

The Lewin Group
Disability-Competent Care Conversation on Care Coordination with ICS
September 5, 2019 – 2:00 pm

Jennifer Kuo: Great. Thank you. Hello, everyone, and welcome to the Disability-Competent Care Conversation on Care Coordination brought to you by the Resources for Integrated Care. My name is Jennifer Kuo with the Lewin Group and I'll be facilitating today's event.

The audio portion of today's presentation will automatically stream through your computer. Phone lines for the event are also available. To access the number, click the black phone widget at the bottom of your screen. Also, as a reminder, today's session will be recorded. A video replay and a copy of today's slides will be available at the resourcesforintegratedcare.com website.

Today's conversation is supported through the Medicare-Medicaid Coordination Office at the Centers for Medicare & Medicaid Services. MMCO is helping beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To learn more about our current efforts and resources, please visit our website or follow us on Twitter for more details. Our Twitter handle is [@integrate_care](https://twitter.com/integrate_care).

We are really excited today to continue testing out a new format for our Resources for Integrated Care event. Today's event will not be in our typical speaker presentation format, but rather a 30-minute conversation with representatives from Independence Care System who will be answering questions from our audience members on the topic of coordinating care for individuals living with disability.

One of the goals with our new conversation format is to engage our audience members throughout today's event so please feel free to submit any questions that you'll have for our speakers.

This slide shows how to submit a question using the Q&A feature on the lower left-hand side of the webinar platform. Type your question into the Q&A box and press Submit to send it. If you don't see a Q&A box on the left-hand side of your screen, just click the red Ask Question button on the bottom of your screen.

So we are honored today to have representatives from Independence Care System, or ICS, as our expert on today's event to answer your DCC Care Coordination questions. We have Rachael Stacom and Elaine Castelluccio. So Rachael and Elaine, I'll turn it over to you now to introduce yourselves and provide a little bit of background on ICS.

Rachael Stacom: Great. Thank you, Jennifer. Elaine and I are very happy to be here with everyone.

So just to introduce ourselves, as Jennifer said, my name is Rachael. I am a nurse practitioner by background. I have been with ICS for about 19 years and I oversee clinical programs and population health.

Elaine Castelluccio: And my name is Elaine Castelluccio. I am a physical therapist by background and I am the director of our disability program here at ICS.

Rachael Stacom: So what is ICS? So since the inception, ICS was created to really help people that are living with a physical disability. And what we aim to do is to improve our members, that is what we call -- the people we work with are members health. They are to make sure they are maintaining or improving their mobility and their ability to be independent in the community. And so, that's what we focus on and the vehicle that we do -- we do that through care management services and creation of programs to help our members stay active and healthy.

And so we began as a managed long-term care through ever -- when we opened our doors in April of 2000. We have had a strong partnership with the Department of Health in New York State. We began at New York State managed long-term care and we have recently transitioned. We are now the first Health Home that is providing specialized care for people with disabilities and we're also a care management organization. So we're partnering with plans to care for their members who have physical disabilities.

Jennifer Kuo: Great. Thank you, Rachael. I'm really excited to have you on today. So without further ado, let's go ahead and get the question and answer session started. We did receive several pre-submitted questions from our audience members. So we'll start with those questions, but we do encourage our audience members to submit any additional questions that you might have via the Q&A feature on the platform.

Okay, so our first pre-submitted question that everyone should be seeing on the screen is -- What core competencies do care coordinators at ICS have? How are their competencies measured? And what training is provided to develop staff who have little or no experience providing services and care to people living with disabilities?

Elaine Castelluccio: Okay. So when we're talking about core competencies, one of the first core competencies that we probably is best to start off with is very basic, which is our disability sensitivity awareness. And that can encompass, and should encompass things including disability etiquette when communicating and engaging with somebody who has a disability. We also have a high level review of structural barriers in the physical environment in many areas of somebody's life, whether it's within their own home, their community, and any other medical provider or wherever they may need to be aware of what those structural barriers and how that can impact people accessing things within their own community and living environment.

