The Lewin Group Disability-Competent Primary Care March 1, 2017 2:00 p.m. EST

Christopher Duff: Good afternoon, everybody. Please take the time to orient yourself to our platform. If you would like to ask a question, the chat feature is located on the lower left-hand side. Content questions will be addressed at the end of the presentation. If you would like to download the slides from this presentation, use the icon at the top right. Live captioning is available at the bottom of the screen.

My name is Chris Duff, and I am a disability practice and policy consultant working with The Lewin Group to develop the Disability-Competent Care model and related webinars and materials. I will be joined by Dr. Judy Chamberlain, Senior Medical Director for Aetna Medicaid. Dr. Chamberlain received her BA and MA degree from Stanford University and Dartmouth Medical School respectively. She completed a residency in family medicine and has been board certified in family medicine since 1980. She practiced family medicine in Maine for thirty years including her three years in residency. She is active in the American Academy of Family Physicians and nationally is a member of the Academy Board of Directors.

At Aetna, her major focus area has been managing integrated care programs, which includes chronic care management, perinatal care management, and long-term care management. She helps to develop clinical programs with members with a particular emphasis on biopsychosocial approach for each member and to fully integrate physical and behavioral health. Additionally, she is a board member for Medicaid Innovation whose mission is to improve the lives of Medicaid through the development, implementation, and infusion of innovative and evidence-based models of care that promote quality, value, equity and the engagement of patients, families and communities. I am truly honored to have her provide this presentation today.

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 a PDF of the 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 fourth pillar: primary care. 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.

The delivery of Disability-Competent Care in a primary care setting is a collaborative effort. It involves a participant-centered approach to primary care as part of the interdisciplinary care team. Particularly for participants with disabilities, care may include involvement maintaining health, prevention of avoidable hospitalizations and establishing transitions protocols to mitigate difficult changes. The responsiveness to primary care is often the key factor in reducing emergency department and inpatient visits and costs. A key to capture this opportunity is timeliness of availability of primary care and the communication between the primary care practitioner and the interdisciplinary team. At this point, I will turn the presentation over to Dr. Chamberlain.

Dr. Judy Chamberlain: Thanks, Chris, and welcome everybody. There is a ton of information on the slides that have been put together for this presentation. I will not, in the interest of time and interest of not boring everyone to death, read them but instead use them as a background for my comments.

So, who are we talking about? We are talking about people with physical or intellectual disabilities or disability due to serious mental illness. Words matter; words matter a lot. Using people *with*, not a disabled person, mentally ill person, but people *with* a disability reminds us that people are not defined by their conditions or their disabilities. We also know that people may belong to one, two, or three groups of disabilities and non-disabilities. Disabilities are not always obvious. That's a problem, but it is not up to me to decide that someone who does not "look disabled" has a disability. It is also not up to me to decide how limited somebody's life may be by a visible disability. These happen to people every day particularly in medical practices.

As a primary care doctor, I needed to be aware that people with disabilities often experience delays in primary and routine care. We often do not think about health education or critical screenings. Cholesterol screenings, diabetes screenings, or PAP smears are often missed in the confusion of caring only for the critical pieces of somebody's disability.

As PCPs, we need to not assume that a new patient with a disability has had all the appropriate age and gender routine care. We know that people with disabilities have difficulty getting to care and may not have been asked the appropriate questions. We will talk about that in subsequent slides.

If we go to the next slide, we see that these are called social factors; these are really more health systems factors than social factors. Things like value-based payments, which are critical in improving healthcare; they have a goal of improving quality and efficiency of care but also trying to control costs. It may be harder to achieve performance measures associated with value based payments in patients with some disabilities.

Providers in a large busy office may choose any easier route. They may concentrate their efforts at maximizing the measures for which they get enhanced payment with their nondisabled patients because that is the majority of their practice panel. This, in patients with disabilities who are dually eligible (Medicare-Medicaid enrollees), becomes more difficult in a value-based model

because of the complexity of coordinating which benefits or care belong to Medicare or Medicaid. It becomes more complex when you have to coordinate not just care but the payment.

We are going to start to talk about delivery of care. The key on this slide is participant centered approach or patient centered approach. This is not unique to disability competent care, but it is critical when working with someone with a disability to recognize who they are, not just what their disability is.

