

## Shared Decision Making: Dialogues Engaging Individuals and Families

**Laurie Curtis:** Hello everyone and welcome to today's Recovery to Practice webinar. I want to -- on behalf of the Substance Abuse and Mental Health Services Administration, and the Recovery to Practice team I would like to welcome you all and thank you for joining us today. It is the third and final webinar in this series on shared decision-making. We have over 80 people registered for today's call, on the call so far, and we know this number will escalate. My name is Laurie Curtis and I am your host today. After some brief housekeeping, and a short overview of Recovery to Practice we will begin today's presentation. At the bottom of your screen you will see a download materials box where you can access today's presenters' bios as well as a PDF of the presentation slides and other available materials. This webinar has been preapproved for continuing education credits from NAADAC the addiction professionals' association. To qualify these education credits, you must attend the full webinar, complete a brief quiz at the end, and the webinar evaluation. You'll get more information on this at the end of the webinar. Finally, if you are a registered attendee you will be emailed a link to view the webinar in an archive recording. This link will be available soon on SAMHSA's website.

This webinar series is hosted by SAMHSA Recovery to Practice, or RTP, initiative. The overarching goal of this initiative is to improve the knowledge and the ability of the behavioral health workforce to use recovery practices every day.

Understanding what recovery means in this context is critical to our success and yours. SAMHSA's working definition of recovering and behavioral health is: a process of change through which individuals approve their health and wellness, live a self-directed life, and strive to reach their full potential. On the Recovery to Practice website are links to a set of discipline-based curricula to promote the understanding and uptake of recovery principles and practices. Developed by six professional disciplines for educating their own memberships about recovery, and behavioral health, these materials are adaptable for use by other disciplines as well as organizations seeking resources to build a recovery oriented workforce.

Recovery to Practice also offers free webinars, newsletters, training and technical assistance opportunities. Check out the Recovery to Practice website regularly or join the mailing list to get information about Recovery to Practice activities deliver to your mailbox.

In today's webinar -- in this webinar series we have defined shared decision-making, we considered how it applies to behavioral health. In our last webinar, we recognized that while there are some excellent shared decision-making programs in medical and behavior healthcare, at its core, shared decision-making is a staff competency along with sets of tools and resources to help support meaningful communications. Shared decision-making is something you can practice today.

We've also looked at some ways shared decision-making is being integrated into behavioral healthcare. In the first online seminar we explored share

decision-making applications with the addiction treatment service. Today, our final webinar of the series, we will look at how shared decision-making approaches can help engage young adults and their families in healthcare conversations. We will also consider how peer programs can you share decision-making tools and resources to help people make the most of their visits with providers. I'd now like to introduce our speakers for the day.

Our first speaker is Iruma Bello Ph.D. a licensed psychologist and assistant professor of psychology at the Columbia University Medical Center. She's also the clinical training director for On Track New York with the Center for Practice Innovations for New York State Psychiatric Institute. Our second speaker is Melody Riefer, MSW, a senior program manager at Advocates for Human Potential. Melody is a longtime advocate and trainer for recovery oriented practices and in shared decision-making. More in-depth bios for each of our presenters can be found in the download material box. I will now turn over the webinar to Iruma. Iruma?

**Iruma Bello:** Thank you. I'm starting my webcam.

**Laurie Curtis:** Okay. There she is.

**Iruma Bello:** Hi everyone and welcome, thanks for joining. In my part of this webinar I'm going to be speaking with you for about half an hour and lets me discuss with you how we use shared decision-making within OnTrackNY.

We have no disclosures to make, and these are some the things we will cover today. We will provide an overview of OnTrackNY, discuss how we use in shared decision-making introducing to young clients and the families that we work with, I'm going to highlight some of the challenges that we encounter, as well as show you some of the tools and resources that we have and then end with an example of shared decision-making in one of our case examples from one of our teams.

