

Dignity of Risk – Disability-Competent Care Webinar Roundtable Series: Training in Disability-Competent Care and Supports

Event 743181

Operator: Ladies and gentlemen, good afternoon. Thank you for standing by and welcome to the Disability-Competent Care Webinar Roundtable. At this time all lines are in a listen-only mode. Later there will be an opportunity for your questions. Now, if you do wish to ask a question or need operator assistance today please press star followed by the zero and an AT&T operator will assist you. Once again, for questions and operator assistance please press star and then zero. At this time I'd like to turn the conference over to our host, Executive Director of the Disability Practice Institute, Mr. Chris Duff. Please go ahead.

Chris Duff: Thank you, Tom. On behalf of the Lewin Group and the Disability Practice Institute I would like to welcome you all to the first 2014 webinar roundtable session. Today we're focusing on the subject of the Dignity of Risk. As John said my name is Chris Duff and I'm with the Disability Practice Institute.

We're providing this webinar under contract with the Medicare and Medicaid Coordination Office at the Centers for Medicare and Medicaid Services. The Lewin Group has engaged the Disability Practice Institute to provide technical assistance to providers working with adults with disabilities.

First I'd like to introduce you to our platform for this presentation. If your slides are not advancing, please push F5 on your computer keyboard. Please note the two icons circled at the bottom of the current screen. The one on the right allows you to access the resources for this presentation. The red Q&A icon on the left is for technical questions. All other comments related to this session material should be posed through the group chat function. The chat icon is next to the Q&A icon and is brown in color. We are encouraging participants to pose and discuss any topics related to the other participants and speakers through this function.

This series will consist of eight webinars, four that will be presented in succession on Tuesdays in February at this time. We will take a two-week break and then resume with the other four starting on March 18.

All of the webinars will be recorded and are available along with a PDF of the slides at the link here. Last year we published a comprehensive Disability-Competent Care Tool describing Disability-Competent Care in three overarching components: first is individualized care coordination provided by an interdisciplinary team; second is redesigned primary care delivery; and third, flexible long term services and [support]. We followed this up with nine webinars focusing on individual components of disability-competent 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 the end of this webinar. And send us ideas for future topics and content. Our contact information is listed at the end of the presentation.

Our goal in this series is to be highly practical using experts in each topic area with organizational examples or first person stories to demonstrate key messages. The presentation will be no more than 20 minutes, allowing the remainder of time to explore questions or issues submitted by the participants.

Beyond the tech features through which you can submit questions and comments at any time, we will be using instant polling to ask specific questions to help guide our presentation. To demonstrate this process here is the first question. The question is what type of organization are you working within? And you can choose one of those four answers. Once you make a choice and submit the responses received will be tabulated and will be present for all to see. We will be putting up another couple of these later on in the presentation.

Today we are exploring the concept and application of the Dignity of Risk, a topic we touched upon a few times last year and which seemed to stimulate a fair amount of discussion. During our presentation we would like to discuss actual situations that commonly arise. So, think about times you or your colleagues have struggled with this issue and either submit questions or call in with a first person story. These issues in real life are not black and white and there's no right or wrong, a call for respectful and open discussion and reflection. The role of the health coordinator is to facilitate that discussion.

Today's webinar will be presented by Kathy Thurston who is a clinical director at AXIS Healthcare in Minnesota. Kathy is a seasoned RN and public health nurse and has worked specifically with adults with disabilities for over 15 years in the managed care environment. Joining her in the discussion will be Mary Lou Breslin. She has been a disability civil rights lawyer and policy advocate for over 35 years. In 1979 she co-founded The Disability Rights Education & Defense Fund and presently serves as senior policy advisor directing the organization's healthcare initiative.

Before turning this presentation over to them I wanted to provide some context regarding the need for this training. Persons with disabilities are wanting and expecting control over their care and support, seeking functional independence and greater participation in the community. To respond to these expectations providers will need to focus on the participant's goals and preferences as delineated in individualized care plans. And they will need to operate as an integrated team.

Through the new dual-eligible demonstration health plans are taking on new populations and benefits which require the involvement and support of providers serving this population and a continuous reinforcement of participant outcomes.

