

Strategies for the Implementation of Disability-Competent Care
Dignity of Risk
June 3rd, 2015 - Transcript

Nick: Ladies and gentlemen, thank you for standing by and welcome to the discussion of strategies for the implementation of disability-competent care. At this time phone lines are in a listen-only mode. We will have an opportunity for a question and answer session. If you should require operator assistance or if you'd like to ask a question later on, then press star then zero on your telephone keypad. At this time, I'd like to turn the conference over to our first speaker, Christopher Duff. Please, go ahead.

Christopher Duff: On behalf of the Lewin group, I would like to welcome you to this session on the Dignity of Risk, which is the fifth in a 2015 webinar roundtable series on disability competent care. As Nick stated, my name is Chris Duff, and I'm a disabilities practice and policy consultant working with the Lewin group in Medicare and Medicaid Coordination Office at the Centers for Medicare and Medicaid Services as contracted with the Lewin Group to develop technical assistance and actionable tools to support providers in their efforts to deliver more integrated coordinated care to Medicare/Medicaid enrollees.

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. Also please note the icons at the bottom of the screen. The second icon from the right allows you to download the slides for this presentation. A Q&A window is open next to the viewer slides. Please enter any questions you may have regarding material, and we look forward to discussing them during the Q&A portion of the presentation.

Beyond the Q&A feature to which you can submit questions and comments at any time, we will be using instant polling to ask specific questions to guide our presentation. To demonstrate this process, here is the first question. What working experience do you bring to this webinar? Please choose all that apply. While you're answering that, I will go ahead and get back to it in just a minute.

This series consists of eight webinars running on Wednesdays at this time through June 24th. All the webinars will be recorded and available, along with a PDF of the slides. Click the link on this slide--www.resourcesforintegratedcare.com. In 2013, we published a comprehensive disability competent care self-assessment tool defining disability-competent care in three pillars-- individualized care coordination, redesigned primary care, and flexible long term service and supports. This is our third webinar series focusing on specific components in disability-competent care. Resources from past webinar series, as well as other related materials are available on the RIC website I mentioned earlier.

Our previous webinar series were all more content laden with little time available for discussion and Q&A. For this series, we are switching that around with only summary content being provided to allow for more discussion. We would like to solicit your opinion on the series, as well as pass webinars and supplemental material. Please take your time to complete our survey at

the end of this webinar and send us your ideas for future topics and content. Content information is listed at the end of the presentation.

At this time, I'd like to go back and review the results on the first polling question. It looks like the vast majority of you are bringing some experience working directly with people with disabilities. We have a few people who actually live with disability, and I'm interested in hearing from them along the way, because I think it's very important that we listen to their voice in everything we do. There are still some in the group here that have minimal experience. It was helpful to see that.

Today Dr. Burrows is returning. Dr. Burrows and will be joined by a new presenter, Karen Luken. Dr. Burrows is currently Medical Director at Upham's Corner PACE program and Senior Medical Director at the Senior Care Organization at Commonwealth Care Alliance, both in Boston, Massachusetts. He is an internal specializing in geriatrics and is a national leader in the development of provider-centered care delivery models, focusing on adults with complex health needs.

Karen Luken has had a long career in rehabilitation, public health, and public policy and has published extensively. Her particular interest and area of expertise is related systems and services with persons with intellectual disabilities and developmental disabilities especially related to health care access and preventative care for this population. Most recently, she has been working on building components of health care homes, integrated, person-centered, and coordinated service delivery systems that make primary, acute, and behavioral health and long-term services and supports.

Today's webinar is focusing on the concept of the dignity of risk within the context of participant choice and direction. The presenters will address these concepts from both a participant and provider perspective and show how they bring them to life through first-person stories. As I led teams working with adults and with disabilities, I've seen this issue become increasingly challenging, as we have worked to integrate adults with disabilities into the community. Like many of you, I was trained as a health care provider where I was expected to bring my judgment to what I thought was best for the individual. This judgment was professionally influenced founded in good assessment and diagnostic tools and competency and focused on physical health.

Over time, though, I've come to see and we've all come to see and appreciate that we are all multi-dimensional with dreams, hopes, and aspirations that drive our actions. In practice as professionals, we must ensure Maslow's Hierarchy of Needs are addressed for self-actualization to occur. Thus this cannot be addressed as purely physical safety or health, but within the context of the individual's overall life.