So, let's start by discussing OnTrackNY and what it is. OnTrackNY is a program funded by the New York state office of mental health, and it is really designed to provide early intervention services to individuals experiencing first episode psychosis. The first episode of psychosis we define as a mental condition that is characterized by symptoms such as unusual thoughts and behaviors, hearing or seeing things that other people don't, or even disorganized thinking. And, people experience first episodes early on it starts between the ages of - the folks we serve are between the ages of 15 and 30. It's really at the first -- when the first symptoms arise that they are eligible for an on-track team. We know that if left untreated these symptoms become worse over time so for young people who experiencing the first episode psychosis getting the right kind of treatment as early as possible can make a big difference.

So, OnTrackNY is an example of coordinated specialty care programs, and there are several of these coordinated specialty care programs that are being implemented across the US. And, the coordinated specialty care is informed by research which was funded by the NIMH and the studies found

that people that are enrolled in coordinated specialty care when they first develop psychotic symptoms tend to do better across time, they have better outcomes. So, in general a CSC team, or Coordinated Specialty Care team, is defined by a very specific framework and key care processes, and we're going to discuss what these are. But, it's focused on enhance collaboration among team members, the team meets together with the young person and the family and the staff really manages a small caseload.

Clients and staff caseload ranges from ten to twenty and one, something in that range. And the CSC program provides time-limited face care to provide treatment for about two years or an average of two years. The way we market OnTrackNY, we think of it as an early intervention program for adolescents and young adults who recently have had unusual thoughts and behaviors, who started hearing or seeing things that others don't. And it helps people achieve their goals for school work and relationships. So, the idea is that when we treat these people and we work with them closely, we're really focusing on their goals rather than their symptoms.

So, what are some of the interventions that our OnTrackNY team delivers? We think of it as a suite of evidence-based practices and what that means is there is evidence-based pharmacology, supported employment, and education, CBT type of interventions, meaning recovery skills, social skills, training, support for psychotherapy and case management, family support and education, and then suicide prevention. And, all these evidence-based practices, which we know there is research to sort of show that people that receive these provide good outcomes, in OnTrackNY we deliver them using, as I mentioned, a team-based model with a lot of outreach and engagement, also a Peer support component and under the umbrella of shared decision-making.

And then, the idea is that we -- I think there is an audio problem so I am sorry to pause but let me just make sure of that. Is this better? Okay - So the idea then becomes that folks can receive this intervention with a lot of outreach, a lot of engagement, and then some shared decision-making. And shared decision-making is one of the frameworks that really goes through all of these processes. So when we are delivering any of these interventions were using shared decision-making in hopes of getting people to achieve recovery or engage in a recovery journey.

So, some of the guiding principles or clinical concepts, that drive the OnTrackNY interventions, as I mentioned are a focus on recovery, a focus on person centered care, shared decision-making and cultural competency. So, we think that in general when people are delivering these interventions as part of the team they're really focused on and are able to do all of these things. Let me take a second to describe some of these in more in more detail.

So, when we're talking about doing these things there's really no steps, these are some underlying principles and none of them stand alone they all inform each other. And the hope is that the team strives to really convey a sense of hope, and that recovery is something that is attainable and shapes the views of the person with the diagnosis, as well as the family. We really think that the client becomes a central piece of the team. The idea is that we know that people benefit from actively

collaborating with their providers, and the goal becomes focusing on people's goals and aspirations and ambitions and this is what drives the treatment planning.

So, when we think of share decision-making, as a principal of the OnTrackNY model, we think it's a collaborative process where people and the providers collaborate to make healthcare decisions and they take into account the best scientific evidence, as well as the person's values and their preferences. So, shared decision-making can benefit both the client and the treatment team. We know that when people engage in shared decision-making they have improved quality of decisions, to increase the client's level of satisfaction, it solidifies treatment alliance, it enhances knowledge of health conditions, and it really contributes to a greater treatment adherence.

And then finally cultural competence we think refers to a client's awareness of - a clinician's awareness of a young person's cultural background and identity, and it can provide an interpretive framework for understanding the symptoms and what is going on. So once again all of these principles guide the process for how the team delivers all of the interventions.