Today we will focus on how to work with participants to identify their goals and priorities, especially when they vary from those suggested by trained professionals. The classic example is a person who smokes cigarettes. By this point everyone who smokes has already been told to stop smoking, scaring them with the horror stories of lung cancer or other secondary complications of smoking has not been effective in getting them to quit if they are, in fact, still smoking. Thus, a discussion is in order, exploring with the participant why they smoke, how much they smoke, and their fears of quitting all in a non-judgmental manner. It's only through this discussion and understanding their motivations that you will be able to see if there is an opportunity to help the individual reduce or eliminate their usage.

For adults with disabilities who smoke at greater levels than the general population, there are common factors contributing to their desire to smoke: anxiety; depression; peer acceptance; and a variety of others. As a result of the discussion you may conclude that you need to build trust with the participant and address other issues and needs before pushing their smoking any further. The concern about their smoking doesn't go away. You are not just giving into their use of cigarettes, but putting it aside for the time being to address at a later time.

Now, I'll hand it over to Kathy for her presentation.

Kathy Thurston: Thank you, Chris, and good afternoon to all of the participants. I'm pleased to be talking to you today about care coordination and the dignity of risk and hopeful that my comments may provide you with some useful tools for the work that you do and ultimately make a difference in the lives of people with disabilities.

So, to kick us off I want to start just with a general statement about person-centeredness and how important that is. A genuine, respectful person-centered approach to care coordination assumes that everyone is competent and has a right to make his or her own choices. As Chris has stated, each of us has the right to make choices in our lives that may put us at risk of poor health or injury and effective care coordination needs to expect and respect this dignity of risk.

Unfortunately, often in our desire to help people with disabilities, healthcare professionals move much too easily into the fix-it or make it right mode. So, we'll unpack that a little bit as we go through the slides.

Everyone needs enough control in their life to choose what they value and reject what they don't, but this is not a comfortable place for most healthcare professionals, in particular when we see the person across the room as vulnerable. We have to accept that some people will choose a path that may put them at greater risk of illness or injury. In an effort to protect people from risk, the healthcare and social safety systems have historically placed people with disabilities into environments that actually cut them off from opportunities to grow and develop and take risks.

And for the most part, we continue to build care and service plans from this avoidance of risk perspective. Therefore, a key challenge for healthcare professionals is to acquire new skills that enable us to better collaborate with people, in particular people with disabilities, and support them to determine the right amount of risk for them. This is really a crucial component of effective care planning and care coordination.

Many people with disabilities have been let down by the healthcare system, so establishing trust may take a long time.

Allow the person the time and space they need to tell their story before launching into questions, assessments, or checklists is a crucial step in establishing trust. It will also lead to a better understanding of that person's basic requirement for happiness and what is most important to them.

This will help us be able to better partner with them to manage risk within the context of what is important for their health and safety.

So, each person has a story to tell. The life they have lived. The life they're living. And the life they hope to live. Without the person's input into a plan of care, it is really just a list of interventions and behavior changes from the perspective of the healthcare professional. It's designed to improve health and reduce the risk of further illness or injury. And while these are good things, that person is really not at the center of a plan that's been built that way. And it doesn't necessarily include things that are really important to them. That can only happen when we create the space and time that will allow them to tell their story.

So, in addition to traditional health risks and safety questions, it's really important to invite them to tell that story and therefore we have to put our checklists down and listen. If we don't, the reflex to interrupt them, correct them, or make comments is so hard wired into us it will disrupt our ability to hear what is important to them.

There are some questions and tools that help facilitate understanding what is important to someone. And I've got some examples for you here. What if anything would you like to be different? Why is that important to you? Is there someone in your life who supports you or helps you? Can you name something that you would like to accomplish? How can I help you with that? So, we need to become skillful at guiding people towards appropriate attainable goals that they're able to articulate and then help them define some action steps that will respect what is important to them.

Once you gain a better understanding of someone's story and what is really important to them, you can talk about one or two things that they might be willing to work on that are also important for them. This leads to developing a more meaningful and ultimately a more effective plan.

So, we'll look at a real person story, and you can listen if you would for his experience, the life he's lived, his hopes, his fears, strengths, and we'll talk about what is important to him as we walk through this story.

I believe each of you have received a document. It would be a PDF document. We're going to look first at John and his story. And as I walk through it I, again invite you to think about how you and your colleagues might work with someone like John. In all likelihood what you are about to hear will sound somewhat familiar.