To provide the presenters additional context, I would like to ask another polling question. How well do you think the concepts we are talking about today--dignity of risk, honoring choice, self determination--how well do you understand them personally?--very well, fairly well, partially, and poorly. I'm going to go ahead and hand this over to Karen at this point. She will be reviewing those polling results in a couple of slides here. At this point, Karen, could you take it?

Karen Luken: Thank you. Good afternoon and I appreciate this opportunity to join this webinar presentation. To set the stage for our discussion on dignity of risk and disability-competent care, I think it's important to first take a look at the principles of self-determination starting with the definition and then a brief look at some historical perspective. Self-determination can be defined as making choices and decisions based on personal preferences and interest with the sense of one's goals and self-direction. People with disability have the same right to and thus the responsibilities that go along with self-determination as all of us. People must have opportunities to exercise self-determination, be supported in those efforts, and have the actual authority to exert control over their lives.

Hopefully, as those last two bullet statements were made, people were nodding their head--yes, I agree. That makes sense to me--but the reality is we need to be aware of some historical context around self-determination that has impacted the choices and opportunities often afforded to people with disability. Let's start by looking at some of the service systems, particularly health systems and disability service systems and acknowledge that many of the service systems are geared towards over protection, which is actually counterproductive to enabling someone to experience personal goals, make informed choices, and thus have the experience of dignity of risk.

There is a tendency often for service systems and thus the staff that they employ to go overboard in our efforts to protect, to comfort, to keep safe, to take care of, to watch over people. As we go through the webinar, I'd ask you to reflect on a time you might have observed a service system being overprotective, perhaps with good intentions, but yet being overprotective. What that overprotection does is actually limit the experiences that people with disability may have to learn, to make decisions, to move towards dignity of risk. This experience core platform means that we need to make sure we take time and provide strategies and support so people are able to move towards informed choice and dignity of risk.

Let's move now and talk more about dignity of risk. The concept of dignity of risk is very closely tied to self-determination and independence. Like all of us adults with disabilities expect that their needs and priorities are respected, that they receive information about their status, particularly their health status, and the options and choices that they can consider are identified, and that they work with providers to partner with them to then follow through and implement their decisions. Our job as a disability-competent care provider is to listen and to learn from the individual, to inform and educate in a way that's relevant and usable to the person, and to respect and support the participants' decisions. As we go through the webinar, Adam and I will illustrate that with some case profiles.

Let's look a little more about the issue of case coordination and dignity of risk. Dignity of risk refers to the individual's right to identify their needs to make an informed choice. An informed choice is a critical aspect of this, so that the choices allow them to experience life, be able to take advantage of opportunities to learn, develop skills and competencies that promote independence and life satisfaction. Thus they're moving towards making calculated risk, informed choices.

Individuals have the right to make choices about their health and their care even if the health care professional might recommend different options or at times be concerned that the individual's choice is endangering their health or longevity. Again, think back to the issue of the overprotection approach that service systems sometimes take. As disability-competent care providers, we must understand our responsibilities and how to move forward with helping individuals identify preferences, needs, and potential risks, as they move toward informed decisions.

Let's move now to looking at a process that could be used by disability-competent care providers, so that you can actually have informed discussions between the individual and the provider. There are four steps outlined here that we'll then illustrate with a couple of case profiles. Our first and necessary step is to listen so we can understand the individual's story, their perspective, and their life context so that we don't overlay our assumptions or misunderstandings on their personal experience. We then learn and understand what is important to the individual. That enables us to work with them to develop a plan that supports their priorities and their goals which we've learned about because we've listened and understood their perspective. The individual then constructs a plan with our support, monitors their plan, and revises and learns lessons as we all do as we put things into play.

Now, let's look specifically at one woman's story that she shared with me about the importance of allowing individuals to make informed choices and accept (inaudible). Let's start by I'll give you some background on Camille. She's a woman in her late 30s, lives in an apartment alone with her cats. When asked to describe herself, she uses the words artist, advocate, and pet owner. She is very close to her mother and brother, but they don't live in the same state, so contact is periodic and by phone and email. She has a lot of friends and artists that she's met over the years that she stays in touch with via the Internet.