And included in this sensitivity awareness is also the idea of doing myth busters for people who have very little to no experience with physical disabilities. We want to make sure that they're aware of things such as people who have goals at a similar age without

physical disabilities, people with physical disabilities have those similar goals. For example, they still may have a goal whether or not they have a disability or not of marriage, career, being sexually active and incorporating that into how they're going to communicate and assess and engage with their members as part of those competencies.

One of the things we feel is very important when doing those type of trainings in competencies is to have somebody with a physical disability, participate in that training if not be the primary lead for those trainings. And we do these trainings both in person as well as in online form on an ongoing basis.

We also look to support the staff in regards to communication and we spend a great deal of time reviewing communication competencies. We do something called the coach-approach which reviews things such as active listening, asking open-ended questions and reflecting on what that member has said back to you.

And of course, part of the competencies that we have expectations for with the staff is looking at -- understanding of the common disease and condition specific processes of somebody with a physical disability. What are those most common medical complications? Such as UTIs, urinary tract infections, wounds or respiratory infections. And what are the risk factors that you're going to look for in those disease processes and in those medical complications? Followed up by what are then the standard interventions that we can review with them, train with them, and then have an expectation that they are applying those standard interventions to address those barriers and risks that we just spoke of?

We try to incorporate this into an orientation and then obviously at an ongoing basis for the yearly performance evaluation. And then more importantly is we use this as a common ground for supervision with the staff and use chart review tools to ensure that it's actually being incorporated into practice.

Rachel Stacom: And I just want to piggy-back on whatever Elaine just said because I think organizations including ours, this is what we learned by trial and error that you can start the training but if it's not -- if you're not assessing, that it's integrated into practice, you're doing yourself a disservice. So training is one intervention to competency but really ensuring that it's integrated into your practice, into your evaluations, into your policies and procedures and that you're assessing that on a regular basis. It's very important.

Jennifer Kuo: Great. Thank you, Elaine and Rachel. Alright, the second question that we received is -- what suggestions do you have for when there are no interdisciplinary teams or liaisons to support participants as they move between care setting?

Rachael Stacom: Thank you. When we talk about this, one of the things we would like to do is try and help and support and facilitate the members themselves to be their own liaison and to give them a sense of empowerment if they have the capacity to do that and we would support them. Our ICS staff here would be able to offer various resources and

support in order to be that point person. And while that's occurring, we as our self -- the social workers, we would be there to be that liaison as they're moving through the various healthcare settings.

We do have staffs here who can -- in the beginning when they may not have that capacity, that skill, or ability to transition from appointment to follow up with what's being recommended, we would have staff that can go with them and attend with them and escort them to follow up appointments. Whether that would be something called an independent living associate, which is promoting the independent living theory of empowerment and self-direction skill to be independent within the community. We may have community health workers join them on a medical appointment. And all the while, they're working with the member directly to assist and facilitate that member to communicate their own needs, have their questions answered and understand whatever follow-ups may be the outcome of those various appointments.

And with that independent living associate who is somebody who's living with a physical disability and has been successful in being their own navigator, that person can work side by side with that member to show them self-direction skills, advocacy skills and practice, really, how to be assertive for one's needs without being aggressive and being clear, and be able to communicate what matters most to them. And that's really providing them ultimately with self management support to try and get them to that point where they -- like I said they can be their own liaison. Next slide.

Jennifer Kuo: Great, great. So our next question is -- How can care coordinators best work with providers and community-based organizations to create the working structure needed to make discovery of health-related programs accessible to people living with disabilities?

Rachael Stacom: So at ICS, and Elaine talked a little bit about this, about the coach approach that we use here. It's really important that we begin by creating a culture of listening, trying to understand what's going on with someone living with the disability and then responding. And then the disability community we'll often hear the phrase -- nothing about me without me.

And so if you're trying to help people improve their health and to make it accessible for someone living with the disability, it's really important that we're hearing directly from them where the unmet needs. So at ICS where we've heard that was -- I think it's around a third -- a half of our population, around a half are wheelchair users. And what we've heard from them was that they didn't have access to wheelchair repairs, right? So at ICS we started a wheelchair repair clinic.

