

Event ID: 677906
Understanding the Lived Experience of Disability

Laura Dummit: Good afternoon. Welcome to everyone to the second in our series on Disability-Competent Care. I hope we have some participants from last week's webinar and some new folks as well. My name is Laura Dummit and I'm with the Lewin Group.

The first thing that I would like to do is to just point out some features of our technology. If you will look at the icons at the bottom of your screen -- well, first of all, this an icon if you are -- if the slides are not advancing on your computer, hit F5 and that will refresh and get things moving again.

We have an icon that is circled on the left of your screen that is where you go to write in question. You can ask questions about either the technology, if you can't hear, or if something isn't showing up, type in a question and then behind the scenes that will be answered. You can also at any time put in questions to the presenters. We are going to be compiling those questions and we will come back to them at the end. We would encourage everyone to put their question in as soon as they think about it.

And right there in the middle is a closed captioning icon. If you want to use that feature, you just click on the icon and the closed captioning will appear.

Now let me introduce this, as I said, second of three webinars that we will be presenting in September. The first, which was last week, was on Disability-Competent Care -- What Is It and Why Is It Important? Today you are listening to Understanding the Lived Experience of Disability. Next week we are presenting the third in the series, The Care Management Relationship. These are all scheduled to be 45 minutes in length and then we are reserving 15 minutes for question and answer. And while all three of these webinars are related, you do not necessarily need to listen to all three to understand the content of any one of the series.

I also want to point out at the bottom of this screen, and actually it's bottom of every one of the slides, the website www.resourcesforintegratedcare.com. All of these webinars will be archived there, and we also have several other products there on the website that we encourage you all to look at.

And, in fact I would like you all to know that these webinars and everything else that is presented on the website were developed under a contract with the Centers for Medicare and Medicaid Services, Medicare Medicaid Coordination Office. The Lewin Group along with the Institute for Healthcare Improvement have worked under contract with MMCO to develop tools and support for providers as they seek to integrate care for dual-eligible, that is people who are eligible from both Medicare and Medicaid. And this webinar series is one of those products under that contract.

What we would like from you today after this webinar is finished is your help. We know that there is a lot more that we could do to support providers under this contract, so we are seeking your ideas on topics, we are seeking your ideas on audiences, and your feedback on how we are

doing. At the end of this webinar, there will be a short survey. We would really appreciate it if you would fill that out and help us as we continue this work.

Now, I am going to turn things over to Chris Duff, who is the Executive Director of the Disability Practice Institute. And Chris is going to get the content moving. Thank you.

Chris Duff: Thank you, Laura. I appreciate the introduction to the webinar here. My [sole role] this morning is to introduce the speakers and then I'll be available to support them in questions at the end. The two presenters today are June Isaacson Kailes and Mary Lou Breslin. June was one of the co-authors in the Disability Competency Assessment Tool that we developed, and it is on the website that Laura referenced earlier. Much of this webinar series is based on the content of that assessment tool.

June is a National Disability Policy Consultant with 35 plus years' experience, training healthcare providers and insurers, government entities, and independent living centers in disability competency and accessibility. She is currently the Associate Director of the Center for Disability Issues and the Heath Profession at Western University of Health Sciences in Southern California.

Mary Lou Breslin has been a Disability Civil Rights Lawyer and Policy Advocate for over 35 years also. In 1979, she co-founded the Disability Rights Education and Defense Fund, known as DREDF, which is a leading, if not the leading, national disability rights law and policy center, and presently serves as Senior Policy Advisor, directing the organization's healthcare initiative. She has been and presented widely on various disability rights topics, focusing more efficiently on healthcare access.

Now, I hand it over to June who will start off today.

June Isaacson Kailes: Okay. Thanks, Chris. As you see, our webinar will cover the lived experience and the barriers faced by many people with disabilities. We will talk about the two-pronged view of healthcare access and some of the barriers faced by people with disabilities in accessing healthcare and some points about decreasing barriers and accommodating people.

Okay. Over to you, Mary Lou.

Mary Lou Breslin: Thanks very much, June. And hello, everybody. The purpose of the webinar today is to talk about the lived experience of disability, as it relates to accessing healthcare. For those of you who attended the first webinar in this series, you will remember that the presenters introduced the idea that people with disabilities experience significant health disparities that don't necessarily have a direct relationship to their impairment.