John enrolled in a Medicaid managed care plan in 2011 and was referred for care coordination. He's 56 years old and he has severe osteoarthritis which particularly affects his knees and shoulders and has greatly limited his mobility for many years. Currently he weighs just under 500 pounds and he is no longer able to walk or bear weight long enough to transfer from his bed to a chair. And he now has been confined to his bed for six months.

He has a significant longstanding mental health history related to depression and anxiety. John has lived in his own apartment for many years. He is dependent in most of his activities due to mobility limitations and obesity. He gets nine hours a day of personal care and homemaking services. He has many interests and he made his living as a professional artist for many years. He also has emotional support from family and friends, but they all live outside the state.

He really has no one to call and help him if his personal care personnel don't show up or the provider is not able to fill his shift. So, his emergency backup plan is to keep his cell phone within reach at all times and call 911 if necessary.

Prior to his referral to care coordination, John had problems with cellulitis and skin breakdown in the back of his legs and abdomen. John also experienced a recurrent urinary tract infection resulting in multiple hospitalizations. In addition, with each admission the cellulitis was aggravated and he developed skin breakdown which extended his recovery time in the hospital. John is highly sensitive about his weight and does not want to discuss this with any healthcare providers. He has stated that he does not want to lose weight and has a history of changing medical providers if they tell him he must lose weight. And as a result John has a lot of anxiety about attending medical appointments and often he does not keep them.

So, that's John. And I'm going to just walk through some of the steps that we took in working with John, in partnership with John, to come up with a workable plan. First of all, it was important to understand what was important to him. The coordinator allowed John time to tell his story and in the process learned about the things that actually were most important to him. More than anything else, he wanted to remain in his home and stay out of the hospital. It was also important to him to have someone in his court, as he put it, at medical appointments to help ensure that his needs, symptoms and concerns were adequately communicated.

Next, a person-centered plan was developed. Next slide, thank you. John and his care coordinator worked with his primary care provider, the PCA provider, the personal care provider, and his sister to

make a plan that addressed both what was important to him and what was important for him. The plan first focused on the areas that John wanted to change: staying out of the hospital and having someone help him navigate medical appointments. This coordinator arranged for an in-home wound nurse who established a home management program. In addition the coordinator worked with John and his primary care provider and urologist to establish an in-home program that would allow for fast response to any urinary tract symptoms. This was then in partnership with an in-home lab service.

And the care coordinator now attends all of his medical consult visits, initial medical consult visits, his annual physical with his primary care provider, and helps him prepare written questions by phone prior to any other medical appointments.

Then the plan was implemented. John's healthcare providers and others in his circle of support accepted and respected what was important to John. John agreed to work on things that were important for his health and safety. As a result, John has had no further skin breakdown. He has not been hospitalized for over a year. And he remains in his own home.

At this point I want to just check in with Mary Lou, my co-facilitator today, and now that we've heard John's story and a little bit of what we did here in a working partnership with him. Just interested in any thoughts or comments about this from your perspective, Mary Lou.

Mary Lou Breslin: Well, hi everybody and thanks Kathy. Well, I think that John's story maybe has some typical elements for many of you who are participating today. I think that the key element in this story was the process of identifying John's specific needs and interests from his perspective and really working on the solutions that would enable him to continue to remain in his home and that respected his concerns over the issues that would no doubt have triggered very significant responses from most healthcare professionals.

Kathy, I'm wondering though just in terms of sort of the long-term plan for him, one of the concerns that he had was his inability to request the help if one of his care providers didn't show up or wasn't able to make a shift. And he was relying on the 911 system. And I'm wondering, given that he has a cell phone and you had worked with him to provide additional PAS services, when he might need them if a shift was not met. How was that process developed and was that a process that you found to be easy to implement through your own system?

Kathy Thurston: So, I just want to clarify the question that you're asking me. Are you asking if his backup plan of using a cell phone to call for help, if that was an effective strategy in his case?

Mary Lou Breslin: Well, I was asking – my understanding was that there was a plan to provide additional care assistance to him when the scheduled care provider didn't show up. Is that correct, or was he really relying on 911 as the only backup?

Kathy Thurston: Oh, right, yes. I mean, typically what would happen in the case of John in particular, but anyone we might be working with is first and foremost the PCA, the personal care attendant provider organization has backup staff to fill shifts. So, somebody not showing up for a scheduled shift and not being able to fill that is a pretty rare event, but it does happen. So, that's the safety net that's in place for people like John. But there needs to always be an emergency plan for the event that, you know, there's a major disaster and they can't find someone to fill the shift and he really is alone for those nine hours where he normally gets help.