So, another thing that's important to keep in mind with young people is how we think of recovery and how do we think of shared decision-making. And Pat Deegan does a lot of work with our group and she helps us develop all these materials, so all of this is really a huge credit to Pat. All the tools that we have that I'm going to talk about. So, she likes to think about and presents to our team, this idea of the continuum between duty to care and dignity at risk, and then over protect versus neglect. And, really what we mean by that is there is a duty to care which means that the team remains engaged with people no matter what decisions they are making and at the same time, folks have a dignity of risk meaning they have the right to make their own choices, to fail, to take risks, and the team has to think through how they might -- their interventions how they relate to the client really falls within the continuum of being either overprotective which we know is not really helpful for people or being neglectful. Which means, letting people sort of, do what they want and not providing support so we try to balance these two poles, the idea staying sort of in the middle between overprotection and neglect, so that it really allows people to really take some risks and figure out what they want to do and how they want to approach the life decisions that they are making while they are in OnTrackNY.

So, how do we do shared decision-making? When we do OnTrackNY, part of the intervention is a series of core sessions, and what these core sessions are very specific pieces of information, pieces of intervention and delivery of psychoeducation, and getting the team to understand where that young person in the family is coming from. And how we do that is through these 10 core sessions that we think everyone receives when they are part of the OnTrackNY team.

So, we really think everyone receives information on early intervention and recovery and psychoeducation. Another session is thinking through what is the person's cultural background, what are their choices, how do

they think about where they sit, not only in terms of race and ethnicity, but in terms of being a young adult, what roles do they play, within their family and in general in their life. And then we have a core session that really focuses on shared decision-making, we also have core sessions on personal strengths, we introduce everyone to the team, and then so forth so we have these other ones on very specific issues that people might be encountering like, do they need social skills training, do they need substance use treatment, etc. But given that the focus of this webinar is shared decision-making, I will just focus on that one core session.

We really start by setting expectations with the client and their families. At the beginning we're setting the stage that the team is going to expect the person to be an active participant in making decisions. The expectation is that the young person tells the team what decisions they need to be facing, and what is the information that they need to know. So for example it could be decisions around medication, but it could also be decisions about returning to school or work, which is a big goal for a lot of the young people that we work with. It could be decisions around where they are in the program, and how to move forward within the program, who do they want to work with on the team, things like that so with the decisions, there's a wide range and we want to encourage the people and their families to bring these to the table to be able to discuss with the team. Then the second step is letting people know the team will help them understand the options that they have available. And then once the young person learns about the options there will be a process, a very systematic process, where the team will help the people make their decisions.

So, when we think of shared decision-making and when we explain it to our young people, we really focus on what is shared decision-making? It is a kind of informed consent process, and it's the best kind, because we move from what are people's initial preferences, based on their values, whatever thoughts they have about their life and the world, to informed preferences, meaning, we are giving them information to help support these different decision points, what do we know and what is the evidence out there. It acknowledges there are two experts in the room, the person receiving the service and the person providing the service. And finally it helps to really clarify individual's values and preferences for decision-making.

So, it goes from very specific steps to help people walk through making decisions. The first step is what we call choice talk, so making sure that people know there are reasonable options, that there's a lot of options out there, and what these are. And then as providers we really think through what are the details, what are the information that people need, what are some of the options that we can give them and what information in a way that they can actually use it. So staying away from jargon, what is the evidence out there. And then using decision talk where we actually go through a process of considering preferences. What are the pros and cons around each of the decision points, what are people's values, what do they think would be a best fit based on what their goals are, and then everybody getting on, sort of, on board with that decision to be able to move forward?

Why don't we do a polling question? If you can, if you guys see the poll, if you can just submit your answers and then we can discuss them. Okay. The answers are still coming in. Can you guys see the answers I guess to the poll? Okay great. So then it's obvious. Everybody can see this and it seems that the majority of people agree that shared decision-making really helps people feel respected because they had a voice and a choice in their care. And that is absolutely right. People want to be involved in these decisions, people feel empowered when you involve them, and the idea is that there is no black-and-white decision that is right for everyone, or that helps people across the board, so it's really important to figure out and let people have a voice and understand all the range of evidence that we have for the different decisions.