Her medical diagnoses are autism spectrum disorder, learning disability, hearing and vision limitations, and a recently diagnosed thyroid problem. Mobility has become extremely challenging lately due to leg swelling, pain, and weight gain. These medical complications actually resulted in an inpatient stay last year that was more extensive than she had anticipated and involved a fairly complicated outpatient plan of care. The team actually recommended that Camille be discharged to a rehab facility following her inpatient stay because of the need for extensive physical therapy and some follow-up specialty care, but Camille was very clear that no--she wanted to return home, go back to her life.

Let's look at what is important to Camille, so we understand how she's made her decisions. It was critical for Camille that she stay in her own apartment and be able to go back to her own life. She understood that the plan of care was going to be complicated, but she did want the possibility or did understand that there was a possibility of future inpatient or brief rehab stays, although she wants to avoid that. She needs someone to be available to take care of her pets when she is away. She wants some dependable transportation to get to her medical appointments, particularly now that there are so many that she is contending with.

Given her mobility concerns and increasing health issues, she wants to have an emergency plan--someone to call beyond 911. It's really critical that she is able to stay out of a long-term care

facility. She's worried that if placed in a facility, even for short-term care that she will lose some of her choices and opportunities to live independently. She does have a primary care doctor that she respects and wants to continue to see and feels that she's "trained" this person to get to know her, develop knowledge about disability, and has become familiar about community resources. As Camille said, "I want to see someone who respects me and will be around for a while." She's been through the experience of having residents and interns and becomes very tired of that constant rotation. She wants that ongoing primary care relationship and then building a team around her.

Let's look at the plan that Camille and her team developed. This person-centered plan is realistic based on what is important to Camille and what's important for Camille. Important for allows the care providers to share information about what they think are the health issues, the health concerns, so that Camille can reflect on that as she develops her plans. The disability care competent team is helping, did help Camille look at some additional service resources and options given the multiplicity of appointments, the challenges with transportation, and her increase in cost for over-the-counter concerns, durable medical equipment, etcetera.

Some of the ways that Camille was able to work with her team and understand some of their concerns about what is important for her was she did begin to raise issues of I want to begin to think about what happens as I get older and other health problems arise. She still wants to return to her home, but she's looking forward. She also does have ongoing concerns about medical costs and wants to have some services and assistance with looking at that.

The other thing that was very clear that Camille is struggling with and that the care provider team can assist with is the reality that sometimes Camille has to choose between regular disability services and other services because often Medicaid won't pay for two or three things on the same day. From Camille's perspective, it's important that her care providers understand the realities of the systems that she has to deal with.

Let's look now at how Camille and her disability-competent care providers implemented and helped her monitor her plan and then the outcomes that she achieved. The team did listen and did accept Camille's wishes to return home and understand that she was willing to live with the risks of complications from her thyroid disease and interested in learning how to manage that condition, that her limited mobility is of concern to her, but that again it's critical for her that she return to her living environment with appropriate support.

What the plan also did was illustrate some of the things important for Camille that she's now seeing as they are important to her. She wants to learn how to prevent leg swelling. She was given information about the realities of skin breakdown and how to monitor for that, so that that could prevent a future hospitalization, and then as she is able to address her thyroid problems, to begin to tackle weight gain and immobility by returning to some physical activity. The plan begins to balance the important two and the important four.

The outcomes that Camille was able to achieve with her care providers--her leg swelling has decreased which meant her mobility has improved. She's not had a hospital readmission. She's not been placed in a facility. She remains in her own apartment with some minimal personal care

assistance. The team was able to help her explore some other resources for medication and medical supply costs. She continues to be active in her artistic endeavors, and she has been able to negotiate some transportation assistance with a friend, in addition to using other services. For Camille, she was able to achieve her goal of making informed choices. The team honored her dignity of risk. She's had some good health outcomes, and she's been able to maintain her adult living scenario and social connectedness.

I wanted to share one other very brief example, looking at an individual and family approach to supporting choice and dignity of risk. This story involves a young adult moving away to college--a natural transition we hope for many people--and how the mother and family supported their daughter in making choices and having the right to dignity of risk. The young adult has cerebral palsy, vision and mobility limitations, and is on multiple medications. Throughout her childhood and adolescence she had a primary care physician in her home town. Moving away to college meant having to find a new primary care provider. Again, that's a natural transition, but it took on some additional elements for this young adult.

