MELODY RIEFER

Hello, and on behalf of the Substance Abuse and Mental Health Services Administration and the Recovery to Practice Team, we’d like to welcome you all and thank you for joining us today for our webinar on psychiatric advance directives. My name is Melody Reefer, and I’m going to be your host today. After some housekeeping and a short overview of Recovery to Practice, we’ll begin today’s presentation.

At the bottom of your screen you’ll see a Download Materials Here box where you can access our presenters’ bios as well as a PDF of presentation slides and any other available materials.

As a special feature, which we hope to incorporate into our future webinars, you’ll find a document titled Five In Five. This refers a document that has five additional resources with links and brief descriptions for you to review. Download this page for further information about our topic.

This webinar has been preapproved for Continuing Education hours from NAADAC, The Addiction Professionals Association. To qualify for these Continuing Education hours, you must attend the full webinar, complete a brief quiz and the webinar evaluation. There will be more information about this at the end of the webinar.

Finally, if you are a registered attendee, you will be emailed a link to view the archived recording. This link will also be available on SAMHSA’s Recovery to Practice website.

This webinar is hosted by SAMHSA’s Recovery to Practice, or RTP, initiative. The overarching goal of this initiative is to improve the knowledge and ability of the behavioral health workforce to use recovery-oriented practices every day. RTP offers free webinars, newsletters, and training and technical assistance opportunities. Check out the RTP website regularly for new opportunities.

We would invite you to join our mailing list to get information about RTP activities delivered straight to your mailbox.

On the RTP website are links to a set of discipline-based curricula to promote understanding and uptake of recovery principles and practices. Developed by six professional disciplines for educating their membership about recovery and behavioral health, these materials are adaptable for use by other disciplines and organizations seeking resources to build a recovery-oriented workforce.

Understanding what recovery means is critical to success. SAMHSA’s working definition of recovery in behavioral health is a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their fullest potential.

SAMHSA’s Recovery to Practice initiative helps you turn these principles into workforce practices.

Now our presenters today are going to help us take a deeper look into a recovery-oriented practice around the use of psychiatric advance directives.

Patricia Siebert is a staff attorney at the Minnesota Disability Law Center. She trains service providers, attorneys, physicians and judges on the use of advance psychiatric directives and other legal rights concerns. Pat also makes sure people receiving mental health services have access to information and training about PADs, which we will be using as a short term reference to psychiatric advance directives, and integrate that work with wellness recovery action planning.

Our second speaker today will be Marie Verna. She works within Rutgers University Behavioral Healthcare Research and Training Institute ensuring that the Institute’s services are based on the
recommendations of people who use behavioral health services. She also conducts training in psychiatric advance directives for a peer work staff working in the Access Center, which is a single entry point call center that serves as the front door for the whole Behavioral Health Services system in New Jersey. Marie not only trains people about PADs, but she also uses the PAD, along with a WRAP plan, in order to practice what she preaches.

Now, just before Patricia starts us off, I’d like for us to complete a quick audience poll. If you look at your screen right now, you’ll see that we’re asking you to select, on a scale of one to five, your experience with developing or implementing a psychiatric advance directive. Just click on the radio button beside the listing that is true for you in the actual poll box, which is located just below the PowerPoint slide.

I see we have quick responses with the largest percentage indicating that they have no experience with psychiatric advance directives. Just a couple more seconds for those of you who are looking where to click.

Wow. So more than half of everyone on the call is indicating that they don’t have previous experience in developing or implementing a psychiatric advance directive, in which case I’m really glad you’re here because you’re going to learn a ton of information today.

With that I’m going to turn it over to our first expert presenter, Patricia Siebert.

PATRICIA SIEBERT

I’m really happy to be here today, and after seeing the results of the poll, I’m even more pleased that SAMHSA is conducting this webinar because I hope that our presentation will be able to encourage and AHRQ providers and people who really use PADs to really think about implementing them for themselves and for clients.

So I got involved with my first psychiatric advance directive adventure when one of our clients walked into our offices in 1989 and said, I want a psychiatric living will. And there was no such statute in Minnesota. Indeed, we just had an end-of-life directive. And we had just received a Supreme Court decision from the Minnesota Supreme Court saying that competent mental patients could make decisions about their treatment and medication. So we were really spurred to work with the legislature to get something in place, and our first PAD attempt became a statute in 1990.

And so here we are, almost 30 years later, and I’m still working as hard as I can to help people and providers implement and acknowledge PADs. So I’m really hoping that this training will encourage some of you to think about PADs as you go through your practice with your clients.

I just want to mention that I’m not a national expert. I know the system in Minnesota really well. I have some experience with other states. But I’m providing an overview here today, and so some of my points and comments that I make will be pretty general. But we’ll try to come back around to maybe some more detailed questions when we get to the question-and-answer section.