Okay, so thanks for participating in the poll. And now let's talk about now that you know what shared decision-making is and how we think about it, in OnTrackNY, and we do this at the beginning, we try to do this as early as possible when people start in our program -- I feel like people are having a problem with the audio, but I'm not sure. If the tech folks can tell me, okay. The way that we do it is we train our team to feel really comfortable doing this but to do it in a very systematic way, at the same time we still encounter challenges when we try and practice shared decision-making. And while these challenges are very relevant to our young people, I think there are relevant across the population. The idea is that we work closely with young people and their families and sometimes combining the client's preferences and their needs and the decisions that they think that they want to make, might change or might be different from what their family really wants and that's a challenge, getting everybody on board. There is also sometimes when people have psychosis they are not as engaged, they may not be as assertive, and that also affects the shared decision-making process, and our team works hard to try to troubleshoot this.

There's also a sense of invincibility that young people sometimes have, as you know, developmentally it's appropriate for young people to want to take risks, to feel like they are the exception to the rule, or what applies to them does not necessarily apply to the rest, so giving advice to them or sometimes when you go through the pros and cons around decisions, that can be quite difficult when young people feel like the rules do not apply to them. So that's even more of a - it's challenge but it's also like a big indicator of why it's important to involve people and to let them sort of take ownership around the process. The other piece, and remember we were talking about the duty to care and the dignity of risk, is the ability for clinicians to tolerate risk, particularly in the beginning. So we have noticed that as people become more comfortable doing work with first episode psychoses and they actually develop more skills and work more closely with young people, their ability to tolerate risk taking becomes -- they develop a higher ability to tolerate risk. So, it gets better, but in the beginning, it's actually a little bit challenging. Then there is, how we think about motivational interviewing which means how we're trying to change behavior, versus shared decision-making, which is before emotional interviewing when we're trying to help people figure out what are the best decisions for them. So for example, you would do something like

motivational interviewing for substance abuse treatment but you would use shared decision-making around decisions about going back to school, or what is really up to the young person and their family and whatever values they have around this. We also know that there are limits around medications, we know that for psychosis, there is not one medication that works the best for everyone, so it's important to really have detailed discussions with young people around the medications and the pros and cons the side effects so they can make decisions about what, about which avenues they're willing to explore.

Finally, the limits of our data, even though we know certain things work we don't know what works for everyone. We know things in aggregate, we do not know things for the individual, so shared decision-making really allows us to get to know and work with people very closely on things that work. For them specifically.

So now I want share some tools with you, that are available in a public domain, so you can actually access these. And as I said Pat Deegan, a psychologist and does a lot of work with shared decision-making and recovery, and she works very closely with our team, she has developed a six-part series for our team that guides them through how to think about shared decision-making and how to deliver this information. So, the idea is that the six chapter, which is actually really important, is geared toward clients and family, so this is something you can even show to clients and families and they can even watch and we tell them to watch it early so they know how to relate to the team and what the expectations are going to be. As you can imagine young people in general do not come in knowing how to engage with mental health services when this is their first episode of psychosis, so this sort of is a nice way to set the stage on setting expectations and getting them to change the frame that they won't be passive recipients of care but instead, they will be able to be, and expected be active participants in the process.

Okay. The other one that we have, and we have several of these tools, this one can actually be found in the OnTrackNY manual, and for this one, it's an aid where we help clients think through what are some of the symptoms that they are having, what are some of their concerns in general, and then they can bring this back to the team to have more detailed discussions. So the idea is that somebody might come in, they might not know exactly what to focus on, or they might have a lot of concerns a lot of issues going on, and to expect someone to be able to kind of, off-the-cuff, talk about these things in a session might be difficult, so one thing the team might do is give them this handout and say why don't you think about this and sort of prioritize what's important for you. What are some of your values, what are some of your thoughts around some of these things that are going on with you, and then that really sets the stage for being able to kind of talk about what are the different choices, what to focus on, and then how to think about what are some of the pros and cons. So, we have a lot of decision aids that we give to people when they are part of the program which sets the stage for doing really good shared decision-making.