As the daughter said, "My new doctor had quite a learning curve in beginning to understand the complexity of my needs, but the reality of they're all quite manageable." She had several health issues arise during her years at school. The tendency was for the medical provider and his team to assume that these were medical emergencies requiring emergency departments and hospital stays, where from the daughter and the mother's perspective, these could be watched, could be managed with appropriate decisions and communication.

The other issue that the mother and daughter think is very important to make providers aware of is the daughter is her own guardian. However, the parents do have health care power of attorney as a support to their daughter should she have an emergency when she is unable to communicate her wishes or needs a buffer between her and the medical system. That health care power of attorney is not intended to supersede their daughter's choices and not intended to take away her right to choice and dignity of risk. Some words of advice from the mother and daughter to all of us are be watchful of the tendency to assume medical fragility. That goes back to the issue of our tendency to be overprotective. As the daughter says, "Not every medical issue is an emergency just because I have a disability." Be thoughtful in the way we evaluate and present options to the individual patient.

The daughter wants the medical team to teach and support her, to learn about her health, including the benefits and risks of different decisions that she may need to take on. Both mother and daughter asked that disability-competent care providers build a scaffold of support starting with respect for their daughter and the family, offering dignity, communication, promoting independence, honoring her health and safety needs, and to be watchful of perhaps our tendency to start with safety and sometimes get stuck on that part of the scaffolding. In this scenario what the mother and daughter told me was that sometimes it's the providers who are perhaps experience poor and that we need to be watchful of some of our tendencies that may counter the individual's right to make informed choices and experience the dignity of risk. I'll now turn it over to Adam.

Adam Burrows: Thank you, Karen. That is a perfect lead-in to what I'd like to address. I'm sure that everything that Karen has said resonates with those on the call intellectually and emotionally, but yet in practice we struggle to respect the principle of the dignity of risk. Why is that? What I'd like to do is address the pitfalls--the traps--that we as providers can fall into as we try to respect the principles of dignity of risk. I'm going to highlight two that I think are the most important.

First, just to consider a moment the principle of autonomy and the process of informed consent--I think, as you know, autonomy is the preeminent ethical principle in health care decision-making and has been in Western society since the Civil Rights movement of the 1960s and 1970s. Autonomy is the basic principle of self-determination, but we have to recognize that disability itself constitutes a threat to autonomy. Persons with disability are dependent on others to get their needs met, and often we assume therefore that they are dependent on others for their decisions as well. We must make explicit effort to protect and respect autonomy of persons with disability, even as we try to provide the support and assistance that they need to have to live with their disability. We really need to try to strive to prioritize autonomy as our ethical goal at all times.

How do we operationalize autonomy in day-to-day medical care? Well, it's through the principle of informed consent. We often think of informed consent as something that takes place when we're about to undergo a procedure. Certainly at those times we need to engage in the process of informed consent, but the process of informed consent extends really to the whole range of health care delivery. Therefore, integrated models of health care delivery are quite broad.

What are our roles as providers in the process of informed consent? Our role is, as Karen said, to inform and to educate, to identify options, alternatives, the potential risks and benefits of each to help the individual understand the situation, the prognosis, and to provide education and council. It is the individual who makes the informed decision and assumes the risk. It's important to always remember that the individual has the capacity for informed consent. They likewise have the capacity for informed refusal. We often get concerned when individuals decline interventions we recommend, but it's always important to remember that the capacity for informed consent also implies the capacity for informed refusal.

Where do we struggle? We struggle in being concerned about our risk as providers as the individual makes a decision. The key point really to recognize is that our role in the informed consent process is to inform, educate, and council, but it is the individual who makes the decision and assumes risk.

The key challenges in trying to put this into practice are number one--not to allow our beneficence impulses to become intrusive and paternalistic. What do I mean by that? Beneficence is the ethical principle that motivates us as health care providers. It's our desire to help others to do good for them. It challenges us as health care professionals when we think that patients are making the wrong decisions or decisions that put them in harm's way. At those times we may try to constrain or limit the patient's range of choices that you can coerce them toward a certain decision that we think is appropriate. This is when our beneficence is in danger of becoming intrusive and we risk becoming paternalistic which is the opposite of autonomy in

health care decision-making. Paternalism applies that one makes a decision for somebody else rather than an individual makes decisions based upon the principle of self-determination.

