read, stereotypes are based on assumptions that run deep in our culture. They are so deep that they can slip by unnoticed unless our awareness is continually sharpened and refined.

I think it's important to self-reflect or to acknowledge any biases that are negative. These biases do not go away. Stereotypes are inevitable. For me, it's about white men with southern accents. Do not ask me where that came from, but that is one of my strongest stereotypes that I have to keep in check and contained. We have to analyze our biases, so that these negative ones do not leak out and cause us to assume things like health, wellness, and disability cannot coexist.

Another expression of underlying bias are images chosen from marketing content. Take a moment to think about pictures and images that promote your services, your plan, your clinic and your hospital. I frequently see images of isolated, depressed people with disabilities being cared for or being poorly portrayed by actors or models. In the disability sub-culture, we use code words and we call these folks fake gimps. We can easily spot them. Stronger images without biases are real people with disabilities who are active and engage socially with others such as partying with friends, singing in choir, parenting, or participating in an inclusive exercise class where some sit, some stand and some use interpreters).

Slide 14 talks about understanding accommodation needs. This means asking, which is honoring and

respecting the lived disability experience. This includes the details, the diversity, and nuances of living with a disability that cannot be duplicated or thoroughly understood unless one integrates the practice of asking, listening, learning, respecting and incorporating information learned from people. It is a critical healthcare competency, and it is use of insider information that you won't get arrested for. Insider information is vital. It is a vital source of knowledge for understanding accommodations needed. It gives depth to the meaning of an important disability tenant which is, you've seen one person with a disability then you have just seen one. It is understanding that disability is not about doing an exercise that artificially tries to simulate a disability in a time limited experience like wearing a blindfold or using a wheelchair. Asking competencies means effective listening and always asking what works for you. Do not make assumptions, and always ask if you can assist them and waiting for an answer. If it is yes, then follow up by asking: "How can I assist you?" Many of us have sophisticated knowledge about our bodies and the most successful approaches and options for our healthcare management.

My favorite story is when I went for a mammogram to a place I was going to for years, and there was a new technician. We need two technicians to get good pictures for me. The technician said: "Oh honey, I've been doing it for years. Let's do it my way." I said to her: "I've been doing it for years too. Let's do it my way." After a brief pause, she listened. I know that is a real sophisticated response on my part, and took years for me to have the guts to say, but in the end, the technician said: "No, you're right. I am glad you spoke up and kept your mind set." Real stories are also covered in a webinar we did in May 2015 called *Understanding the Lived Experience of Disability* (https://resourcesforintegratedcare.com/physical_disabilities/disability_competent_care/webinar/webinar2/lived_experience/2015).

On Slide 15 is the third competency: attending to the details of accommodation needs. Once the need is established, it should be recorded, referred to, and updated, but how do we know what someone needs? It is critical to ask everyone. A routine question I use is: "Will you need any assistance with getting on and off the table or other equipment, walking, seeing, reading, filling out forms, communicating, speaking during your appointment, or will you need an interpreter. I just want to make sure that all of this information is still correct." This is information that needs to be recorded in a consistent place and referred to before and during appointments and updated. The details have to be probed if someone says yes either by the receptionist or by a callback from a staff member. One resource for you is questions to ask for identifying communication and accommodation needs. Those illustrate some of the probes underneath the questions and put that in the chat box that resource (<http://www.jik.com/pubs/VerifyingNeeds.doc>).

Slide 19 is about physical access. Physical access is probably the best to understand but not necessarily communicated or available and not always known to member services, care managers, case coordinators, social workers or others. They need to be able to communicate accurate information about provider's accessibility when asked.

Slide 20 talks about physical access and how it has to be a part of evaluating network adequacy, so that members are not confronted with insurmountable barriers leading to appointment failures. That means passive travel barriers. These might as well be the Great Wall of China for people with mobility disabilities. Examples include buckling sidewalks, one missing or unsafe curb ramp, lack of accessible parking spaces, and waiting areas or bathrooms that are too small to accommodate mobility devices or to

navigate in.

The call to an office clerk who may not understand the meaning or details of vague questions such as is your office wheelchair accessible contributes to the risk of appointment failure. Better practice is the use of consistent and accurate information derived by using a detailed well-constructed survey that is tested.

One example is the one that we did in California

(<http://www.dhcs.ca.gov/formsandpubs/Documents/MMCDAPsandPolicyLetters/PL2012/PL12-006.pdf>)

Slide 22 is better labeled as accessible medical equipment, which is also a form of physical accessibility. Height adjustable chairs and tables, along with dependent or assisted transfers, make it safer for participants and staff. Accessible wheelchairs located with other vital equipment is important for getting accurate weight. It is a critical part for the standard of care for many visits and being told to guess your weight is unequal or inadequate care or being told we will examine you in your wheelchair is also inadequate care.

Slide 23 is about communication access. That is about using information and providing aids and services. Communication access is probably one of the least understood and where the greatest mistakes are made. Communication access means providing content in methods that are understandable and useful by people with reduced or no ability to speak, see, hear or limitations in learning or understanding. This includes people with cognitive and intellectual disabilities and people with limited language proficiency. Communication access takes many forms and formats such as audio, digital, large print, pictures, model, braille, readers, writers, computer assistive real time captions (CART), accessible websites, and good procurement contracts that make sure that material is always available in those formats.