And to Elaine's point about empowering someone to learn how to care for themselves, we have people there that can show them how to care for their own wheelchair and maybe make simple repairs. We also knew that when a wheelchair was broken that they needed a back-up because that is someone's legs. So it's really -- I use that as an example

to know that we found an unmet health need and then we figured out -- okay, well how can we address that?

The other thing is to take look at where your partners in the community. So are there people out there with resources to meet those unmet needs where there is inaccessibility to address them? And if -- with them, we link and we coordinate and if they're aren't, maybe we can share the cost of creating a program which we're all very conscious of our dollars, right? And how do we maximize the return on investment? And if you could find those organizations with similar missions, then partnering together has been very beneficial.

You also -- I can't understate this enough, is to have a network of providers that understands this population. And so we work with many different resources in the community. So for instance the MS Society or Mount Sinai Hospital that has both an MS center and a spinal cord injury center to look at ways of partnering together to make a health -- programs accessible.

And then we also work with -- Elaine talked about independent living models and organizations that are out there as well. So it's really about understanding, talking to the people you're trying to serve, coming together with a plan and then making sure that you're circling back to see how successful you are because we always have to tweak, right? And to do that on a continuous basis. Next slide.

Jennifer Kuo: Great. Thanks, Rachel.

All right, so another pre-submitted question we received is -- People who are living physical disabilities are at a higher risk than people who are not living with physical disabilities for behavioral health conditions or substance use. What can care coordinators and providers, including medical and behavioral health providers do, to be more effective in working with people who are living with these co-occurring conditions?

Elaine Castelluccio: So one of the approaches that we have found and have been recently utilizing in the last couple of years and it's been proven to be effective is something called motivational interviewing, which many of you on the phone may have heard of or even have put into practice. And motivational interviewing was originally developed and put into use for folks that do have substance abuse or chemical abuse and has now grown in population for people who are just looking to change into some sort of positive -- make some positive change within their lives. And there's kind of a common theme you're going to hear throughout our answering of the next several questions, is that it really comes down to understanding what motivates and what matters most to the member.

You'll hear us say this a couple of times in a few slides and what is really impacting their life. And based on what's impacting their life, what change are they willing to make because there has to be buy in from the member in order to even try to do some coordination and certainly with the member at complexes, what has been asked in this

question of somebody who has various medical co-conditions or behavioral co-conditions compounding all together. So, in using motivation, we're trying to get to the root cause of why these behaviors are getting in the way, are a barrier for whatever change needed to occur.

So, one thing that we've gotten better at over the years is really asking the why. And there's a great article about asking the five whys to get to really the root cause of something. In trying to ask those questions and engage with the member with motivational interviewing, is really asking to do that in a non-judgmental way and to not be offended if someone's angry.

And one of the things they said in this, in the training for motivational interviewing which struck us -- was that anger is often the first that you will see and the people who push away are generally the people that need you the most. So, if we can keep our assumptions at bay, if we can keep our conversations non-judgmental, we may have better interaction with these complex cases that we're discussing, and also realizing that there may be things that are playing a role here, like a history of trauma or a substance abuse -- we make an assumption that there might be substance abuse.

Well, there actually, for people with physical disabilities, it could be that they're using substances to treat a medical condition, especially with the popularity and the evidence showing that what could be the medical benefits of marijuana, for example. A lot of our members are on medical marijuana for the use of spasticity or muscle spasm management. And again, just as Rachel said in the slide earlier, the importance of linking this member to a provider that really understands disability.

If they have a lot of behavioral health issues and have some barriers already, if we send them to a provider that we haven't vetted and we haven't partnered with, and that we know understands physical disabilities, that appointment is less likely to be a successful as if we sent somebody who is a medical provider, who really gets what they're going through and understands their experience. This is another situation for these complex cases where we can look to an independent living associate or program to really help with the guidance and show a positive spirit of a similar lived experience, where the end result is, again, we want to go back to that self-management support and share decision making. Next slide.

Jennifer Kuo: Great. Thanks, Elaine. All right, so the next up, what are some effective strategies for sharing information among interdisciplinary teams, including care coordinators and healthcare providers? Are there examples of tools to support this?