On the next slide, we look at challenges in primary care. Truly competent care for people with disabilities needs a team approach. In traditional primary care, it is, at its worst, fragmented, episodic, poorly coordinated, and suffers from poor information sharing among providers of care. As patient centered behavioral health homes has become more common, they have encouraged more coordinated care that is more patient centered and involves all of the members of a person's care team and circle of support.

When you move beyond that to a fully integrated system of care that is something that we are working hard on as a Medicaid organization; it means that the medical and behavioral provider, ancillary provider, family and patient are all working from the same care plan. They all have access to the same information. They are basically working from the same playbook. This can be as complex as sharing information via a very robust health information exchange or making sure that everybody has an input or paper copy of the care plan, medication records, and anything else that is supporting the person with the disability. It does not require a big fancy health information system. That may make it easier, but you can do it without that.

This is an actual patient. Not one of mine, but someone that Chris and I became aware of. This is Pedro who was a 27-year-old from the Dominican Republic. At 17, he suffered from a spinal cord injury. When he was 27, he moved to the Northeast United States because he thought he could get better care, and there was extended family, including his mom, in the area. Shortly after he got here, he went to the emergency room. He still had his trach; he had chronic respiratory insufficiency, constipation, multiple pressure ulcers, incontinence, and a urinary tract infection. He ended up hospitalized for the extended period of stabilization, and ultimately was discharged to a nursing facility. Remember, we are talking about a 27-year-old here. His goal, not surprising, was to live with his mother, manage his own care, get a job, and build relationships. He had physical barriers and behavioral barriers that made this difficult. As a family physician/primary care provider, what could I do to help? He needs somebody who understands how to help someone with a disability, and he needs a care coordinator. He also needs a coordinated group of clinical providers, not just a PCP but a behavioral health provider. He would benefit from peer supports. He needs daily personal care; I am sure he does not want his mother to do that. He needs mobility assistance, and he needs all of this paid for somehow. Therein lies the hang-up; how do we get it paid for? This is where, as a primary care physician, I need the help of a care coordinator to help me find resources for him.

What can his new PCP do? All the bullets on this slide are critical. The first thing is my relationship as a primary care doctor with Pedro. I have to listen and share his concerns and help him share in the problem solving. Second, I have to maximize his physical and emotional health

to maintain his independence. Can I do that, as a PCP, by myself? No. That takes a team, and that team includes Pedro. Then we need to be proactive in treating what can be treated to avoid rehospitalizations. We can develop a care plan to make sure every member of his team, including Pedro, knows how to help with his care and keeping him healthy and independent. His care would address his medical, behavioral, functional, and social issues and everything that could help him be successful and every barrier that might worsen his experience.

However, most primary care doctors, myself included, are not used to thinking about care plans beyond what is my plan and what am I prescribing for him. Most doctors have no idea what a true care plan is, and you do not want the PCP's developing them by themselves. It is helpful if a care coordinator or a care manager can help develop a care plan and show the PCP the value of a complete plan including how that care plan can make the primary care doctors' jobs easier. We are used to seeing the person, and then they leave the office. You have to help primary care physicians understand how a full care plan can make everybody's job easier and benefit the person that they are caring for. It seems obvious to me now, but it was not when I was in practice.

Obviously one of the hallmarks of primary care is an annual well person visit. You think Pedro is not a well person, but it does not matter; he gets a well person visit. There is a lot of him that is healthy. The standard care includes making sure that I, as his primary care doctor, knows all of his medicines. For someone who is seeing three, four, or five providers, that can be a challenge. The PCP should review the care plan so they understand who part of the team is and how each person is supporting that patient. Obviously part of this is prevention and health screening. I cannot forget that because the person in front of me may have pressure ulcers and other things medical issues that need to be attended to. It doesn't matter what age that should come up. In some way, it needs to be addressed. Again, remember that the social determinants of health are critical. People with lower socioeconomic status and higher social risk factors are less likely to get appropriate intervention.

The next slide focuses on primary care resources for disability competent primary care. 24/7 availability is something that every primary care has. Does that mean the primary care physician, themselves, are available to this person 24/7? Absolutely not. It means that there is someone available, and ideally, someone who has access to be able to read the patient's medical records. So, that requires some kind of health information exchange or ability to get on a medical records platform. Obviously accessibility for testing may go beyond physical accommodations. With somebody in a wheelchair, you have to think about how to get them in for a mammogram. For someone with quadriplegia, prep for a colonoscopy can be a nightmare. What about person with a behavioral health disorder who really cannot be alone; they need someone with them. I know most x-ray technicians do not want someone else in the room when they are doing the x-ray, but you may have to allow for.