Another challenge in implementing this and putting it into practice is that we often adopt a very limited definition of risk and of safety and that the emphasis for cognitive thought is a whole other realm of safety--the realm of psycho-social safety and risk that we need to take into account and not limit our thinking about safety and risk to the purely physical realm.

Then last we often think that we have to eliminate risk. For example we can prevent someone from falling from preventing from walking--an extreme example, but often we set as a goal the elimination or near elimination of risk. That's not necessarily our objective as health care providers, but our goal really is to mitigate risk to the extent possible, to truly offer and provide supports and services and care that reduce the risk, to provide meaningful options, to be generous with those, to mitigate risk to the extent possible and not necessarily to eliminate it. In the process of informed consent, we also have an obligation to advice about residual risk even after the adoption of the care plan that respects the individual's preferences and provides them with meaningful options, supports, and services. Next slide.

The second pitfall involves our sense of self worth as providers. We tend to define our professional success based upon medical outcomes, such as achieving a hemoglobin A1C of under seven or preventing falls or getting a patient to adhere to a low sodium diet. What this will be addressed with each of us is that we need to redefine success so that we are helping persons with disability achieve their goals. In doing that, we come to recognize that achieving their goals may entail risk, and we have to perhaps assign a lower priority to the medical goals that we're more accustomed to, familiar with, and which inform our professional sense of self worth.

The key point here is that person-centered care really means upending or even subverting the institutional or professional paradigm of exerting control. What we learn in community-based long-term care, what we learn in integrated models of community-based long-term care for persons with disability, is that by surrendering control of all of those outcomes, allows us often to achieve control by changing the dynamics so that what we're trying to do is help the person achieve their goals we regain or gain a further control over the situation.

A few challenges in really putting this into practice are reconciling our traditional medical goals with person-centered goals. That cuts two ways. One way is that we have to change our thinking and reassign priority, but it also works the other way that as we develop trustworthy relationships, as we build that scaffolding that Karen described, we develop relationships with patients so that over time perhaps they come to recognize the value of the medical goals that you think would really serve their interests.

Also more broadly, we have to redefine quality and this is work that the National Quality Forum is already undertaking. We're also adopting very narrow and medical definitions of quality. As we implement broad holistic systems of care, we need to adopt broad and holistic quality measures as well. Next slide.

I'd like to use three quick snapshots to illustrate some of these points. These are all drawn from personal experience. The first case is one that was presented to me in my role as chair of an ethics committee. It's a parenting managed situation and a variation on a theme that occurs every day everywhere. This is an 80-year-old woman who wants to live in the family homestead despite mobility impairment, obesity, multiple chronic medical conditions, inconsistent family support, and a cluttered household. The providers are very concerned about the risk of her Medicare needs, falls, and injuries worsening with chronic medical conditions. The team wants to find some way to compel this woman to move from this family homestead which was at the end of a dirt road, and into town into a nursing home. She was resistant and the team was struggling with this conflict between her autonomy, her desire to remain in her home, her wish to maintain that dignity of risk living in that home, versus their beneficent impulses and concern about the patient's wellbeing.

What we try to do in our ethics forums is try to reorient the team's goal to those of the individual and recognize what is most meaningful to her at this point in her life, while also offering meaningful choices and offering supports and services and allow her to mitigate the risk. In this situation, one of the outcomes was to offer her a brief tryout in a nursing home in town just to see what her experience was with it. The team also offered her a brief trial at another housing facility. Ultimately, she chose to remain at home, and the team was going to support her in that goal.

The next case involves one of my patients. This is an 88-year-old woman who was hospitalized after she fell from a chair. She was trying to retrieve something from a closet, and she ended up in the emergency room. She had a lump on the back of her head, but the rest of her evaluation was completely normal--all of her injury tests, including her cervical spine CT scan. She ended up on trauma service in the hospital. After 24 hours at the point of discharge, the team requested a physical therapy consultation, as is typical. The physical therapist documented a need for 24-hour supervision. The woman had been living independently at home.

The trauma surgeon prescribed a hard cervical collar--compacting collar--and a wheelchair. That would've been this woman's historical plan, which would've been catastrophic to her. It would've been contrary to her goals, but also would've put her at a very different kind of risk--risk of loss of mobility, loss of function, dependence on others, skin problems from the collar. I could go on and on. Ultimately, we were able to redirect her discharge to home and provide the home-based supports and services and the education that she needed. She is doing fine without the collar, without the wheelchair.