Health disparities among people with disabilities, as you know, are likely owed to a variety of very complicated factors. We know that social determinants of health play a role in disparities. For example, in the context of disability, people with disabilities experience high levels of poverty and material hardship, which make it difficult often to acquire care and engage in disease

prevention. So it's against this backdrop that we want to talk about what some of the specific root causes are.

Substantial research has been undertaken over the last decade and it's revealed essentially three major problems. First is the lack of provider awareness and education about disability. And this results in misinformation and stereotypes about people with disabilities that can affect outcomes of care and disease prevention. Second, the limited capacity of healthcare providers to accommodate people with disabilities in healthcare settings is also a significant problem. For example, policies that don't insure sufficient flexibility so that people often who require such flexibility, as extended exam time to ensure effective communication, or for any kind of physical assistance that might be required. And third physical barrier such as inaccessible facilities and exam equipment, such as exam tables, weight scales, mammography equipment and so on.

So against this backdrop, the Disability Rights Education and Defense Fund has produced a series of video interviews with people with disabilities who discuss really quite candidly their experiences attempting to acquire healthcare. And these interviews can be accessed on the website at the URL shown on the slides, but I want to just sort of pause at this point and show you a few short excerpts from these videos that illustrate some of the problems and barriers that I have just mentioned and put really a human face on these complex issues. And just by way of introduction, the brief three-minute video presents snippets from longer interviews featured on on the website I just mentioned. So could we just now take a look at the video and then we will come back and talk a little bit about what we saw. And we are going to hope our technology works today.

[START VIDEO]

Interviewed at the Ed Roberts Campus, Berkeley, California 2012.

Elizabeth Grigsby: So when the doctors told me they wanted me to go to a nursing home. It just like my life as I knew it was over. Nobody was listening to me.

Denise Jacobson: Here's the letter that accompanied the lab results. "My impression is she is far more intelligent than she looks.

Unnamed Interviewee: And the next thing I know he's filled the syringe with a drug. He has without any commentary rammed the needle into Charlie's shoulder, and I look and notice that the needle is at a 90 degree angle, and so I'm watching Charlie who's now becoming hysterical, and I'm crying out, "What in the world are you doing? What is happening here?"

Fred Nisen: --and some people don't think I'm intelligent enough to communicate with just because of the way I talk.

Denise Jacobson: --and I don't have the energy to deal with all their misperceptions.

Dr. Kripke: There have been policy papers written by every major organization, the National Council on Disability, Institute of Medicine, the Centers for Disease Control, the World Health

Organization, the Surgeon General about health care for people with disabilities and people with developmental disabilities, and they all come to the same conclusion, which is we need to train healthcare providers.

[END VIDEO]

Mary Lou Breslin: Okay, let's just pick it up from there, so the people you saw in this video speak very candidly about their experiences seeking health care. Elizabeth Grigsby, the first woman you met, is a long time wheelchair user, who has cerebral palsy, and who's been living independently in her own home for a number of years. She is employed at a part time job, and she is supported with person attendants who she hires and trains. I'll give you that background about her, because in her interview she describes repeated communication problems and issues she experienced with her health care providers. She sums up I think quite eloquently her experience by saying that they just were not listening to her. And as a result, she was threatened with unnecessary institutionalization.

Denise Jacobson, who is one of the people you just met, is an author, a wife, a mother, an educator. She reads an excerpt from a letter a specialist wrote to her primary care physician, which indicates a deep level of misunderstanding and truly a lack of knowledge about the lives of adults with disabilities and the letter was really rife with stereotypes.

Fred Nisen, a practicing attorney, remarks on how he is often treated as though he doesn't have the capacity to make his own decisions and respond to questions, simply because of his speech impairment. If you'd like to learn a little bit more about these three individuals or their experiences, I urge you to take a look at their full interviews.

So what else can we learn from these stories? It seems to me that several themes run through these excerpts. Disability stereotyping, negative assumptions and misinformation affect the quality of the health care these people received. While provider education is required all levels, as Dr. Kripke noted in her remarks about the national studies that have drawn attention to the issue. It's equally important for managed care plans and other plans to understand the types of accommodations people with disabilities might require and to be prepared to assist them in acquiring these accommodations.