I used to laugh that I was the last physician in Maine that still did house calls. The reality is that house calls are difficult to do in a busy practice, and you do not get paid enough to do them. However, it is extremely useful to see how someone lives in their home setting particularly someone with a disability. There are home care medical groups that will do this. Also, home health nursing can be a way of getting clinical eyes on someone who has difficulty leaving their

home. When I say clinical home health nursing, I mean behavioral health or physical health. Seeing somebody in their home who has difficulty getting out or just to understand how they live can be critical. Behavioral health homes can also provide a haven for people with serious mental illness. It may be difficult for someone who is disabled with a mental illness to go to a regular, busy primary care practice. It would be better if we can find a way to provide them complete care in a behavioral home. It may be more comfortable for them and they may be much more willing to participate.

We are going to start talking about preventive care and health education. Health and wellness can coexist with disability; I would say they do coexist with disability and are as important with people with disabilities. This gets forgotten all the time.

The next slide describes managing the visit. In my practice, we had some patients with disabilities who routinely were scheduled to arrive half hour before I was schedule to see them or some patients who routinely were not asked to wait in the general waiting room. It was either too difficult for them to be in the room with strangers or too difficult to have the kind of stimulation of kids running around them and people waiting. Sometimes the need for additional time or a quiet space for them get ready to see the doctor can be very important. New patients were always booked for longer visits in my practice whether they had a disability or not. If I knew, for instance, that someone with a disability that limits their mobility had an appointment, I might put them with two slots. The first slot would be to meet me with their clothes on, in their wheelchair, and talking. Then for a half hour, I might see other patients, and then my assistant would help them get ready for an exam. For the second slot, I would come back and do the exam.

It takes a little planning and extra time, but it can make it much more comfortable for the person with a disability. For the first 16 years of my practice life, I had a tiny practice in a town of 4,000 people. Physically accessible exam rooms and exam tables are expensive, and we only had one. We had four exam rooms, but only one was easily physically accessible. It is critical to make sure that that room is booked for the patient with a physical disability at the same time as the appointment. It would do no good to book someone in his motorized wheelchair for an appointment, and then have one of my associates doing a procedure in the only room where he could comfortably get around. Your front office staff needs to think about that. You may need a larger exam room to accommodate family, caregivers, sign language interpreters; you cannot cram them all in an exam room that is only meant for the doctor and the patient.

What about standard care for people with disabilities? It is something that every primary care provider needs to think about regardless of a person's abilities. You need to think about tailoring care for people's individual needs. For people with disabilities, this is critical. We need to include families and caregivers, but it is important to ask outright or watch for non-verbal cues that a patient with a disability would not want their caregiver present for the entire visit and to respect that.

One person that to comes to mind is a young woman that I cared for. She had a significant physical and developmental disability, and she came to my office with her mom. She lived in supported housing, and her mom would bring her to the office. Her dad was a family physician

partner of mine, and so I had to tread lightly with them. When she would come in with her mom, she would regress to sort of 5-year-old behavior and be difficult. At one point, her mom left the room, and she changed entirely. She was more collaborative with me. She would not talk to me when her mom was in the room. When Christi came back in, I was very frank with her. I said, "You need to stay in the waiting room, and I will come get you if there's something you need to know. You need to let her come in by herself because she wants to, and she knows what she needs to say. It makes her a more active participant in her care." That was news to her mom, but it worked well. You should absolutely include caregivers but also understand that, even if you think intellectually they are not able to participate, you have to give them that opportunity.

The next slides talk about secondary conditions. You have to assume that people may have other conditions besides their disability, and they may not be related or inevitable. There may be some that are more likely. For instance, if I am seeing an adult with Down Syndrome, I can expect that weight and obesity may be an issue for them. It does not have to be an issue or it is not always related. As a primary care physician, having protocols in place to identify and treat secondary conditions is really important and also screening for secondary conditions particularly depression and behavioral health disorders. Except for people with intellectual disabilities, depression screening should be no different for what we do for the general population and is something that should be part of every primary care visit. Screening tools for co-occurring disorders like depression have not been validated for people with significant intellectual disability. However, behavior changes can alert to possibility of depression, things like sleep disturbance, changing in eating, weight loss and weight gain and asking for self-support. The other thing that primary care physicians often forget to do is ask patients about risky behaviors. We know that there is a high rate of tobacco use in people with severe mental illness or serious mental illness. We cannot assume that somebody, say an adult with a developmental disability living in a group home, does not smoke.