We have this other one, very specifically, tied around medications for example. So, this is something that allows young people to highlight how

they see themselves and the things that are important for them. Which may not be on the team's radar immediately, they may not even think that the team is paying any attention to that. We know that if we can get on the same page and find some common ground with young people around what is important to them, then they are more likely to make treatment decisions that they stick with and that they feel better about. So, with regards to medicines we will have decision aids like this that can help the process.

So, now I want to share some data with you, from the RAISE project. Remember that I discussed that OnTrackNY comes from RAISE which were some projects, some research projects, that were funded for the NIMH. And we collected some data, and we want to see how did we know that people that were involved in RAISE felt that the team was doing some shared decision-making and doing really good shared decision-making so we did a qualitative study, and we asked people, so when you and your team have talked about your treatment, how much do you feel that decisions about your treatment were joint decisions between you and your team? Because to us, that would be an indication that shared decision-making is being done. And as you can see in this graph, we have that most people, so over 50% felt it was done a lot, a little bit more felt it was a moderate amount and a little bit felt it was little, so for the majority, people felt very much involved in the decisions that the team was making with them. And as you can see, a very small less than 5%, felt that they were not involved at all.

Similarly, we asked people, in the past month how much did you and your connection team pay attention to preferences regarding to your preferences regarding work and school. So not just what the team thought was important but paid attention to what the client's preferences were. And once again you can see on this table, for the most part, people thought the team was really paying attention to the preferences. And what they want to do in supporting their preferences. Here we have when you meet with your connection psychiatrist how often does your psychiatrist involve you in decisions around which medications to take? And similarly, people felt very much involved around their medications. Which once again speaks to the idea that even the prescribers are hearing people's perspectives, hearing what they like and what they don't like and then figuring out what next steps to take around the medication based on this.

So, now for this last piece, I'm going to discuss a case example, how it might play out in an on-track team. So, as you know, we see young people so this is Tom he is a 24-year-old man who was recently referred to a OnTrackNY team following a first hospitalization for psychosis. Some of his goals are to work with the supportive education and employment specialist to return to school, at the same time his parents do not think he is ready. They think that he should stay home, and make sure that his symptoms improve before he engages in school work. So, this is a typical scenario, and we would think very clearly on okay, so how do you approach shared decision-making with Tom and his family given that everybody has a different idea around how to approach this problem or what they think should be addressed.

And now I'm going to give you some tips. So, the first part is discussing options and preferences with Tom and his family, this would include the

team, Tom, whoever Tom identifies as a family, it might be mother, father, siblings, it could even include friends, girl-friends, whoever would be important social support for Tom. And together everyone will discuss a different option. So what are the options? The options are to go back to school or not to go back to school, but there's actually a lot more options than that. There is what school, when to go back, so within our teams, for example, people might go to a mainstream school, or they might decide to go to homeschool, or they might decide to do something online, or they might decide to even switch schools if they feel it might be a right it's a better fit. Then there really is a weighing of the pros and cons in a very detailed way, what are the choices, and what are some of the options. So, what about transportation? What about finances? What about how would medications support this? Or not support this? What could the team offer? So for example, somebody wanting to go back to school, the family might believe we don't want them to go back to school because the symptoms might interfere, if it's a school they are paying for like college like they don't want to pay for tuition maybe, and have this be too much money, and how the person fail out, so our team then would kind of delineate well we will help with follow along support, we would help people really think through how they might engage in school and how the team would give them support, so we take it away from the black and white of yes school, no school, to a very detailed discussion around this, and then coming up with a plan around okay what is the decision that everybody will be on board with, and what are the steps to implementing this. And that's how we stay away from the extremes of overprotect and neglect and we really allow people to take risks but with a lot of support from the team around their decisions. So, that is the end of my piece of this and I'm happy to answer questions but think now we will send it - we'll transfer it over to Melody who's going to presenting the second part of the webinar. Thank you.