Rachael Stacom: So, I think this is a great question and certainly one of the challenges that we face, where we have been most successful in doing is, it is when we -- in communicating, it's really when we establish a relationship. And remembering, you know, it's just -- it's just like how we interact with our friends and our family right? If you're comfortable with one another, if you know one another, things are going to move along much more quickly.

And so we have really seen that the power of a face-to-face meeting someone, talking to them in-person can really make a big difference. So, we encourage staff to go on visits. We know you cannot do this for everyone, but really thinking about where are those critical points in time, and can we go along. And so we have several boots on the ground staff here that will go out and join people on those appointments to really talk about what's going on and what the next step should be.

We've also put the care manager in the clinic once a week, or less frequently, or more frequently depending on the volume of members that go there. So, we, right now, have two partnerships, for example, with MS Centers where they have a high volume -- sorry, Multiple Sclerosis Centers. We use acronyms way too much in medicine and healthcare.

So where we have a high volume of our members and so we have the social work on-site there to support them. And it's really facilitated that the care for those people, meaning if they need -- so many times, you come in for an appointment and people get a list of next steps that can often be overwhelming and difficult to manage. So, if we can get in there and then put a plan together for the next 3 months, so when they come back, they've actually been able to do those steps, it has made a huge difference, and not just for the member, but for the provider because you really -- the more that we have shown that we can deliver, it creates buy in, and it fosters a relationship.

The other thing with providers is that people are really busy and so these MS clinics that we are in, this is a progressive neurologic disease, but the neurologist is booked -- double booked every 20 minutes, and so time is of the essence. So how can we make sure to make that conversation worthwhile, and so establishing communication preferences if we're not face-to-face, how would you like to receive information, email? Do you want to use the phone? Do you want to talk? Is there someone in your office who should be our contact? And we also utilize communication tools like SBAR, right? So it's very concise. What's the situation? What's the background that is pertinent to that situation? What's your assessment? And what are recommendations, if any? Sometimes, you're like -- I really need you to make the recommendations here. So we have been successful when we've created a relationship and we're partners truly and moving forward to try to help our members. Next slide.

Jennifer Kuo: All right. So our next question comes from a health plan. Could you describe best practices for coordinating between multiple agencies and stakeholders involved in care? We want to make sure our participants' care needs are met, but services aren't duplicated.

Rachael Stacom: Yeah. That's a great question. I feel like we live in a day where there are many different organizations in, trying to provide care management. I call it Care Management-itis.

One of our colleagues tells us a story about her mother-in-law who was in the hospital and three different care managers walked in, one from Medicare plan, one from Medicaid

plan, and one from the hospital because everyone wants to help someone, but things from the member's perspective, that can be quite overwhelming. So I think when you have different providers in, to really setup some time to talk about the member's care.

At ICS, we create a new plan of care every 6 months. Ideally, you want to do this with the member and the providers. Sometimes time doesn't allow that so doing prep work, just like that question that Elaine answered, if you can't have someone there, right? You want to coach them before. You want to talk to them before and then look back after to see how it went. So we want to do that here too. We want to review the goals and how we think we're going to meet them. We want to be really specific in identifying who's doing what and when. And we want to play to each other's strength, skills and expertise because we don't want to take on everything of care management when someone -- this is what someone does every day and they can do it in 5 minutes so they can pick -- it could take us hours.

So we want to create that plan of care and we want to, together, and then we want to update it regularly, right? So we talk about SMART goals here. I'm sure you have -- many of you have heard this, right? Whether it's achievable goals and interventions, we can do, who's doing what, who's doing it when. And we want to give that to the member, right? And it should always be member-focused. What matters to them and it should be aligned with that. And that's why we really want the member to be present when we do this because we're ultimately here to support them.

And then at ICS, I think it's really important that you have one quarterback. And so that's here, the care navigator, and that they are responsible for the overall care coordination. So did everyone do what the providers -- that organization is circling back, right? How is it going? Were you able to do what you needed to do? And then closing the loop and saying -- okay, because we wish every plan that we put in place went together perfectly, but often we have to re-adjust and so circling back, readjusting and then making sure everyone is in alignment and updating that plan of care.