I remember one patient of mine; we tried to help him quit smoking. He kept saying he was going to. It turned out the barrier to him stopping smoking was that his aide smoked. The only time the aide could leave to go outside to smoke was if the patient went out with him and also had a cigarette. So, the aide was sabotaging our efforts at smoking cessation because the aide wanted a cigarette. Until we got through that, it was a real challenge. You cannot assume that someone who cannot lift a cigarette to themselves does not smoke or consume alcohol or have other risky behaviors.

The next slide is titled cancer screening, but I want you to think about this as screenings in general. We know that there are major disparities in access to cancer screenings due to disability status. There are barriers to access for many screenings. People with disabilities are often underinsured, have less access to healthcare, and may engage in riskier health behavior. We know that there are studies that show that people with advanced disabilities are not getting screened for cervical cancer and other diseases as much as other people their age. Barriers for them include physical barriers, healthcare, costs, healthcare provider discomfort, and physical difficulty for some of them.

What do we do about this? Making sure that a primary care practice has in place standard

prompts that say whatever this person's disability is, they are still 50-years-old and should be referred for colon screening or this woman is 40, 45 or 50 and she should be referred for a mammogram no matter what disability she has. Overall, it is important to make sure that it is not just the primary care physicians, but that the whole office is oriented to say everybody gets screened. Health plans can be instrumental in providing training and community outreach and can enlist primary care doctors who are already doing a good job at this to train other people. It is important to remember that while osteoporosis screening for the general public does not happen until 60 or 65, for someone like Pedro, he is going to need it at a younger age because his bones are going to get thin faster since he is not using his muscles and is not walking.

The next slide is more about barriers to screenings and why screenings have been missed. My favorite site is the United States Preventive Task Force website (https://www.uspreventiveservicestaskforce.org/); I just love the information there. None of the screenings on this website call for screening for people with disabilities. Although they admit that the verbal screenings may have to be modified for people with significant intellectual disability, none of the screenings are different. That's very important to remember.

Now, we are going to talk a little bit about sexual health because, let's face it, primary doctors avoid talking about this with everybody especially people with disabilities. There is a lack of information on their needs or untreated needs. People with disabilities have the same needs and desires. You need to do a sexual health history, and you need to offer education, screening for sexually transmitted infections, and birth control. Also, it is really important to be aware that, particularly for women with physical and intellectual disabilities, they may have been sexually active, and it may not have been consensual.

Pedro had a spinal cord injury when he was 17. We cannot assume he does not have sexual desires, and we cannot assume he was not sexually active before his injury. As his primary care doctor, I would have to think about that and ask about that. In fact, I would think that some of the acting out behavior might be because he is angry that he has lost his manhood. As his primary care doctor, I would need to open the door for discussion, find out what his thoughts are, and be open to what his sexual orientation is. I do not know whether he is gay or straight. We need to ask. He is probably not going open up to his mother about his sexuality because he is a young man and because he is a Hispanic man. He might not want to talk to me, but he might want to talk to a peer; someone else with a spinal cord injury who is a similar age and has been through what he has been through. If somebody does not bring it up, then he is going to think that nobody wants to talk about it.

We are going to talk a little bit about primary care networks and accessible offices. I am not going to say a lot about networks. Disability primary care was not something I was taught in residency; we did have one session on sexuality, and it was good, but it was one hour out of a three-year residency. Most of what I learned came from listening to patients and caregivers and being open to suggestions and corrections when I messed something up and remembering to look and speak to the person, not the disability. In a practice, this is something we can help get developed. There is often someone in a PCP's office who has experience with people with disabilities either in their family or in prior work and has expertise to share. Practices can also, if

interested in becoming more disability competent, ask their patients with disabilities to participate in focus groups or work groups to help them improve their disability competent care.