It is an unrecognized large group of the population that benefits when content is offered in formats other than standard print. Almost everybody benefits from pictures and models. Audio format helps many people with moving, seeing, and learning with language limitations.

Slide 26 is about programmatic access to services. It is needed by some to be able to benefit from the physical communication and equipment access. For example, transfer on to and off of a height adjustable medical equipment is safer for all though some still need transfer assistance. However, lift training does not exist in many places. Hence, we hear: "We will examine you in your chair." This is unequal treatment.

A woman explained in a focus group about delayed visits to doctors' offices because it takes a village to get her on and off the exam table. That means she does not go for preventive care appointments.

Other types of programmatic access/assistance include longer appointments to accommodate people who need more time to speak, ask questions and understand answers or to use interpreters or CART. Program access includes sending forms out ahead of time or reading and filling them out at an appointment as well as transportation assistance.

The goal with PEPC is to integrate these needs into practice. When making referrals for healthcare or community services, the needs are meant. The number of referrals are not failed attempts but successes.

The answers to the questions about needed assistance have to be highlighted in the record in a consistent and prominent place where they cannot be missed and are not buried in the electronic health records or missed because the user has alert fatigue. In the ethics system, the header comes up in a yellow header, so they will not be missed. I call these quality service accommodation alerts. They are referred to before and during appointments and are routinely updated.

Slide 29 is our Star Wars graphics. We work with many health plans, and find that the integration of accommodation needs across services is a huge problem primarily because data systems are built on a variety of incompatible platforms. This is a big problem that needs attention. For example, even though all of the Medicare plans in California have good data regarding physical accessibility of primary care, specialists, and ancillary healthcare providers, the staff (case coordinators, care managers, and others) cannot always access the information or it is not always provided in the provider directory or on a plan's website. Staff, in an attempt to do something, will reverse back to the inadequate practice of calling and getting inaccurate or uninformed answers.

Another aspect of this that needs attention is that current requirements remain silent regarding the integration of accessibility into network adequacy. This is a critical bridge to healthcare equity for a large slice of the population. For example, there may be 15 gynecologists in a prior network who are within the allowable time and distance requirements of a member who is a wheelchair user, but if none of these gynecologists have physical access to and through their facilities, height-adjustable exam tables, lifts or available trained personnel who are able to assist with transfers then none of the providers can provide the member with effective care. Should this not be a key element of network adequacies?

On slide 30, we have Anne. The objective of achieving successful referrals and navigation includes the integration of this accessibility, which means all players and staff need access to accurate information to help Anne take advantage of community services as well as healthcare services.

I am not known for my patience, and I want change to occur in nanoseconds but not in geologic or glacial time. I reluctantly learned that you and I have to be raging incrementalists to be real change agents.

On Slide 32, we go back to your next action list. What is on your list? This is multiple exposure material. To hard wire this culture and systems takes sustained and continued attention to those AAA and PEPC. The results mean that you will not have to scramble at last minute to meet known and documented needs. You will be able to offer accessible moves without unnecessarily disruptions, wait times or delays. It's part of that right stuff at the right time using the right delivery methods.

I will take the opportunity to list items for you that you may have on your list.

1. You can be an incremental improvement makers; use this content to look at what works, doesn't work and needs work in your area of practice.
2. You can assemble small work groups or learning groups to do a deeper guide.
3. You can thread this content into the places where these topics are or need to be discussed or need to be discussed.
4. You can integrate this content into your quality improvement discussions.
5. You can use your advisory group to probe and discuss what needs work.

6. You can use the DCCAT tool you heard about in this webinar series.
7. You can get feedback on integrating questions regarding PEPC in your member satisfaction survey.
8. You can use another tool called the competency planning checklist for providing healthcare for people with disabilities.
9. You can bring in trainers and consultants to help.
10. You have the opportunity now to ask us those challenging questions.

Back to you, Chris.

Christopher Duff: Thank you, June on a wonderful and very detailed presentation. I appreciate it. We are going to go to some questions. Before I do that, I want to clarify. People were asking about access to the previous webinars. The PowerPoint slides are available immediately. In fact, the slides for this presentation are available on the RIC website (https://www.resourcesforintegratedcare.com/DisabilityCompetentCare/2017_DCC_Webinar_Series/Access). The recording will take a week or two to access that. With that said, I have a couple of questions. Several questions have come forward.

First is, what is required of me, a health plan, in terms of the access of our provider network? I think it is unrealistic for all of our providers to be fully accessible.

June Kailes: It is unrealistic, but what is realistic is offering accurate information about which providers are accessible and factoring in network adequacy to make sure there are enough of different types of providers that can offer access. Some plans have addressed barriers when there have not been network adequacy and offered assistance when there have not been barrier removals. There are nice new models out there that are doing that. Back to you, Chris.