**Melody Riefer:** Thank you so much. Excuse me. Give me just one second. It's great to spend some time with you all this afternoon, and I, when I saw the information that Iruma was going to be sharing, I was really excited about it because I think, if we can improve the quality of services that are presented to people early on, as they are trying to gain mastery over these type of psychiatric symptoms that they are experiencing, the better off they'll be which is an obvious thing, but the better off the system will be. It will be able to make sure that folks get a good start and a deeply grounded foundation for their recovery throughout their life, and the interventions that OnTrack and the things that are being learned through the RAISE project through the National Institute of Mental Health, are just really ground breaking. And so, I hope ya'll enjoyed that information as much as I did.

But I want to take a little bit of a different spin, and talk about the way peer providers are involved in the shared decision-making process, and there are a number of things that we have to consider when we head in that direction. The first thing is how do we even define peer? And that is -- differs depending on who you're talking to. So certainly in common vernacular, the way the whole world defines peer is that it's a person who is an equal in life experience or in station in life. And so people globally have an idea of what a peer is. A lot of time we think about it as a classmate or peer is used within the context of peer pressure, but

were people who are alike have some sort of interaction, and so when we talk about peer in the behavioral health world the same level of information and understanding is communicated but there's a bit more to it than that. So we look at peer supporters, who are as you see in this definition, people with a personal experience of recovery, from a mental health, substance abuse, or trauma situation, who has received specialized training and supervision, to guide and support others who are experiencing similar mental health, substance abuse, or trauma issues toward increased wellness.

So, this definition comes from the International Association of Peer Specialists. It captures the different level of what peer is, we also then look at what is it that peer providers do? And so peer providers do a number of things, you can see some of those listed here in bullet points. I will not read the whole list to you but I do want to point out that the main thing that peer providers do is carrying forward the message of recovery. In the behavioral health world, we haven't always talked about recovery in fact we frequently talk about the opposite of recovery, and that is, mental illness is a lifelong disorder, you will have it for the rest of your life, that it will limit your options, but we know those things are not true. And so, as we have had more research to believe what we've always known, anecdotally, it's created this opportunity for people who have a personal experience with recovery to come into where services are provided and say, hey this is not all gloom and doom. You can have the life that you have always hoped for. And there are things that you can do to help increase the odds of that and those are then the things that peer providers do. So, providing support, or helping people how to navigate the systems, or helping people connect with the right professionals. That then becomes the focus of the work.

We also know that of all of those things that happened, it's important to note that the support that is provided to people includes all types of conditions, and so, peer work doesn't just live in a particular place, in fact the whole idea of the impact of peer support existed long before there were any kind of certifications, processes, or trainings, or billable activities for people called peer specialists. In fact, peer providers as we look at it as an organic process, are people who step up and step into people's lives, and help people move towards wellness and so, peer supporters now in a formal way, can be in mental health centers, and inpatient settings, outpatient settings, in jails, in respite programs, run programs that are completely and 100% led by and created by people with the experience of recovery. And then even with that, developing specialties where either through specific life experience or specific additional training, offer information to folks. So, we also find that there is great concordance between the principles of shared decision-making which Iruma already spoke to, and the principles of peer support. Glyn Elwyn has written "the skills of shared decision-making are unlikely to be developed, let alone exhibited, unless the clinician agrees with the guiding ethical principles. At its core, shared decision-making rests on excepting that individual's self-determination and shared decision-making is as desirable a goal, and that clinicians need to support patients to achieve this goal wherever possible, and Peer specialists and supporters are able to deliver that type of care and that type of interaction, with people. And so, it is important that even in

systems where there has not been an adoption of shared decision-making, peers can teach other peers about shared decision-making and the person can begin to advocate that that level of care or the type of care become the model for the services that they received. So, in some ways peer providers can be the Trojan horse and carry in this message, to help people spread the word about share decision-making.

There are six core elements of activation and activation is the secret sauce to recovery. And so, these elements are really important and these are the things that should drive how we look at the activities that we advocate for in shared decision-making. Things like symptoms and self-management, engagement in activities that support health and wellness, and number three obviously, involvement in treatment decision-making, collaboration with health care providers, critical performance based selection of providers, and navigation of the provider system. So, having this input helps people be connected to their services and so, just really quickly, a couple of examples. Pat Deegan, who's already been alluded to, created a software program that helped people engage in shared decision-making. But it not only helps the person prepare for shared decision-making, it also helps the providers prepare, so those people benefit from this approach because it provides a little bit of behavioral tailoring to help keep folks focused on what they are looking for in an outcome.