In his case, fortunately – knock on the desk – he's not been in a situation where he's needed to call 911. We've been able to adequately pull together staffing for him.

Mary Lou Breslin: What key lessons do you think you organizationally learned from the interaction with John that is most useful for the folks who are participating in the webinar today?

Kathy Thurston: Well I could talk a long time about that but I'll try to state it briefly. While I've been able to sum up John's story in a handful of slides and a few paragraphs, none of this happens quickly and not without bumps. So, I think the message I would like to relay is this is complicated and challenging, even for the most seasoned staff. And in particular we emphasize the importance of establishing a trusting relationship over time with folks and so one of the downsides of that is that it's really difficult to not be personally invested in that recipient after you've been working with them for two or three years. So, what I would say is it's so crucial to have team meetings and care conferences and be checking in with people so that they have the kind of support they need to continue to do good work with people. When you feel like you're supporting a situation that is potentially harmful to someone, that can really eat away at some of our professional staff.

So, that's just an ongoing challenge when we're working with people who have complicated lives.

Mary Lou Breslin: I'm wondering if you can comment a little bit on the role of the primary care physician in working in the care coordination team. Wondering if it was difficult to find a care provider that was interested in supporting the dignity of risk kind of goals that you established with John.

Kathy Thurston: Yes. John went through quite a few medical providers over the years that we've been working with him. We've been fortunate to continue to be able to find primary care providers, in particular. The physician that's working with John right now has been really instrumental and helpful in recent months to help us begin the dialogue of life sustaining treatments, looking down the road. John's goal, what's most important to him, is to stay out of the hospital and remain in his own home. And so a natural dialogue that really needs to take place, it doesn't always happen naturally, is so what happens John if your urinary tract infection makes you need to go to the hospital to get treated and survive.

And we're not very far along that path with John right now, but we are fortunate to have a provider here who is very comfortable in engaging him in that discussion.

Chris Duff: I think at this point what I may do is try to open up the phone lines for comments from the participants. I also wanted to remind people to feel free to use the group chat function, that's the brown icon third from the right at the bottom, no, third from the left at the bottom. And that's just a way to kind of chat with each other.

So, Tom, could you come back in and instruct people on the phones?

Operator: Thank you. Ladies and gentlemen, if you wish to ask a question please press star followed by the zero. You'll hear a tone indicating you've been placed in queue and an operator will assist you. Once again, please press star zero for questions.

Chris Duff: Thank you. I see that the poll results about having an organizational policy is actually much better than I thought it was going to be. Almost 60% of you respond that you do have a policy. That's great. And that's something that I know is always an ongoing issue. And this leads to a question that I have for Kathy. And that is what systems do you have in place to ensure that your staff follow your policies and expectations regarding respecting the participant's dignity of risk?

Kathy Thurston: Well, we do several things. We have a weekly seminar, care coordination seminar, specifically to ask – where the staff brings forward challenging situations, situations where they're feeling challenged. And not all the time do those situations involve people choosing to live with a certain amount of risk, but frequently that's a concern that's brought forward. So, that's a relatively informal setting that involves managers and supervisors and care coordination staff talking together. And that's an opportunity to remind people of the person-centered approach that is a fundamental part of the work that we do.

It's built into performance reviews, job descriptions, and is part of regular training. Any trainings that we do always bring it back to person-centeredness and listening effectively and using motivational interviewing skills.

We have implemented over the last year and a half formal training on motivational interviewing with all of our care coordination staff. We've built a team of care coordination motivational interviewing internal experts who facilitate motivational interviewing coaching circles every one to two months. And it's a peer-to-peer process where they're helping each other become more skilled at that. So, just a handful of examples.

Chris Duff: I think this would be a good example of if any of you who are attending this webinar have some experiences that would broaden what Kathy said, please either call in or share your experiences in the group chat line.

Similar to the questions from Mary Lou, a question came in through the Q&A and that is what do you do about emergency plans. So, Kathy I'm assuming that the part of the whole care coordination process is you identify emergency plans with all participants. Can you talk a bit about how you build that into your discussion with them around risk?

Kathy Thurston: Yes. For all of the recipients who are referred to us for care coordination we do an initial greeting and in-personal health risk assessment. That's repeated then typically once a year, sometimes more often if there are changes. But one of the components of that health risk assessment is to ask questions about what is important to people in addition to kind of getting all of that – the assessment types of questions that we have to ask – but we begin and end all assessments with questions that have to do with what do you hope to accomplish, what's important to you, and then begin to talk about some of the things that appear to be important for them for their health and safety.