Christopher Duff: The California Survey of Primary Care Settings that was linked in the chat about 30 minutes ago is a great tool with a lot of diagrams and data on it that all health plans are expected to administer in all their primary care clinics every other year. They put it in their database, so member services and care management staff can have access to it and know which provider has what level of accessibility in terms whatever the issue may be. That is what we encourage plans to do. You cannot expect that providers will be 100% accessible, but the important thing is knowing who is and in what detail and making sure the member gets that information.

June Kailes: When we look at provider directories in California, we have the opportunity to know whether that is a provider I can use or not. We've got accessibility indicators listed in terms of parking, restroom, internal and external pathways, equipment and scales.

Christopher Duff: That is great. Of course, California is way ahead of us. They have been doing this for 15 years, but you have to start somewhere, and this is one place to start.

Another question: when I refer a member to a provider, is it my responsibility to communicate their accommodation needs or is it the provider's responsibility to identify? I do not want to be disrespectful of the member by doing it without their express permission or request.

I think they are concerned about being condescending and patronizing by speaking for a participant to a member.

June Kailes: Chris, I think the answer is yes and yes. I think it is never a mistake to repeat or reinforce the importance of accessibility both by the staff member making the referral as well as the member or participant. It is important that they know how to develop their own survival advocacy skills and ask for any needed accommodation, and that they not be complacent about thinking: "I told them when I called" but we found what really works is to tell them when you call, to remind them the day of your visit and remind them when you get there.

This is a survival skill set for people with disabilities, and it is a great coaching mechanism for staff to use with members in terms of teaching those survival skills.

Christopher Duff: Great. I want to thank Jennifer Valentine for putting in the chat function what they are doing in Oregon, which I think is great. If anyone wants to connect with Jennifer directly to find out what they are doing with their plan and what their expectations are, put that in an e-mail to one of the people on our last slide, and we will make sure to get that to her. I appreciate you doing that, Jennifer.

Another question: can you offer way to easily convert information to audio?

June Kailes: You mean audio format? Sometimes you need information converted quickly, such as when recommending someone get an emergency procedure such as a colonoscopy. Those are complex kinds of instructions. If you need them in audio and quickly, what do you do?

There are some easy things that we forget about such as if someone has a smartphone, you can read it into the recording device on their phone, or you can read these complex instructions into their voice mail. You may have to do it in part one, part two, part three, but it is doable. You cannot assume that people live with somebody that can always read things to them. Sometimes they do, but sometimes they don't.

I think it is important to not forget medication labels, which is a huge area of adverse events because they are not able to read the label. There is great new technology out there that translates the contents of medication labels into audio. You can affix labels to any type of container. There are good technology out there such as Google script talk. I am also working on a fact sheet related to other tips that might take a little more time.

Christopher Duff: Great, thank you. Thank you very much. I wanted to get to a question that came in over chat. I don't know if June or I will have an answer, but I will give it to June and see.

Are there any HIPPA concerns when leaving detailed instructions on voicemail? For example, they are leaving detailed information about a member's needs for an upcoming visit?

June Kailes: Well, I will take a stab at that. I think you're doing it with the member's permission, and sometimes you are doing it with the member right there, so they can actually to listen to what you are putting on their voice mail. It is all with the participant's permission. You are not giving diagnostic information. You are giving instructions as to how to prepare for a procedure. Chris, your turn?

Christopher Duff: I agree with what June is saying. When in doubt, if you are a provider or a plan, go to the compliance office and ask about internal practice. You are right to always be concerned about privacy, but I think there is a way to do this.

We are nearing the end. We have two minutes left, but I will give June one more question.

Can you give us an example of the probes you mentioned when asking if they need assistance?

June Kailes: Let's say someone says: "I need help walking." The probe would be "Will you be walking, using a wheelchair or scooter or what do you use? Will you need assistance being able to move from your scooter to the x-ray machine or the exam table or the diagnostic char? Will you need a hand or do you need lift equipment? Tell us specifically what you may need? Can you step up on to a scale?" You are probing those kinds of details.

Christopher Duff: All I would add to that is, the California Primary Care Site Survey and what is being done in Oregon will give you some of the details. For example, for getting up on a table, there is more to just having the exam room be accessible. Can the person get into the exam room? Are they going to need equipment to transfer? Just becoming familiar with those assessment tools will you help you become familiar with the kind of drilling down that you will need to do.

Even though we had another question come in, I think I need to wrap it up. I want to thank everyone for your questions. The last question that came in, we will try to send to June to see if she can follow up on it correctly with you.

We are going to wrap up the presentation now. Please send any feedback you have to the RIC e-mail address on this slide (RIC@Lewin.com). Additionally, please take time to answer the survey that you will see on your screen at the end of the webcast and will be e-mailed to you shortly.

Again, I would like to call your attention to the resources we have online at the Resources for Integrated Care website including the Disability-Competent Care Self-Assessment tool.

Please join us in one week from today for our fourth webinar, Disability-Competent Primary Care. The presenter will be Dr. Judith Chamberlain who is the Medicaid Director for Aetna. I would like to thank you for attending. Thank you.