You would like to be able to identify your disability competent primary care doctors or practices. It is not easy. Beyond knowing that somebody is complying with all of the ADA rules, it is hard to identify who is truly giving disability competent care and who isn't. Over time, physicians, care managers, care coordinators and doctors can figure out which practice is more willing and more able to care for people with disabilities. We would like them all to be participant-centered, responsive, accessible and collaborative. For all of our folks who are dually eligible, we want them to have an interdisciplinary care team. We want to make sure that they are getting what they need and want. That is a stretch for a lot of PCP offices, and it takes work. As health plans, we can help our practices.

One of the things I did with our practices is give them a survey. We used survey monkey because it was easy and asked everyone in the office, from the front office staff to the doctors, to talk about how comfortable they were with disabilities and how much they felt they knew how to help them and where they thought barriers were. The next step to that was to work with them on a performance improvement project. If we are going to do that, we need to help them to get better and reward them for doing it.

What about using primary care practices? Again, health plans need to be willing to help them to develop the quality improvement process and give them the data they need to do it. Practices need to remember that it goes way beyond the doctors and the nurses and the clinical people. When someone first contacts a primary care office, who do they talk to first? They talk to the receptionist. If they have difficulty speaking or a behavioral health issue that makes it hard to talk to them or express their needs without sounding angry or sounding as if they are having a hard time or if you have an engaged parent of an adult with disabilities, it is the front office staff who need to cope with that. We need to help them from the beginning to the end to make this a better process.

The next slide talks about accessibility. Provider directories can tell somebody if an office is physically accessible. It can tell them if an office has co-located physical and behavioral health, but determining who is good at it and who is not takes time to figure out. Physical accessibility and co-located behavioral health care can be used for markers for practices that are paying attention to being disability competent. This becomes a process that has to be developed over time. You cannot make a list and check off the disability competent practices and mark the ones that are not. It takes time to figure that out.

The next slides are titled pain assessment and management. We are thinking about pain as a symptom. When I look at these slides, I think of this as any symptom that may be expressed differently than people with a disability. There has been a hypothesis that people with disabilities experience more pain than the regular population, but there is not a lot of data to support this hypothesis. So, what I want people to think about here is that awareness and expression of many symptoms including pain may be different in people with some disabilities.

In the next slide we talk about kinds of pain. For Pedro who is quadriplegic, he will have skin breakdown without pain. We know that for people with severe cognitive impairment, pain may have huge behavior issues; it may be difficult for them to function until we treat their pain. One person that comes to my mind is a man who was in his thirties and severely intellectually disabled. His caregivers would recognize behavior changes in him as indications of pain. They were incredibly good at this. I could not tell; he seemed the same to me, but when they came to me and said "David is acting differently. There is something going on; he has pain somewhere," it usually turned out he had an ear infection or strep throat. They were rarely wrong. Almost always, if they said he was different, they were right. He had no way of telling us. He was non-verbal. For the people that paid attention to him, it was obvious.

Then we think about Pedro. He may not feel skin breakdown or if he injured himself, but what about pain that he does feel such as headaches, neck pain, and upper extremity pain? He may not be able to help himself when he has pain. His emotional and behavioral responses will be colored by his physical disability and his culture. As his PCP, I would need to think not just about his disability culture but his Hispanic culture and how that colors his approach to almost any symptom.

The next slide goes over a little bit more about pain and remembering that everybody experiences pain differently not just people with disabilities. Everybody functions differently with pain. Some people go to bed when they have a headache, and some people keep on going in the middle of a heart attack. Pain is tied in to our attitudes about pain and our beliefs about pain. For some people with disabilities, it is helpful to educate them about the causes of pain or other symptoms, and what they can do about it. If you feel like you have control over a symptom, it is easier to cope.

Do they have someone in their life with a positive outlook and attitude that will help them? Exercise also helps. Some people, not just people with disabilities, may see pain as a sign that they should stop doing something; that may not be the case. In folks with disabilities, whether physical, intellectual, or emotional, physical therapists may not be ready to help them in a way that they need help. In this case, as a PCP, if I were referring someone with a significant disability to physical therapy, I might want to call that physical therapist and prep them. I would tell them more about this person and how to help them. I would explain to them what my understanding would be and understanding with the patient about how they are going to approach this intervention.