And finally, providers within Health Plan Networks should be assessed to determine their capacity to appropriately care for people with disabilities and plan should maintain information about this capacity that members might require -- might need to ask questions about. Tools are available to assist plans and physicians, and some are available through the resources section noted at the end of this webinar.

Okay, so let's go onto the next slide. This will be slide eight. Okay, can we just go onto the next slide, please? Good, thank you.

Disability Competent Care from our standpoint encourages a view point about disability that triangulates and integrates the disability experience. That's the clinical -- not only the clinical -- the disability experience, but the clinical aspects of impairment and the functional limitations

that flow from impairment that may require accommodations in clinical and diagnostic settings. We make these distinctions because they are often confused in clinical settings and care decision and outcomes can be negatively affected.

For example, one of the people we interviewed for our healthcare video project had a lifetime mental health disability. When she sought care for a lump on her scalp, her health care provider thought her complaint was a manifestation of her mental health diagnosis. In fact, later tests revealed that she had a tumor. This is an example of the perception of disability inappropriately influencing clinical judgment.

And just a quick personal example, I recently had an echocardiogram, and as the long-time wheelchair user with a neuromuscular disability, I needed assistance to transfer on to an examination table. Echocardiograms are typically conducted in a supine position, but mine was conducted while I sat in my wheelchair, presumably because it was too time consuming to arrange a transfer onto the table. It happens that the results were compromised because the back portion of the heart cannot be seen clearly due to the fact that I was not lying down when the test was conducted. In these examples, a Disability Competent Care approach would have considered the disability experience along with the clinical aspects of the impairment and appropriate accommodations that might be required to ensure effective testing and diagnosis.

Okay. Those are just a few examples that put a human face on the experience of disability and health care. So, I'm going to turn this over to June now who's going to talk about the two-prong definition of access to care.

June Isaacson Kailes: Okay, thanks Mary Lou. Well, Prong 1, covers the fact that everyone needs access to timely health care that is affordable and has quality providers in usable locations. So Prong 1 is well understood, the right doctor, the right care, doctor specialist level care; the right place, the ability to get care, to get to it; and the right time, in a reasonable timeframe.

Well, you have to have more than these rights to Prong 2 to achieve real access for people with disabilities. So this second prong of access is actually often overlooked. So Prong 2 is where access gets drilled down in terms of meaning, because it also involves getting to, into, and through facilities, on and off of medical equipment, to be able to communicate, and as needed to receive assistance getting coordinated clinical and community-based services.

So back to you, Mary Lou.

Mary Lou Breslin: Okay, thanks. Let's just put some data to work here to describe what June just mentioned. Just to add a little dimension to the third bullet in particular, on the list June just read, I want to just point to a study of access barriers that were surveyed by Managed Care Health Plan nurses on-site at primary care practices located in multiple counties in California. This study revealed that among over 2300 health care provider locations in the state, only 8.4% of providers had a height adjustable examination table, and even more surprisingly, only 3.6% had available an accessible weight scale. So this really shouldn't come as any surprise then that people with certain mobility limitations are not likely to be examined, using best practice techniques if they can't get on the examination table or be weighed. So we point out the fact that

data is supporting the fact that equipment is often not available or not accessible to people with disabilities and the impact on their medical outcomes can be quite significant.

Okay, let's go on to the next slide. In an additional study which adds some additional weight to the concerns that we're raising about accessibility of medical services and facilities, a study that was recently published in the Annals of Internal Medicine conducted by residents at a medical facility in Boston, who telephoned 256 specialty practices in locations across the country and asked if the practice could accommodate a patient who was described as a large individual who used a wheelchair, and the results were quite startling. Some of you may have read the results of this study which were featured in a piece recently in the New York Times.

Of the review of 256 specialty providers, 56 of the providers or 22% reported that they could not accommodate the patient. 4% reported that the building itself in which their practice was housed was physically inaccessible. 48 or 18% reported their inability to transfer a patient from a wheelchair to an examination table and only 22% reported the use of height adjustable tables or a lift for a transfer. And the practice of gynecology was the subspecialty with the highest rate of inaccessible practices at 44%, quite a startling figure.