The third case is another situation, and this is another one of my patients who ended up in another hospital. She was a woman who had spent much of her life in an institution on anti-psychotic medications, had tardive dyskinesia--a movement disorder--as a consequence of that, but lived with her daughter who was a wonderful caregiver and who fed her very carefully. These providers unfamiliar with this patient wanted to deny the woman access to food and spoke to her daughter about placing a feeding tube. Again, we were able to intervene and bring the team to recognize how important it was for this woman to eat, even perhaps at some risk, although she had never revealed any, and what was most important to her at this point of life.

In both the second and third cases, it's important also to recognize what a vulnerable moment discharge from a hospital or facility is. It's a critical time medically, but it's also critical time ethically. It's a time when autonomy can be threatened and choice can be constrained. I know there are care coordinators and care managers on the phone. It's really critical that you from the outside get involved on the inside where the institutional paradigm may be very, very different than our paradigm on the outside, where the institutional paradigm may dictate limiting the risk of the institution rather than respecting the dignity of risk of the individual. Chris, I'll turn it back to you at this point.

Christopher Duff: Thank you, Adam and Karen. I appreciate your presentations. I'd like to start off by reviewing the results of the second poll. That is familiarity with the concepts of dignity of risk, choice, and so on. People said that--almost over 25% said very familiar with it, and the rest of you were fairly or partially. I think that what this shows--and I would've answered fairly myself just in the sense of it's where those lines go in between the responsibilities are what I personally struggle with on that. Let's just open the phone lines right now, so Nick, could you give the instructions, please?

Nick: Ladies and gentlemen, if you'd like to ask a question, you may press star and then zero. An operator will gather your name and provide further instructions. Once again, you may press star and then zero on your telephone keypad at this time.

Christopher Duff: While we're waiting for some questions to come up, I would like to start with a question that we received to the Q&A, and it's from Tara. This is, I think Adam you mentioned the accrediting bodies, but Karen, you might have some input too. Are the accrediting bodies redefining quality using the principles outlined in this presentation? For example, adopting person-centered care plans in lieu of medically-centered care plans?

Adam Burrows: Yes, that's happening. I was very fortunate to be a member of a workgroup for the National Quality Forum--NQF--that was working to endorse quality measures for dual-eligible individuals in integrated health plans throughout their settings as well. What the workgroup quickly recognized is that the quality metrics out there are very inadequate. We identified and measured that. Others have sort of picked up on this. National Quality Forum endorses the measures, but groups like NCQA develop measures, and so NCQA and others very quickly picked up on this and have been hard at work to identify quality measures that really not match more appropriately to what we think represents our quality of care for persons with disability in integrated care plans.

Christopher Duff: That's very good to hear. Karen, do you have anything you want to add to that?

Karen Luken: This is Karen. One of the important set of measures that is used in the service area of intellectual and developmental disabilities are the personal outcome measures developed by the Council on Quality and Leadership. It does address issues such as personal goals, health and wellness, personal rights. However, I don't think it directly addresses dignity of risk, and so I think it's an area where, although interruption and developmental disabilities have a strong history in self-determination and promoting personal outcome, there is still this struggle that

Adam described around truly allowing autonomy and the risk of health decisions to rest with the individual. I think we still have more work to do on that, and promote that scaffolding approach of respect and dignity in communication supporting health decisions.

Christopher Duff: I do like that--the language of scaffolding approach. That makes a lot of sense. We have a couple of questions around the issue of one thing that's needed is coaching and educating participants about how to assume greater control and responsibility for themselves. Many of them have been trained to be passive. That's generally something that the system is getting going and moving and that's good.

Where I think people are struggling is many of us are used to the role of being an advocate. Where is the line and how do we interface with a guardian. Now, as an advocate, we're probably not guardians, especially if we're a provider or in a health plan, but where is the line between an advocate, a support person, the care coordinator, and then ultimately a guardian? Where do you draw those lines and how do you understand that and at what point do you put forward the question of the individual's ability to comprehend adequately and whether they might need a guardian? Karen, do you want to start with that and then we'll let Adam respond?