Jennifer Kuo: Great. So our next question is another one from a health plan. Are there resources that are available for health plans to better support participants living with disability?

Rachael Stacom: Okay, so what we have found works best is really working closely with the resources that are within our own neighborhood and really looking at the local disability organizations, and working closely with them where we can consider them partners in care.

For example, we work very closely with the New York City chapter of the National Multiple Sclerosis Society. And we also work with New York Spinal which is in New York chapter of the national organization called United Spinal. And in working with our local chapters, we could support each other. We can look to what resources to build, local chapters can assist our members with and refer to their services, and vice versa. They can

book to what ICS has, and so is the resource for their membership and for the folks that they serve.

Many of those organizations as well. We have taken advantage of some of the trainings that they offer for both professional staff, as well as the members that we serve.

And so in coming together, it kind of answers to that previous question about duplication of services as well. And we can serve together with our community neighbors as a resource for care coordination for people with physical disabilities, looking at our local independent living centers, and especially if they're -- Mount Sinai is a spinal cord center of excellence, various MS centers, or multiple sclerosis centers that are in New York City, and working closely with them to provide better care coordination and utilizing each other as a resource.

And then for example, we can go nationally, for example, we're partners and a member of the National Disability Mentoring Coalition, which gives us the opportunity to look at what grants are out there, what educational opportunities are out there, and additional training services that we could take advantage of.

Elaine Castelluccio: So just to piggy back on that, so if people are listening, and they're not in the New York City area, go to those national websites, and they will show you where the local chapters are, the local organizations.

Jennifer Kuo: Alright. I know we're running short on time, but I'm going to squeeze in one last question because I think it's a really good one. So the one that's on the screen – As a substance use disorder counselor, we're tasked of addressing sleep, diet, exercise and medication management including pain management. What are potential gaps in care coordination to look for when counseling a participant who's living with a disability?

Rachael Stacom: So that is an excellent question and I'm glad we get to discuss it, because the gaps are really often the barriers that people with disabilities are facing when they're trying to stay healthy. And as a care coordinator, you need to have a level of awareness of those barriers and their risk factors, and how to prevent or address them.

So as I said before, you need to be able to develop and maintain a specialized network that can meet those health needs, so for example, in order for people to exercise if they're in a wheelchair, they need an adaptable gym, if someone needs to get a GYN exam, they need a table that they can transfer on to, and that have stirrups that are adjustable. And you need to keep their level of function always in the forefront of your mind, right, does this work with where their abilities are.

And then when things arise, we need to respond quickly, right? So for instance, Elaine said, urinary tract infection, yes, that's one of our most frequent reasons of hospitalizations, because what happens is that, someone goes for -- neurogenic bladder can often happen with people with spinal cord involvement, condition, so they get frequent UTIs, they have resistance, so if they don't do a urine culture, the clinician

doesn't do urine culture, they're going to become septic, right, if they put them on regular standard UTI medication.

So really understanding the disability and then looking at where, okay, what are the best practices and integrating them into your organization.

Unfortunately, the reality is, there aren't enough providers and care coordinators that understand these things. So that's why we're happy to be here with you today and that resources for integrated care are helping spread the word.

Jennifer Kuo: Great. Alright. So unfortunately, we are out of time, but I'm happy we were able to get that last question in. I just want to quickly mention that the remainder of the slides in this deck, so like 17, 18, 19, do list some additional resources, some from ICS, the CMS office of minority health, and also resources on this topic that are available on the RIC website.

I first want to say a big thank you to Rachael and Elaine, this is I think was such an informative webinar, we really appreciate your expertise that you brought today to answering all of the questions that were submitted. Also a thank you to our audience members for your questions and also for your participation on today's event.

If you have any questions, feel free to reach out to us at RIC@Lewin.com. And lastly, we do want to hear from you. You should be seeing a brief evaluation survey pop up on your screen, so take just a moment to complete that survey and give us feedback on today's conversation format, and any ideas for future topics and resources on disability competent care.

So we hope today's conversation was useful, and thank you again for joining us.