The next slide talks about pain management plans. The planning for how to manage pain, whether acute or chronic, has to keep the person with the disability at the center. The strategies have to be developed together; the interdisciplinary care team may want to weigh. Everyone has to be on the same page.

This is Pedro. Five years later, he is 32 and living with his mother in subsidized housing. He has personal care attendants. He is independent; they got him a power wheelchair and has peer support. He continues to have problems with skin ulcers but are being proactively managed. Instead of waiting until they are huge, they are noticing them and treating them beforehand. He is stronger and wants to start driving.

So, what is my job as his PCP now? My job is to see him regularly, be proactive about prevention and treatment of his chronic problems, and make sure that I am part of his IDT. Realistically, in a busy primary care practice, can I attend an IDT meeting once a month? Absolutely not. Can I call in for the last five or ten minutes? Sure. Can I have someone from my clinical practice call in? Yes. Can I make sure his care is coordinated with his other providers? Yes, I absolutely should. Can I make sure I pay attention to standard health maintenance and screening for him as he gets older and make sure that I am looking at Pedro and not as a guy in a wheelchair? Yes.

In conclusion, I think what is critical is making sure there is a team approach to care for people with disabilities and that we take the time that is necessary to make the teams functional. At the center of the team is the person that we are trying to help.

Jessie Micholuk: Thank you, Dr. Chamberlain, for that great presentation. As our host mentioned, please enter any content questions that you have into the chat box. We have a question that has come in already, and Dr. Chamberlain, if you are able to answer it, we would love to hear it.

Are there any organizations or agencies that can provide lists of PCPs that work specifically with people with disabilities?

Dr. Judy Chamberlain: In most states that I have worked in, there are disability advocates, and they will usually know who is out there and who is good because they hear it from the people they are dealing with. I wish I could tell you that local medical organizations or hospitals or health plans would always know the answer to that question; they do not always. I would look to the advocates to give you that answer or some information.

Christopher Duff: This is Chris again. I agree with what you said. I also appreciate what Ben typed in to the chat about some things in California. They are leading us on this issue. The other thing that we would do is hear from our care coordinators what worked with primary care doctors and what practices were the most responsive. Slowly over time, word spreads because as Dr. Chamberlain said, there is no database that gets at disability competency. It may get at some of the components of accessibility, but it does not really get at competency.

Dr. Judy Chamberlain: That's where I said, you have to reward the practices. Realistically, it takes more time. In my busy practice, I could probably see 30 or 35 people in a day; 40 if I worked really late. However, if half of them had significant disabilities, then I would see 20. I cannot live on that; well, I can, but it would not be great. If a practice steps up, and says we want to be good at this and this is a mission for us, then we need to reward them in a lot of ways. Financial rewards is one way but we could also help them out. We could help them with getting more accessibility equipment or more education so they can do things more efficiently. We need to reward those practices.

Somebody asked about routine dental care. That is a huge problem particularly for people with significant physical disabilities. There are resources, and I did not think about this for this

presentation. There are some training programs available to help teach the dentist, the patient, and the patient's caregiver how to get through a dental visit. Dental visit for somebody with a significant behavioral or intellectual disability can be terrifying. There are training programs to help with that. Dentists do not come out of dental school knowing how to help somebody that is scared to sit in their chair. In my practice, I had one man who would not come into the exam room, I could sit on the floor with him in the hallway and do most of what I needed to do. You cannot do that in a dental office. There are resources out there to help those dentists that are interested and willing to learn.

Christopher Duff: I have heard in a couple of different states over the years that sometimes the FQHC, federal qualified health centers, will have a dental practice themselves who has competency or will know of a dental practice. That is a good resource. The advocates in the community are also good resources. I have heard of dental programs where they are willing to do specialized care some of which may require general anesthesia. Those are a couple of places to start though those are local answers; you cannot answer them on a national basis.

I want to get back to rewarding primary care practices. Other things that I have seen and heard, is that some plans are willing to, with a portion of their members, give a PMPM or a monthly capitation to the practice to serve participants. That means the doctor has more dedicated time. That is a model that has been fairly successful in geriatric care. The problem is figuring out which individual.

Another thing I heard is quoting that can be done for longer appointments that reward the practice. There are a variety of strategies, and if we can come up with anymore, we will send it out with the links.

You mentioned earlier about physiatry. Can you please explain the role of physiatry, geriatric, and primary care and how they fit together or don't?