Karen Luken: Okay. I think that one of the challenges with guardianship is it's viewed as all or nothing, and it should not be seen that way--that there are types of guardianship and one type is the health care power of attorney, which hopefully all of us have, given that we may face health and medical emergencies. Guardianship can be guardianship of the person, of finances, of health, so I think our role, particularly those in the service system, is to understand if someone has a guardian, what type of guardianship, and then to explore with that individual and the guardian how that came about, if that's a static decision, because guardianship can be changed.

I also think that in my work with guardians, I think you raised an important, point, Chris, that we need to provide education and support to guardians about many of these medical and legal and health issues, so that they have information that will enable them to support the individual. I was at a meeting this morning and we were talking about the issue of advocacy and self advocacy and a mother talking about her son who was an adult and the many times of life transition with getting a job, moving away from home, learning to drive, having a girlfriend--how each of those were important milestones that also generated quite a bit of anxiety. Now what she needed was to look for broad support to help her with her anxieties so that they would not impede her son's ability to make decisions and move forward. I think there is much that we need to learn, but to understand guardianship is a very complex phenomena and that it's not an excuse to not support the individual becoming informed and being supported to make decisions.

Adam Burrows: The issue of decision-making capacity, which obviously is a common issue in the population that I work with. It's important first to remember that capacity is task-specific. Capacity is decision-specific. An individual may lack the capacity to make an informed decision about a complex medical procedure--undergoing aortic valve replacement--but may be capable of making an informed decision about where he or she wants to live, what he or she wants to do with her day. It's important to recognize that capacity is decision-specific.

What is the standard for capacity--whether one can engage in the informed consent process. Can one understand the situation? Can one understand the proposed intervention and alternative? Can one understand the risks and benefits, and can one manipulate that information in a meaningful way?

Once again to note, as I said earlier, we tend to think of informed decision-making and informed consent is limited to certain procedures, but we should adopt the same general principle with all decisions, especially if they are decisions that we wrestle with--where someone should live, whether someone should assume certain risks, independent, mobility, eating, and so forth.

Christopher Duff: Thank you. A question here from Mark Steinberg really is a follow-up sentiment. Are there some ways to find best practices that a plan or a provider can use to assess the degree of a person's ability to make informed consent and comprehension?

Adam Burrows: As I said, it really is systems of informed consent and capacity of decision-specific. Karen, I'm not sure if you have any other things you want to add to that.

Karen Luken: I think it's another example similar to some of my comments around guardianship that consent is not a yes-no. As Adam said, it's task-specific, but that consent is an involved discussion and that there are steps that can be taken to teach someone about the consent process using developmentally appropriate resources. In my work, when we were doing research around women's health issues and the women needed to consent, we did not use the standard consent form that was text heavy and very difficult for many people to really understand. We developed different consent forms that had more visual queues that were larger font. We tested them out with people. I think looking at how we present and share information to individuals who we think may have some cognitive limitations is important.

I also think the environment in which we provide that information is critical. If it's a noisy environment, an environment that is not their typical environment--all of those factors may make it difficult for the person to attend to what we're saying. It may be that that is interfering more than the ability to respond to a specific task decision. I think we should really look at how we share information, the environment, and are there others that can, with the person's agreement, be part of this shared and supported decision-making process?

Christopher Duff: I think that's an excellent point, Karen.

Adam Burrows: In geriatric medicine, it may come to the conclusion that an individual lacks the capacity to make a fully informed decision and to accept risk. At that point, we often like to involve family members, surrogate decision-makers, health care proxies, to help make an informed decision on that person's behalf using the principle of self-supported judgment and what is most important to my mother and my grandmother, what decisions can I help her make? Ideally, is to have it made directly with all parties present.

Another point I'll make is that the person's capacity doesn't need to be done by a third party. Often in a hospital setting, we rely upon psychiatry consultants to help us assess decision-making capacity that may be appropriate in settings like that, but in everyday decision-making, really a

trusted and trustworthy provider would be the best person to assess whether an individual is capable of that informed consent, capable of refusal, and engaging in that process.

Karen Luken: I think it also goes to, whether it's in geriatrics or with someone with an intellectual disability, is who is this person? How do they normally make decisions? How do they communicate their preferences? If this is a new person and a new relationship, that's adding multiple layers of difficulty, so figuring out some of those baseline approaches--how do I communicate typically? How do I communicate when I'm having a great deal of stress? I will do things differently, and we need to understand the person in the context of what's currently happening and then try and learn as much as possible about the individual as a whole person.