One of those is talking about an emergency plan. So, that discussion happens with every recipient regardless of their level of need or the extent of their disability or other health conditions. So, what will you do if the supports and services that you rely on are not available to you on any given day. What's your backup plan, is there family, do you have neighbors? And in some cases like John's it really is, you know, we have to rely on the first responders in the community if he really is without the help that he needs.

It's a fundamental discussion that happens with every recipient at least annually.

Chris Duff: Thank you. Mary Lou, a question has come in from Marilyn and she's a policy analyst. And she says that she has encountered both covert and overt hostility to these concepts on the part of legislators. Any recommendations on how to change the underlying social infrastructure to facilitate implementation of risk taking?

Mary Lou Breslin: I think it's a great question because I think having what Marilyn is encountering is the kind of paternalism that the disability community has been facing historically when we work for integration in the community, when we try to reduce dependency upon institutionalizations from federal funding.

I think that one of the key elements in working effectively with legislators and with legislative staff, particularly on state initiatives, is really to bring real stories to the forefront. And obviously we have to pick our stories relatively carefully but I think that presenting the success stories, particularly from the perspective of the provider as Kathy is doing today takes us a long way down the road to making the case from a human perspective and also making the case from a financial perspective. So, marrying the two elements in terms of legislative education I think is the first step. Obviously shaping policy interventions is the more complicated discussion possibly for another webinar. But it seems to me that one of the very first steps is the business of letting legislators know and understand why this is an important goal, what the benefits are to the individual and what the benefits are ultimately to society and from a cost perspective to the provider.

Chris Duff: I also think it's a great question. And I would just like to reiterate what Mary Lou said is it's a change that's happening in this country as a whole. I think it started back in the '60s when the country started deinstitutionalizing people with developmental disabilities and pushing them – getting them into

the community. This is certainly going to continue to be a long term dialogue. Our responsibility in the healthcare world is, of course, to support the broader question and dialogue, but I think the more we can bring it back to talking about John and John's life and John's priorities, that is where we as a care team working with these individuals need to focus.

We also have an interesting question from another person that's very related and that is, "Can you give a dignity of risk example where the member's situation calls disagreement on the team's approach and how do you deal with this disagreement. And I'll warn you up front that there's going to be a follow up question from me about a disagreement amongst family members and your participant about how to handle a situation."

So, basically how do you process disagreements or conflicts among those who are involved with John or whomever it may be?

Kathy Thurston: Oh, gosh. Okay. So, this is Kathy. I'll take that one. Of course those things happen. Thinking about the team, yeah, I mean, one scenario I can recall – this has happened more than once – where the medical provider and the member recipient, care coordinator, and family are not all on the same page in terms of the risk that someone is willing to live with and wants to choose to live with.

There's not a black and white answer to those kinds of situations. I think the most helpful thing to think about is why do we end up in that place because I think it happens because we haven't sat down sooner, before you're kind of in the crisis mode, and mapped out from the recipient's perspective, again back to how do I want to live my life in the future. And what kinds of treatments do I want to agree to versus what I don't want to agree to, or changes in my living environment, or the kinds of support that I get.

In my experience it's the lack of proactive dialogue and really taking the time to listen to that individual that gets us into those situations where you have, whether it's the medical provider, or a family member, or a friend, or a care coordinator, or a case manager – because that will also happen. That's when we get into those dilemmas and you just have to kind of work your way through it. When you find yourself in the situations and pull all the parties together with the focus on what's really important to that individual and how do they want to choose to live out their days.

Kind of a convoluted answer to that question, but I think no matter who is in disagreement it's probably because we haven't had the honest conversations going on.

Chris Duff: Mary Lou, do you have any comments on that?

Mary Lou Breslin: Well, I think it's a really great question and I think it's – having been in the situation where family members can be in disagreement with the person who is receiving the coordinated care and sometimes with the physician, I think Kathy's answer is a good start, the communication issues have to be worked out from the beginning.