In this specialty study, practitioners were really very open about the reason they were refusing the patient, and that's because of here he was defined as a person who was heavy and he used a wheelchair. They showed very little understanding of federal law that requires accessibility feature such as the Americans with Disabilities Act, not to mention the need for accommodations to ensure best practices for all patients including people with disabilities. The disability competent care philosophy recognizes that people with disabilities encounter these barriers, and it works proactively with providers and health plans and advocates and others to build collaborative service delivery systems with fewer barriers.

So, now I'm just going to turn this back over to June.

June Isaacson Kailes: Okay. Thanks, Mary Lou. So, for many, we are Prong 2, maneuvering through the healthcare system is actually a complex and dense minefield full of access, attitudinal and competency barriers. And the common impact of these barriers is a feeling of being beat down by the experience of, for some, intolerable hassle factors -- can't get transportation, can't get accessible parking, can't get into the office, can't understand the information, can't get on the equipment.

These experiences can culminate in a real assortment of feelings of frustration, fatigue, failure and fear. And for some, continuing the effort of pursuing care is just too exhausting, too overwhelming or too degrading, and this can lead to postponing or avoiding care resulting in the downwards spiral of lack of care, delayed diagnosis, worsening conditions leading to deteriorating health that eventually requires more expensive and extensive healthcare.

A colleague of mine once said, you know, when I go for a healthcare, I want to focus on my care. I don't want the process of getting healthcare to be my career. So let's take a look at these elements and at removing these barriers.

Attitudinal access is another key element of Prong 2. In part of the disability core competencies, training needs to include a process of having healthcare personnel examine these beliefs and biases, prejudices and stereotypes and fears regarding disabilities. Where do they come from? And how they may affect working with in the healthcare of people with disability.

So, in terms of stereotypes, these are common and look at the next slide in terms of the reaction that people hear from their providers.

Negative attitudes and misconceptions of the [up] people can contribute to again wide gaps in healthcare disparity. Now you might laugh at these. But you know, we didn't make any of these up. So people were told, "There is no reason for someone like you to be tested for AIDS." The test should be administered to those who really need it, i.e. people who are "sexually active." Or "It's best that you not have children," or "You don't have to worry about osteoporosis because you can't walk," or "Of course you smoke, if I were you I'd smoke too," or "Getting a mammogram is hard for you, so you can just skip it."

Take Sandra Jansen, a 36-year-old woman with a developmental disability who was at first rejected for her heart-lung transplant because doctors assumed she would not be capable of handling her follow-up care. Two different hospitals actually rejected her as a candidate for a transplant because of her disability. But after intensive pressure from the disability community, Stanford Medical Center did perform the surgery, and the doctors reported that she followed her complicated medical regime without a problem.

Another example, a wheelchair user needing to start chemotherapy was told, "This is an ambulatory clinic and you are a wheelchair user. You can't walk, so we can't take care of you here." And I was once told by a specialist I had just started seeing, "You know I thought you'd need a lot of extra care and attention until you began asking questions."

Attitudes also offset expectations. Note the contrast in how these messages are communicated, "You will never be able to work again," versus "You will have to explore alternatives that will allow you to continue to work." Or "You will always be an [invalid]" versus "we will have you explore ways to use your strength and skills to meet your goals," or talking to parents or a spouse for a child, "You will have to care of them," versus "Together you can explore ways to maximize their independence."

And one more dramatic example, Tom, a man with cerebral palsy, was wheeled in the [Grand Round], on a stretcher wearing a hospital gown. After Tom was wheeled out of the room, the third year medical students were asked to evaluate his rehabilitation potential. They thought he may be able to work at selling pencils in the neighborhood or in a supportive work environment. Meanwhile, Tom changed back into his white medical coat and he returned to the classroom. Now these same students had to deal with him in an entirely different way. As Tom put it, "These students had a bias when they saw me on the stretcher, and then they had to deal with Tom Strax, MD, Doctor, Podiatrist, Associate Professor and Assistant Medical Director, which was a very interesting leap. The students had to confront the difference between their beliefs and Tom's reality, capabilities and status."