Adam Burrows: We sometimes talk about our values history--what has been meaningful and valuable to this person? Taking risks is a very human endeavor, but some are more risk-adverse. Some are more risk-tolerating. What has been valuable to this person in giving this person life meaning throughout his or her personal history?

Christopher Duff: One thing I'd like to add I learned years ago out of the IVDD community and that is the circle of support. We tend to be a little into learning in having these conversations with the person and the caregivers and the team. If we're scratching our heads and struggling, we need to continually remind ourselves who do these people use as their circle of support and make sure we're bringing them in, as was somewhat mentioned before.

Nick, I just want to quickly check in with you to see if there is anyone on the phone lines?

Nick: There are no phone questions in queue.

Christopher Duff: Okay.

Karen Luken: I have one other thought I'd like to mention.

Christopher Duff: Yes.

Karen Luken: Look at this from a system standpoint. Adam talked about ethics committees, human rights committees. I think it's really critical that service systems, whether it's a hospital, a disability agency, social services, involve everyone in their community, which includes people with disability to be members of those committees, so that they can offer their perspective.

Again, I was at a meeting this morning when we were talking about advocacy, self-advocacy, family advocacy, and excluding people means we're not getting their perspectives and their experience and their expertise on how to construct the right forums, the right approaches, how we deal with challenges. I would encourage all of us to think about, as we put together our advisory committees, our review committees, that we include everyone as a potential member in a meaningful way where we teach them about the committee, mentor them, so that they are becoming informed and then educating providers, so that we can become disability-competent care providers.

Christopher Duff: Good point. At this point, I'm going to go to two quick closing polling questions. Could we pull up polling question number three? This will give us impressions about future trainings. Have you or have you seen your colleagues struggle with situations that we've discussed here? We'd like to get a sense of the frequency of that. We'll give you a minute to respond to that.

Then the final polling question--why don't we look at the results of that before we move on to the final polling question? Periodically, frequently--so this is something that's on the ground. Some of the questions we've gotten in, you see it in the relationships between caregivers and consumers. You see it in shared living settings, so I know that's where a lot of providers I hear it from.

Then the last polling question is really more about the future. Would you be interested in additional opportunities to explore these issues? We're trying to get you to tell us a bit more about different ways of doing so. While you answer that, I'm going to wrap this up here. Any questions that we've received in the Q&A we will respond to offline. Then next week at this time, we will explore the concept of the community participation. We'll have a couple of presenters talking about how to support people with disabilities engaging in their community. Everyone who has signed up for this webinar and other webinars will receive notice of future webinars and provided the resources that we are able to provide.

Adam has let me know that he has one last statement he wishes to make here. Adam?

Adam Burrows: There was a question online about non-compliance. The question went--it seems the idea of non-compliance can be confusing if individuals claim choice and right to risk decisions. Can you speak to this? Yeah. I think this really gets to the heart of it, and that it's important to remember that individuals have every right to decline our intervention. They have every right to engage in what we may perceive as self-harming behavior.

Once again, our role and responsibility is to develop trustworthy relationships with them, to educate, to council, to guide, and hopefully bring them to a point where their goals and our goals are aligned, where they understand and accept the value of what we're recommending. Ultimately, the principle of autonomy tells us that individuals can make their own decisions. Individuals can non-adhere, can non-comply. Our responsibility is to understand why that is, develop relationships with them, and try to bring them to a point where we are more closely aligned and that we're taking it off of self-care management principles that we think will help them.

Christopher Duff: Thank you, Adam. I appreciate that very much. On the last slide here, there's a link. I guess maybe it's not the last slide. We do have a link to the questionnaire. It is on the last slide. If people would just take a minute or two to fill that out, that's very helpful. As we're wrapping up this series, we're trying to figure out where do we go from here, so your comments and your suggestions would be very helpful. In the last audience survey that I don't have time to review, we also asked--kind of gave you an open-ended opportunity to make suggestions. We'd ask that you put those in the Q&A box on your screen here, just so you can make additional comments that we will build into our plans for the future.

Thank you, Dr. Burroughs and Karen. I appreciate you taking the time to present, and I appreciate everyone attending, and please join us next week for our next webinar. Thank you very much.

Nick: Thank you. With that, that does conclude conference today, and we thank you for your participation and for using AT&T Executive Teleconference. You may now disconnect.