But I think there's also occasionally some fundamental strong disagreements and different perspectives about what level of risk is acceptable. And I think ultimately although the resolution has to sort of work through the various points of view of the participants and the coordination and team members, I think ultimately one of the most important factors is to sort of go back to what Kathy mentioned at the beginning of this webinar which is the need to listen to what people say they want about the way they want to live their lives. And that ultimately it's sort of the job of all the care coordination team members to differ to that preference to the extent possible and to argue in favor of it. And it seems to me if everybody agrees that that's the operational principle then it's easier – not easy – but easier to begin to sort of unpackage the differences of opinion and place them in the context of what the person wants themselves and potential work toward an agreement or at least if not a consensus at least a general sense that everyone agrees that the steps that are being taken are moving toward that person's goals.

Kathy Thurston: Do I have time to do another comment?

Chris Duff: Absolutely.

Kathy Thurston: Okay. So, this made me think of an often played out – unfortunately an often played out scenario – for some of the recipients we work with here. And not really giving people the opportunity to talk about what's important to them. When someone has a high level spinal cord injury, for example, or very advanced MS where their mobility is severely impaired and they are struggling with wounds, pressure wounds specifically. This is a scenario that often – this is often what will happen in situations.

A primary care provider will be overwhelmed by the rule management and refer the individual to a wound clinic for specialty care. And ultimately once that door is opened the path is going to end up in wound slap surgery. And this is an area that we are constantly working on here in our organization to bring it back to, so what is important to that individual and were they given a real opportunity to have a dialogue about how to manage these wounds. And do they want to have surgery to fix those wounds that will require them to be in bed rest for many, many, many weeks and to stay with a wound prevention protocol long term that will require special attention to taking the pressure off by not being in their chair throughout the day without break.

And we don't believe that in most cases, if not all cases, that that kind of really informed dialogue takes place with people and before they know it they're on this path that isn't the way they want to live their life at all. And what then happens is they get labeled as non-compliant or non-adherent with the wound care plan. And fundamentally they never wanted that anyhow. So, I'm just throwing that out there because I'm hoping that might stimulate some questions and comments on – that's a real hairy one.

Mary Lou Breslin: This is Mary Lou, can I just jump in for a second and sort of add to that example? I think that in some cases the wound care problem arises because there has been a breakdown in communication between the folks who are responsible for dealing with adequate wheelchair seating and cushioning.

Kathy Thurston: Absolutely.

Mary Lou Breslin: And often when – quite frankly I think that the examination from potential pressure problems doesn't take place in a physician's office or doesn't take place by a care giver. And the process of trying to head that problem off has a couple of components before it turns into the acute situation that you're describing. So, I think that those are opportunities for sort of improving as you go forward what the protocol is for trying to keep track of what's happening and whether or not the durable medical equipment is adequate and there's really good attempts to observe what's going on before it gets to a crisis situation.

Kathy Thurston: Oh, absolutely. Yes. Absolutely.

Chris Duff: I also really appreciate you raising the whole concept of the provider labeling the person non-compliant, so be it just kind of checking off, "There's nothing I can do." It's like giving up, throwing your

hands in the air. And what we're trying to talk about here in care coordination is you just keep going at it and you just keep going at it in different ways. Non-compliance means that we haven't come up with the plan that's working for the person. And so I really appreciate you putting that concept on the table.

Kind of somewhat related to this, there's a question that came forward that I think is interesting and it's from Dan R. The question is how do you deal with risk taking/dignity of risk with an individual known to be deeply depressed who seems to want to take the risk but may be expressing the passivity of depression instead? In other words, how do you sort through what is just simply depression and "I don't care."

Kathy Thurston: Oh, great question. Well, first and foremost, this is all done in the context of assessment information. Hopefully having adequate information about the individual so that you would know if there is a history. So, of course, in John's case he did have a history of anxiety and depression. His bigger issue was anxiety, but it was actually fairly well managed in his case. He was good about taking his medications and situationally things would happen that would exacerbate that and there were interventions we could implement such as helping him with his medical appointments to reduce that anxiety.

So, we would say first and foremost that we need to make sure that people are well connected with mental health professionals and that here is a fair assessment evaluation of that and not assume it's just because they don't care about whatever but that there might actually be something going on. So, I think we have to be diligent in looking at the whole person and making sure that we're not just overlooking something crucial like adequate treatment for depression, that that's been vetted out and there's a good treatment plan and they're clearly making their desires known and they're of sound mind and we would pursue what's important to them in terms of the level of risk that they're willing to live with.

Chris Duff: Thank you. John, let me just take a break for a second. Are there any questions on the phone lines?