So with that, when I talk about psychiatric directives, I really like to reinforce the importance for both individuals and providers to understand that psychiatric directives are really an outgrowth of some of our constitutional rights, in particular our right to personal autonomy. There are other ways to talk about it. A right to privacy, a right to self-determination, a right to informed consent. They’re really all part of a development of the law in the latter half of the twentieth century that has made psychiatric advance directives possible.

So I just wanted to briefly mention the legal underpinnings of psychiatric directives. I think it’s a good way to help understand how important they really are.
In the sixties we had a number of cases with the United States Supreme Court that looked at the right to privacy under the Fourteenth Amendment to the U.S. Constitution, in particular looking at to what extent we have a right to make choices about our own bodies. The cases that are most famous in that regard are *Griswold v. Connecticut*, which was about birth control, and *Roe v. Wade*, the abortion case. But what they really looked at in the overall decision was the extent of the right to privacy under our Constitution.

Then we really had movement really sparked by the Karen Ann Quinlan case in 1976 which talked about to what extent does a competent person who is dying have a right to have their choices honored. So we got the notion of a competent person and having their expressed wishes followed through on.

This was really buttressed by the idea of a medical power of attorney right about the same time, and in 1976 California passed the first medical power of attorney statute. And it kind of makes sense if you can appoint someone to handle your finances, why not someone to handle your medical decisions?

And as far as psychiatric directives go, in the 1980s in particular there were a number of state and federal right to refuse medication cases which really looked at the rights of individuals with mental illnesses, including people who are under commitment, to make their own medical decisions, in particular regarding medication if they were competent to do so. And the courts basically said, we don’t distinguish between people who have a mental illness and other people when it comes to self-determination.

This is just a slide – this is the case in Minnesota that really addressed this issue, and the court said, to deny mentally ill individuals the opportunity to exercise that right is to deprive them of basic human dignity by denying their personal autonomy.

So we’ve got some really important constitutional underpinnings, and the result of the living will concept, that power of attorney or agent concept, and the right to make psychiatric care choices equals and resulted in PADs as we know them today.

There are a couple of other factors that I wanted to mention when it comes to the role of PADs. There’s been more research, in particular in the last ten or 15 years, in the social sciences regarding the role of greater self-determination in a person’s sense of self and quality of life. And I’ve just cited a couple of studies that have really included that people with disabilities who do have greater self-determination have better employment, less physical and sexual abuse, and really more success in the community as they integrate. And I think PADs are an important piece of that self-determination.

And apparently Congress did too, because in 1990 Congress passed the Patient Self-Determination Act which required providers who take Medicaid and Medicare to ask people if they have a directive and to note this in the medical records, and to also educate staff and community about directives and patient rights. And some of the trainings that I’ve done over the years have really been as a result of the requirement that providers educate their staff about directives. And I think even just asking people, do you have a PAD, do you have an advance directive, sort of generates not only interest in that tool, but also, oh, maybe I should find out more about that.

So these statutes have all really generated interest and possibilities for advance directives. And there are number of good reasons, I’ve touched on a couple of them, but I just wanted to really emphasize a few things that PADs really help people with.

I think PADs operationalize individuals’ choices regarding treatment and services. People know what works best for them. This is a good tool with legal teeth that will help them put that in writing and educate others, as well, on what works for them. And if you’re a provider, that’s all good information. That’s really a good thing to be able to have in front of you when you work with someone, especially, for example, in a hospital setting, if it’s someone you’re not familiar with.

It also is a good vehicle to start talking with not just providers, but families and friends, about planning and recovery and what works, and how to institute that in your care and treatment.
A psychiatric advance directive is also a good vehicle to attach other kinds of documents, like temporary transfer of custody, genuine financial powers of attorney, and other instructions, and I will talk about that a little more later.

PADs are really a form of informed consent. If I go to the hospital and I’m going to have surgery, one of the things that happens is the hospital puts an informed consent document in front of me, and hopefully that’s after they’ve already talked to me about the factors that you see here right now. What my condition is. The risks and benefits of the surgery. Treatment options other than, let’s say, surgery. The consequences of consenting. It’s important to factor in my values, beliefs in making that decision. And then I have to communicate that I’ve made that decision, and usually in a hospital setting, that’s in writing.

Well a PAD is no different, and the factors that go into a PAD, which is a form of decision making, I try to avoid the term “informed consent” because it’s broader than that, it’s informed decision making. Some of the information might lead you to say no, so it’s not informed consent. So I use the term “informed decision making.” And a lot of these factors will be really important to the development of a PAD.