So moving along, communication access, another part of prong two, to get, understand, and use information and offering the right auxiliary aid and services. Now this access is the least understood and where the greatest mistakes are made. Seeing, hearing, speaking, reading, remembering, and understanding cognitive and intellectual abilities and limited language proficiency prevent many people from receiving and understanding health information.

Many benefit with and without disability from being offered information in audio formats, particularly helpful to those with seeing, learning, and reading limitations, and many benefit from written information that summarizes the information—handouts, email. And many more benefit from health and wellness information and education information that is provided in these alternative formats, something that we need to work with vendors to insist that they supply more frequently to us. The need for and use of an assisted listening device, which amplifies volume, can make the difference in effectively communicating with people who are hard of hearing.

In next slide, almost everyone benefits from the use of pictures that are easy to understand and people benefit from demonstrations. These pictures illustrate, for example, when to take meds or how to use eye drops.

Website access is critical to avoid having to later do expensive website retrofits. [You know] use of the electronic health record or the personal health record in portals that allow us to make appointments, communicate with doctors, renew prescriptions, etc., are growing exponentially, so access is key.

For me I take advantage of sometimes downloading these forms and filling them out before I get to a provider or I bring my own set of information to the provider already ready to submit. The problem is that sometimes when I get there and they say fill out these forms and I say, "Well, everything here that you need I have checked," and they say, "Oh, no, no, no. You have use our forms or you will have to put them on the right color sheet." And I say, "if you want to be able to read the information, you put it on your forms," and I get a look.

In terms of access to medical equipment, there is a lot of magical thinking about this. So as we see in this slide, once piece of magical thinking goes like this where in the next slide the provider says, "Just hop up," and magically this wheelchair user is supposed to hop on the trampoline, do a triple summersault and somehow land on the exam table. Gymnastics at its best. So there are lots of things that make equipment inaccessible. You know some times we hear directions like look here, read this, listen up, stay still, don't breathe. That can be a difficult to impossible for people with a variety of functional limitations.

In next slide here is me on a bad hair day practicing my Cirque du Soleil act getting on an exam table. And for some, well-placed grab bars are helpful, but for others, getting transfer assistance is critical. Lift teams, lift equipment and lift training is lacking in many places. Hence, we often hear this, well, like Mary Lou said, "We will just examine you in your chair." This is common, but a substandard and representation of unequal treatment.

One survey responder told us, exam chairs are impossible to get in and out of, and I have to get my husband or an office worker to help me. I have delayed visits to doctor's offices because it

takes a village to get me on and off on exam table, which means I don't go for preventive care appointments. And getting weighed, well, believe it or not, some people actually do have to go to this pictured loading dock to get weighed or the hospital laundry, and that's only if they are lucky. Getting weighed on accessible scale needs to be where all the other vitals equipment is. Getting weighed is a vital part of the standard of care for many visits. And being told to guess your weight is unequal and inadequate care.

Another prong of access to vital is physical access. As you see in the next slide, physical access means planning for accessibility, but not as pictured here in this tight exam room with no room for transferring, no room for maneuvering, and no height adjustability to aid in transferring, and no restrooms that are usable or waiting areas. They are too tight and too small to accommodate mobility devices or accessible routes. These paths have travel barriers, are barely perceptible to most people. What they might as well be the Great Wall of China for people needing accessible routes to get to the healthcare facility.

Physical access is probably the best understood of accessibility, but not necessarily available. And providers must be aware and know and provide the information to member services so they can share accurate information regarding accessible providers when asked and when needed. Physical access must be a part of readiness [in] network and the network capacity equation.

Coordinating care can be exasperating. As pictured here in next slide, understanding how to use this sometimes complex network, getting providers to talk to each other is something that is -- well, they will cover a lot more detail in the next webinar. What navigating and coordination includes what I call quality, service, accommodation alerts. That is what front office and back office staff need to pay attention to in terms of needing longer appointments, assistance transferring, using the high/low table, the adjustable table, use of an accessible scale, getting an interpreter for an appointment, using the assisted listening device, and health records, whether electronic or paper, should flag these QSAs.

For me after 20 years of seeing the same provider, they finally got it right only after I said, "How many decades will it take for you to understand I need the height adjustable table?" And I said, "Put a note on front of the chart that I need this." So people with disabilities, they want to be an active partner in their care, not passive. People want to actively share in goal setting and be respected for our experiences. This model respects the expertise of participants who have lived with their disability and their unique healthcare needs. Many have sophisticated knowledge about their bodies, and most successfully have selected and know the approaches that works best for them. People can be active problem-solvers if we honor their years of learning with and knowing what works.