Operator: Not at this time.

Chris Duff: Thank you. We're getting a lot of questions through the chat and the Q&A, so I think I'll continue to go through that. And another one has come up here from Anthony E. If the idea of the process is to weigh the patient's desires versus the type of care he/she actually needs, how will safety

decide and how is it determined what patients or we use the word participants are safe – or how is it determined that participants are safe?

Kathy Thurston: Trying to process the question.

Chris Duff: I think it goes to another question that we've received also which is under what circumstances do you consider initiating guardianship or conservatorship on behalf of the participant? When do you think that they're not, that they cross the line to imminent danger and therefore respecting the dignity of risk is more ethically questionable?

Kathy Thurston: Yes. I hear it. You know, I would say, and this would be true if you look at our policy procedures, we don't have a black and white procedure that says when this, this, and this is happening you make a referral for guardianship or commitment. Those are really vetted out very carefully with a team and I think there are very extreme situations, but certainly if you've got a situation where there's a history of severe persistent mental illness and there's a history of danger to self or others and we're starting to see those behaviors exhibit themselves, we're going to be talking about going down that other path where things are more restricted. But I think generally speaking the tendency is to go there too quickly without carefully evaluating with all the relevant circle of support participants, the individuals themselves, immediate family, long term health care providers, and any other support that they might have.

There's really nothing we can do in terms of care coordination that's going to guarantee someone's safety. And so looking back to the question about how do you know that someone's desires versus their needs has them in a safe situation, the caution I give to all of us is who is defining safe. And if someone is competent and able to make their own decisions, they are the ones that decide what's a comfortable safety level for themselves versus that being imposed on them. And that's fundamentally what we're talking about is, you know, navigating that path where we're not being completely paternalistic and controlling someone's life and decisions, you know, versus pointing out to them do you understand that this decision that you're making, these are the things that could happen and may very well likely happen to you when you make that choice. So, it's making sure that they understand the risk, the potential long term effects of that choice, short term effects of that choice, and that they're really confident to make those decisions.

Chris Duff: Mary Lou, do you want to add to that at all or provide insight?

Mary Lou Breslin: Well, I like the fact that Kathy I think was clear about, the test for determining competency is a really rigorous one and it's certainly a legal one. And I think that just as the conversation was unfolding here I was just thinking about the kinds of risks that people who do not have disabilities take every day with their behavior, both in terms of alcohol consumption, smoking, all kinds of risky behaviors that people engage in that don't come under scrutiny by the medical profession because they are not – or by a care coordination team largely because they are not receiving public benefits and public healthcare through a managed Medicaid system.

And I think that the idea that we're combating paternalism here through this idea of the dignity of risk is a really important element in the overall discussion. Because someone solely has a disability and is in need of various kinds of support services should not abrogate their right to take risks that they see fit to take if they are competent to make those decisions. I'm really restating what Kathy already said. I think that we need to keep in mind that people with disabilities are really no different than people who do not have disabilities in terms of their right to take a risk and their right to live their lives as they choose.

The fine line really is to make sure that the danger to self or others test is met when there's the assumption that there needs to be an intervention of some kind.

Chris Duff: Mary Lou you're frame on that with bringing it back to the overall change that we're trying to bring about in the healthcare delivery system, people get more engaged, take more responsibility for their own behaviors and their own actions and decisions. And that naturally brings in a bias that we all need to be sensitive to and responsive and call each other on if we bring a bias perspective to any of the populations we work with .

There is a question here related back to the question from June and that is have you encountered situations where it's hard to distinguish between the dignity of risk and a suicide related path? In other words, do you see their behavior or your fear is that their behavior is basically a path of suicidal ideation?

Kathy Thurston: Yeah, you know, we have not found that to be really a challenge. I mean, if someone is assessed to be going down a suicidal path, suicidal ideation. We have protocols that are staff are trained in and we have crisis resources available that we would connect our recipients with in those circumstances. I actually don't think that it's difficult to make that distinction. The mild "I'm kind of

depressed or anxious” less explicit harm to self is where it’s a little trickier, I think. But I’m speaking from our experience here that that’s usually a pretty clear distinction when someone is in that state of mind. We’re listening for the words that say, “I have a plan, this is what I’m going to do,” and we’re just down that path of crisis management at that point.

Of course, that’s not a dialogue directly. I can’t ask the individual if I’m answering his or her question.