And so, another example and this one is really exciting because it was a peer run program that says we will study and learn about shared decision-making in peer services and have a whole recovery center work from that principle. Recovery center of Hamilton County which is in Cincinnati, Ohio, set about to learn what they could about shared decision-making. And, the way they did that was they joined a BRSS TACS shared decision-making community. So BRSS TACS is another SAMHSA initiative that focuses on recovery and it authors a virtual learning community and a collaborative learning community which were virtual trainings that people could attend, to learn deeply about shared decision-making, and then put that practice -- get that practice going and work together in teams to benefit each other, and so in this program, they trained peer staff and members, they completed a demonstration project that led to the implementation of shared decision-making, and it added an increased skill set for the folks who were certified peer specialist so they had an even deeper wealth of knowledge that they could share.

So, our vision for shared decision-making, and their vision, is to empower individuals to make more informed decisions with providers in education and peer support. And we can help realize that vision by making sure that on a national level, peer providers by any other name, whatever you call them, get exposed to and learn about shared decision-making. That shared decision-making is wrapped into the curriculum that is used around the country for certification processes, that Medicaid can be used to incentivize shared decision-making, that we develop decision aids that are easy to use and available to providers, and to educate people to expect request and participate in shared decision-making. There are number of resources and readings that I would highly recommend as you wrap up your summer you might want to print some of these out and read them while you're at the lake or the ocean, it will do you some good. But

at this point I'll turn this over to Laurie who will lead us in our comments and questions. Thank you all very much.

**Laurie Curtis:** Hey, everybody. Thank you so much Iruma and Melody for your presentations. I was delayed because there has been a very active chat this afternoon, and that's always delightful because people are taking on what you're saying and they are thinking about it. A couple of questions have been raised that I would like to share with you. I think one of the most powerful issues, to me anyway, actually came in the chat. I'm going to start with you Iruma: one of the attendees was saying, that people at her organization -- workers, employees -- would be scared of shared decision-making because they would worry that people would choose to not take medications. In your presentation you started with shared decision-making about which medication people would take -- but the fear is it would turn into a whether to take medication or not. How do you handle some of those concerns within OnTrackNY?

**Iruma Bello:** You know that's a really great question and when we think of OnTrackNY, medications are not mandatory to participate in OnTrackNY, so we really start from the premise that it is people's choice, and yet we find that if I'm quoting the data correctly about 80% of our OnTrackNY participants are taking medications. Because the idea is that by presenting as a choice, and having a very detailed discussion around what are some of the concerns and if a prescriber can address those concerns, and get on the same page with the young person and family, the it doesn't become this I take medication or I do not, it becomes I'm taking something that is helpful for me. I'm taking something that is relevant for achieving my goals, you take something that is bigger and then people are on board. So, you're right it is a fear but I think we do a lot of training with our team to not get stuck in the black and white mentality.

**Laurie Curtis:** Melody do you want to add to that? I bet you're chomping at the bit to add to that!

**Melody Riefer:** Yeah I am, I mean I think that's absolutely correct, what Iruma said. And it's much more meaningful to have an honest conversation about using medication or not, then it is to just have somebody say, yes, and then go off and not take the medicine. Which we know happens. And so if these - if there can be transparency and we can talk about what's beneficial and what are the risks, and then to really make a better informed decision, then I think that people are able to, even if they decide not to take medicine, pull in other resources, that can help support them to a greater extent maybe in lieu of medicine.

**Laurie Curtis:** Great. Another question that came up is on dealing with differences of opinion between a young adult and a family member. That can be highly contentious, and one of the participants asked about how does that work with guardians? Particularly if the guardian isn't agreeing with the decision that perhaps the young adult and a clinician may be making. So, Iruma, how can you deal with this conflict issue with the third-party parent and guardian?