Dr. Judy Chamberlain: When I say primary care, if I am thinking family practice, then it is not a separate specialty. If I am thinking primary care and internal medicine, they are also doing geriatrics. Primary care and pediatrics are not. Physiatry cuts across all three groups because physiatrists have special expertise in helping people with physical disabilities. They help figure out what the best mobility equipment might be.

A prime example is when I was helping a state with a review of needs for some of their kids. There was a two and a half-year-old with spina bifida paralyzed from the waist down, and they wanted to get him a motorized wheelchair. They had a video that he could run the wheelchair, but the motorized wheelchair cost \$20,000. So, I called up a pediatric physiatry office in Boston and asked them to explain this. From what I can read, this child developmentally needs to be independent. He needs to be able to interact with his peers without his mother or his teacher pushing him and putting him on the floor with them. He said you are exactly right, and we know that small children who are physically disadvantaged need to be mobile enough to be independent or they do not develop the developmental skills they need to grow up.

So, I told the state they had to supply him with a \$20,000 wheelchair. I was not on their Christmas card list that year, but he got what he needed. I would never have known that if I did not call up someone in physiatry specifically in pediatric physiatry. Sometimes it is a matter of co-caring for a patient, and sometimes it is just a matter of calling up and asking the right questions.

Christopher Duff: That is also a great example of the role of advocacy for primary care. Bottom line is, if she or he is your client, then you have the responsibility to do what Dr. Chamberlain did.

Another question that came in, and I hear this a lot, is about care coordinators finding primary care doctors resistant to participating in appointments with their members. Do you have ideas there?

Dr. Judy Chamberlain: I think the first thing is that the primary care doctor may have no idea who this care coordinator is, and why they want to participate or speak to them. You have to remember that primary care offices are designed to keep the doctor busy seeing patients and not doing other stuff. As a care coordinator, if you call a doctor's office, it is unlikely they are going to put you through to that physician. When I was a Chief Medical Officer for a plan up in Maine, I would call them directly because they would put them on the phone for Dr. Chamberlain. Then, I would have the care coordinator sitting on the phone right next to me. There is a little pre-work that needs to be done. The other thing is that a patient can have anyone they want in with them. If a patient says, I want this person to come with me, there should not be any discussion about that. There might be, but there should not be.

The real key is helping physicians understand what your role is and how you can make their job easier. The first foot in the door is often saying, "I can help this person, so they stop being late for their appointments or missing appointments." If you do that, they will love you, or telling the primary care doctors that you will help this person follow-up on things they suggest after the appointment. Those are the two really frustrating things. Somebody has Medicaid/Medicare, they are reliant on public transportation, and they show up hour late for an appointment, do you see them or do you not see them? If you can say to them, I am here to make sure they get to you then that helps. I am here to be more efficient is what you are saying to them.

It is still a battle, but sometimes what it takes is doctor to doctor conversation for them to say, "This is what my folks can do for you, so please let them in the door." You will find some physicians who are never going to be welcoming, and I would say to make friends with some of the other people in the office. Make sure that the front desk knows who you are. If the physician has a medical assistant or a nurse that they work with, then make sure they know who you are. Sometimes you just have to be persistent. I wish they would all be welcoming, but they are looking at you thinking, "How are you going to make my job longer or harder than it ought to be." I think it will help if you can show that is not what you are there for.

Christopher Duff: Thank you, Dr. Chamberlain. There are also resources that we dropped into the chat earlier on that might be helpful with this. There is a tip sheet that is about to come out for

care coordinators that was developed by a plan in Minnesota that they gave to the care coordinators on how to introduce themselves to the doctor and how to be supportive in the appointment. We will get that link up to people if it is not up already. I need to bring this to a close. Our time is up, and we try to stick to the timeline, so we are going to have to wrap it up.

Please send any feedback you have to <u>RIC@Lewin.com</u>, and answer the survey that will appear on your screen at the end of this webcast. Again, I would like to call your attention to the resources that we have online including the Disability-Competent Care Self-Assessment tool.

Next week, we will be talking about care coordination. Our presenter will be Rachael Stacom, Senior Vice President for Care Management Independence Care System of New York.

I would like to thank you again and the Centers for Medicare and Medicaid Services for sponsoring this webinar and the entirety of the Disability-Competent Care work. Thank you for attending.