So last story. I went for a mammogram a couple of years ago and there was a new clinician. And I explained, it takes two people to help me hold still in the right contorted position. And the provider said, "Oh, I have been doing this for years. Let's do it my way." And I said, "I have been doing it for years too. Let's not do it your way, because I know what works." Or the common transfer battle that people sometimes have goes something like this, "I know you are taught to transfer people that way, but trust me, with me this is the more effective way."

So, to summarize this, real access is not just installation. The best access, with all attention to details and the training, may actually never happen. It's not just having the elements, the tools, and the services, the physical, the equipment, the communication, the attitudinal, and the navigation and coordination access. It's knowing where they are, how to use them, and really having experience to do so. Readiness takes time. This is multiple exposure material that needs to be incorporated into your processes, procedures, protocols, policies, and practice. So there is much we can do because we are all faced with a series of great opportunities brilliantly disguised as impossible situations. And there is the slide with resources available for you and reference materials and much more on the website listed at the bottom of these slides.

So, back to you, Laura.

Laura Dummit: Thank you very much. That was a really very compelling presentation. Cynthia, would you open the phone lines now for questions.

Cynthia: Ladies and gentlemen, if you would like to ask a question, please press "*" then "0" on your touchtone phone. You will hear a tone indicating you have been placed in queue and operator will take your name and further instruct you. If you are using a speakerphone, you will need to pick up the handset before pressing the numbers. Once again, for questions or comments, it's "*", 0".

Laura Dummit: Thank you and while we are waiting for some questioners to queue up, we got an early question from John Arnold who first of all thanked for this -- putting a face to the problem. He then goes on to ask whether you have considered how to engage or activate consumers to engage with their providers or in their models of care. June, do you want to start and answer that question, please?

June Isaacson Kailes: Sure. And we -- John, we are going to spend a lot more time on that issue in subsequent webinars, but the DCC model really does emphasize the interdisciplinary care team's role in helping a provider to strengthen their active participation in healthcare, sometimes through coaching and motivational counseling. It's a critical part to make this all work and supporting people in really talking and requesting and being clear about what they need and not falling back to a more passive role in terms of healthcare and not accepting what they know could easily go wrong unless they indeed speak up clearly, loudly, and often repetitively. Mary Lou, do you want to add anything to that?

Mary Lou Breslin: Well, I just want to add that I think that there is a significant move now based on the fact that there is such an interest in moving low income people with disabilities to the managed care, is that many of the managed care organizations are being asked by both CMS and state to involve stakeholders, including seniors and people with disabilities, in the decision-making processes that they are undertaking now through various kinds of advisory committees and advisory boards and through consultation. So I think that the process of involving consumers in development of policies and practices is just beginning to gain some credibility and some resonance and increasing, at least in some states, in an institutional way, particularly through the managed care systems.

Chris Duff: Mary Lou, this is Chris. Let me give one concrete example of something we did in Minnesota. We had a member advisory group, got together every single month, open meeting, and over half of the meeting time was dedicated to the concept of open mic. We would simply discuss whatever was on people's minds. And that was extremely useful for us to stay on top of what was really happening. Some of it is they let us know about perhaps our phone system that was not working well. But one concrete example was someone was saying they had an accident recently in the transport because their wheelchair wasn't tied down well enough. And that got three other people to pipe in and say that happened to me last month. And out of that just simple discussion, we realized we needed to do an initiative around working with transportation providers on appropriate wheelchair tie downs. That's simple, but that's an example of how listening to the group and just simply engaging with them can teach you a great deal.

Mary Lou Breslin: Let me just add a quick footnote to that, Chris, if I could. We are working with a managed care organization in Northern California that's going to be making the transition to serving dually eligible beneficiaries, people who are on both Medicare and Medicaid. And this particular plan has put together a fairly extensive advisory work group made up of organizations that serve seniors and people with disabilities, many of whom are run and directed by seniors and people with disabilities, to serve as advisors in the course of developing this transition. And this has been a very proactive candid open period for discussion, for sort of fine-tuning the process that's being used to advance these new programs, and I think that it's been a real interesting model and would encourage particularly health plans that are in this process now or in a process like this to look at that as a good example or just a complement to what you talked about in Minnesota.