**Iruma Bello:** I think that there is an added complexity when you are working with parents for people under 18. And once again I think it's a similar answer you try to stay away from the black and white of it, of what's one person's opinion versus another person's opinion and let's battle it out, but instead to really figure out what are the underlying concerns. Why does the young person see it one way, what was behind the guardian's perspective, sometimes people want to make a decision based out of anxiety about not having all the information and providing some -- whether it's psychoeducation around or providing scientific evidence around one thing versus another and giving people an opportunity to think it through and flush it out and bring it all to the table. The young person's perspective as well as the family perspective, helps demystify that decision and helps people get on the same page and at least be willing to try it out. Because that's all we're asking when we do shared decision-making, let's take that first step and all of us be together on that first step. We do not have to stick with it if it does not work.

**Laurie Curtis:** Melody would you like to add to that?

**Melody Riefer:** Yeah. I think that there's kind of an answer or an approach for when somebody is under age, but when somebody is an adult, it gets a bit more complicated, because you have to address whether or not the person is a legal guardian, be that a parent or someone who is assigned to that role, or is it a concern family member, and then the approaches are different, in terms of who kind of has the final word. But there's been some recent research about decision-making within a kind of triad or greater. So usually shared decision-making is framed as something that takes place between two people, but when you add in another opinion or several other opinions, it of course gets more complicated. The goal of course is, again just like Iruma said, to avoid the edges and to move into more transparency. So it's not an either/or, or a black and white, the moving into why someone feels the way they do. Shared decision-making isn't about making a decision and sharing it from whatever place you are sitting. It's really about everybody contributing some expertise and coming up with what is the best solution, and knowing that you can then make another decision. So you may try something on to see how it fits, and that's part of the decision. In that way, you keep the conversation moving forward. And to me, that's the strength of shared decision-making. It's always moving forward.

**Laurie Curtis:** I think you make an excellent point Melody, and I think one of the things that is exciting and I think you both, Iruma and you Melody, have alluded to it, is that the kinds of decisions we are talking about making here are revisit-able. In other words, they are not dead-end crossroads, this is it, this is the way it needs to be forever. You know, we're thinking the decision we're making is largely what is the next step? And can we try this out, how do we know it's working, how do we know it's not working, how do we know things are getting better, how do we know things are staying the same? And that becomes the focus of the kind of shared decision-making that you are both talking about and it sounds to me very much that that's a pivot-able element in any shared decision-making, but especially important with working with young adults.

**Melody Riefer:** Absolutely.

**Laurie Curtis:** Alright. And with that, I'm afraid we need to close off for this afternoon. We had a very interesting webinar. And I certainly appreciate both Iruma and Melody, your spending time with us. Talking about shared decision-making, your experiences and some of the training that you have provided.

If anyone would like more information from either Iruma or Melody, please do not hesitate to contact them. Here are their emails, and you can also contact Recovery to Practice directly. Me or any of our team at the Recovery to Practice email below. We are also excited to let you know about some webinars that are coming up, we are in the process of developing our webinar series for next year, and we would certainly love it if you would email to us at Recovery - [RTP@AHPnet.com](mailto:RTP@AHPnet.com), and let us know what you would like to see from Recovery to Practice webinars. We're very interested in hearing from you. We also would also like you to know that we have a webinar coming up on October 4 on Psychiatric Advance Directives, if you're on the Recovery to Practice mailing list you will get information about that webinar. Please register and join us.

If you're interested in NAADAC continuing education hours, please click on here where you will be directed to a page with an evaluation and a quiz to complete for your certificate. If you do not need NAADAC hours -- If you do not need NAADAC hours, you can download a certificate of participation for this webinar as well as the presentation slides in the download materials box near the bottom of your screen. Please everyone, be sure to complete the feedback questions that will automatically load onto your computer when we have completed the webinar. We really do value your input, and find it extremely helpful as we develop materials for next year.

So, on behalf of SAMHSA, I want to thank you all for taking the time out of your day to attend today's webinar. This concludes our call for this afternoon, and please have a great afternoon. Take care. Bye, bye.

**Melody Riefer:** Thank you.

**Iruma Bello:** Thank you.