Chris Duff: I think that’s – you made a couple points if nothing else engaging in the dialogue and that if you have a relationship with the person you can sort through their depression/anxiety/fear from active moving down the path towards suicide. And that makes sense.

Kathy Thurston: Right.

Chris Duff: We have just a few moments left here and I want to flip it really almost the other side of this whole discussion with a question that we received. And it’s directed to Kathy, but I’m interested in your perspective, too, Mary Lou. If someone is aging into disability and feels that living in their home is no longer an option, how can the care coordination team introduce the idea towards self-direction while respecting the participant’s concerns and their preferences to live in a more restrictive setting? In other words, how do you introduce the idea of a range of risk instead of going to the other extreme of being institutionalized?

Kathy Thurston: Well, my response to this is – I feel like I’m repeating myself a lot, but assuming that we’ve been working with someone over time and they’re aging over time, this is a conversation that doesn’t wait until someone turns 65, or 75 might be a better number to choose nowadays. But, that first and foremost people need to know about all the variety of opportunities and options that are available to them as they age with disability and other health conditions that are chronic health conditions.

In some cases, some people may benefit in terms of their health and safety from moving from a more independent setting to a setting that has more services in place. That’s not necessarily a bad thing if that’s important to them. But I think sometimes we wait too long to have that dialogue and people don’t necessarily understand that they can continue where they are. We may need to bring more services in if they want, or just support their desire.

I can't honestly say that we've had a situation where someone has asked to move to a more restrictive setting. We may have had that and I'm not aware of it. I'm fascinated by the question. But, again, I would back it up to that in my mind that would happen in the situation where people maybe weren't given information about the fact that they could stay where they are. So, that's where you start the dialogue.

In working on a plan that's person-centered you're not just talking about today and the next six months. This is your life now and how do you want to live your life going into the future and then revisiting that on a regular basis or monitoring how things are going and anticipating some of those changes that people will experience either emotionally or physically as they begin to age.

I'd love to hear if Mary Lou has anything to say about that.

Mary Lou Breslin: Well, I loved your answer, Kathy. But when Chris asked the question I was thinking that the situation may involve someone who actually is perhaps new to your system or a managed care system and has not had the benefit of the ramp up that you've described to offer the interventions and offer the services so that they're aware – the person is aware that they're available. Or, perhaps the person is making the assumption that there really no choices and that this is the inevitable sort of end result of the acquisition of certain disabilities or certain impairments. And that the process of trying to reverse that longstanding perception I think is where you would be coming in and offering the alternatives and trying to present them as a menu that people could choose from.

But I think it's probably harder to reverse the process of assuming that one has to be living in a more restricted setting when there hasn't been this opportunity for education along the way. I just think it's a greater challenge at that stage. And I think it's probably a challenge that a lot of organizations are facing with older people who as they age are really experiencing more significant limitations that do need accommodations and do need services and the methods to do that have to be sort of set out in ways that can be contemplated before decisions are made.

Chris Duff: I need to begin wrapping this up at this point. I want to call attention to something that was going on in the chat lines. Mindy C talked about aging into disability and I think this especially happens, what we were just talking about when someone feels like they're a burden on those around them. And I think the ADRC is bringing a really unique set of competency and experience to health plans they're partnering with to look at the options that work with the person through, again, through care

coordination, discussion, and dialogue, and relationships to look at the options and support that can be brought in, or different options short of the other extreme of a nursing home setting.

I think this boils back down to the plan and the care coordinator's comfort and relationships to pull in ADRC's – that's Aging and Disability Resource Centers – or Centers for Independent Living who have more experience in having this discussion.

I think at this point we have reached the hour. I wanted to thank everyone for joining us . I appreciate all of the discussion going on in the chat room. I think there were some interesting ideas put forward there.

We also ask that you answer the short survey that's up on the website right now. It's a handful of questions that will give us some guidance both in terms of this webinar as well as the future.

For those of you who have been with us in the past, you see that this is a whole new format we're trying to work with, integrating the chat and the phone lines and the Q&A. And so we really want to see if this is working well for everyone.

So, take the time if you would to respond to the survey on the link on your screen. And we hope that you will join us next week when we're talking about meaningful participant engagement in the health plan or provider.

Thank you very much everyone. Bye-bye.

Operator: Ladies and gentlemen, that does conclude our conference for today. We thank you for your participation and using the AT&T Executive Teleconference. You may now disconnect.