Laura Dummit: This is Laura, I am going to read one more question that we got through the chat feature and then I am going to -- after a quick answer to that, I am going to turn over to Cynthia to see if there is anyone on the line. This question came in from Rachel Robeson from CareMore. How do you deal with the providers and staff that do either two things when verbally communicating? One is talking to the caregiver or family member only or speaking only to the patient and disregarding the caregiver in strict adherence to HIPAA.

Mary Lou Breslin: Well, this is Mary Lou. Let me just jump in and say that I think the basic rule for communication is that the person who is receiving care is the person with whom the provider should be communicating and the family member or the friend, the partner, the caregiver who might be accompanying the person to a visit should be mindful of directing the provider's communication to the person themselves, if the person themselves has not been successful in doing that on their own behalf.

It is true that communications are proprietary in terms of HIPAA, but in general there are permissions given for individuals who are assisting people to be a party to those communications. So the more important issue I think is the recognition of the expertise of the individual who is receiving care. It's not the -- it's a very typical example in a restaurant where someone will -- a wait person will ask someone accompanying a person with disability what they want to order. This very typically happens in the medical setting as well rather than asking an individual what's going on with them. So, I think the etiquette and protocol is to make sure that

every party involved in the process to make sure that the questions and interaction are directed to the person who is affected by the care.

June Isaacson Kailes: And that includes the actual person knowing that they could say and coaching them to say, "You really need to be talking directly to me." Back to you, Laura.

Laura Dummit: Thank you. Cynthia, is there anyone with a question on the line now.

Cynthia: And I am showing no questions in queue at this time.

Laura Dummit: Okay. Thank you. Let me return back to a couple of questions that we got online. First of all, here's one question that came in, maybe very basic. But what do I do if I simply don't understand what a person is saying?

June Isaacson Kailes: This is June here. That's really a common issue and it's communication access and there are a number of things you can do. Sometimes, for example, with Denise Jacobson in the video, sometimes it just takes a little bit of getting used to their cerebral palsy accent, to relax, take a deep breath and always – to never guess what people are saying, to never finish a sentence. And if you just can't understand, to actually communicate with someone like Denise, and saying, "Denise, I am just not understanding you, what should we do? How can we make this communication work?" Sometimes it's good to partner with another provider or assistant who may just have a better ability to understand somebody, for example, with a CP accent, but problem solve with the person.

Mary Lou Breslin: This is Mary Lou. I would like to just add that I think in that situation, anxiety and fear may be interfering with the ability to communicate, the anxiety of not understanding what the person is saying, and June's recommendation to take a deep breath, start over, and don't be fearful about asking specifically for the person to repeat what they have said because you don't understand them. They want you to understand them and you want to understand them. So the process of sort of requesting that they repeat what they've said is -- and understood in very typical way of going about ensuring that the communication is effective.

June Isaacson Kailes: And as you wait for that to happen in the emergency world, sometimes we say, let's just agree, show me a way that you would say yes, show me a way that you would indicate no, or that you would indicate I don't know, as an interim way while you problem-solve in a better way, a more effective way to communicate. Laura, back to you.

Laura Dummit: Okay. Thank you. Up on your screen now, you will see a URL. We would really appreciate it if you would click on that and fill out our short survey. We really want to make these webinars and all of the products under this initiative useful for you and your work. So please take a minute to fill out that survey.

And I am going to just preview to you what the next slide says, which is about our third webinar, which is next Tuesday at 2 o'clock, which is going to be on the Care Management Relationship.

The next slide after this you will see is contact information of all of our speakers and our key contact at CMS, Kerry Branick. And as June and Mary Lou said earlier, here are some materials for you to reference in your spare time. I want to remind you all that this webinar and the one we held last week are going to be posted to the URL that's at the bottom of each of the slides, again that's www.resourcesforintegratedcare.com. Further, you will receive an email in the next day or two that will include this link, so that you have access to all of the materials we are presenting and developing under this contract.

Thank you very much and that takes us to the end of this webinar. Thank you.