So as providers you have an important role in the information piece of that informed decision making. One of your jobs is to educate your clients about risks, options, benefits, and consequences. And the other part of it is to really not be too tied into how you communicate that, but really look at a culturally-holistic approach. So I might have a client who is Native American. Implicit in the treatment for mental illness might be using a smudging ceremony. I think that is something that is very doable and something that could very easily be a piece of a person’s psychiatric directive.

So, just briefly, the basic legal components of a PAD, and this can vary from state to state, are instructions. Some states only have agents. Some have both instructions and agents. It really depends on your state. But even if it’s just an agent, I think there are ways you can indicate to that agent what your wishes are.

And then, like a will or other legal document, the PAD has to be executed, which basically involves witnesses. Usually two or notarization. Again it depends on different states with different requirements. Some might have a competency declaration. Most of them address conflicts of interest, for example, it’s not a good idea for an employee of your current provider to be an agent.

And then, importantly, you need to know if the PAD locks in when you are incapacitated or whether it is revoked at any time. So that’s something that’s specific to your state. Your protection and advocacy program should be able to direct you to information about PADs in your state and may even have forms.

So I’m not going to dwell on instructions because Marie is going to go into that in a lot more detail. I just want to note two things. PADs really set treatment providers for parameters and agents. And that’s really key to an effective advance directive. And at the same time as you’re setting treatment parameters, it’s important to understand that a PAD is not a wish list. I might want to go to Hospital A, but Hospital A doesn’t have any open beds, so I end up in Hospital B. I’m not necessarily entitled to go to Hospital A. It’s really – I’m standing in my own shoes as a competent person, and some of it depends on the resources of the providers at that moment in time.

I think an agent is so important if your statute allows an agent, and there is a way for a person to appoint an agent. They’re like the pinch hitter. When you’re not able to go to bat, they should be able to go to bat for you. Work with care providers. They can also be much more flexible in terms of unforeseen consequences that you might not have anticipated when you wrote your directive.

A PAD can address record access. I think this is a really important issue for providers because often when a person is not competent to make a decision about releasing information, they’re not sure what to do. If you have an instruction in your PAD, or your agent has given the authority to both review and release information, and you’re working on a discharge plan, that’s a really good thing and it is supported by HIPAA.
So I mentioned earlier kids, pets and finances. With our directives in Minnesota, we attach a designated temporary custodian document. Most states have something like this. It allows you to designate a triggering event for the transfer of custody of your children. Ours is good for six months. We tell people attach it right to your form. The same thing with a power of attorney so that someone can pay a person’s rent, or pay their bills. And if you have pets that need to be cared for when you are in the hospital, those kinds of instructions are really important to put into a PAD.

So Marie is going to get into some of these questions in more detail and we can circle around to them at the end of the presentation. But generally speaking, if a person is competent, they can prepare a directive. I’ve worked with hospitals in helping people prepare directives as they are being discharged, as part of their discharge planning process.

The big caveat here is if a person is under an involuntary medication court order, there’s usually a finding that the person is not competent to make decisions about medications. So that would be a consideration in at what point in time does a person develop a directive. If under a court order that says they’re not competent, that’s not a good time.

Where to keep a PAD? Some states do have PAD directories. Nowadays my clients tell me that they just put them on flash drives or on their Smartphone. People put their PADS on the refrigerator so that if EMTs have to come for some reason, or the police are there, they have that PAD at the ready for emergency personnel. And, of course, it’s really essential that if you have an agent, an agent have a copy of that PAD.

Provider obligations in implementing a PAD. Marie will be going into more detail about these concerns and the ins and outs of this as well. I just want to highlight that a provider has to act in good faith according to applicable standards of care and consistent with reasonable medical practice. And I like to think of this as what works. The person has identified what works, and if we can do it, let’s do it. So I want to encourage people to really take a broad approach to this and really do their best to honor a directive that is in front of them.

Implementing a PAD does involve clinical judgment because often PADS (inaudible) or activate when a person is no longer capable of making those medical and mental health decisions. As long as they retain the capacity to make those decisions, generally speaking, a PAD doesn’t kick in. It’s there for the times when they are not able to make those decisions.

I think there’s some confusion about whether a provider can override a directive. I think generally speaking invalidating that document is really a legal issue. And where the provider, so called, invalidates is in saying, I can’t follow a particular instruction in the PAD because. So I think that’s an important decision because sometimes PADS end up in court cases, and it’s important to recognize that the document itself might be valid even if a provider feels that they cannot follow a particular instruction.

So if providers in good faith follow PADS, or a provider in good faith does what an agent tells them to, and they feel they cannot implement a certain instruction, most states provide directions for what they do at that point. For example, in Minnesota you have to notify the patient, document your reasons for refusing to follow the instruction in the chart, and, if necessary, transfer care. And if you do these things, you, in most states, are covered by legal immunity. So really working to implement a PAD if at all possible, in good faith, does protect you.

Penalties can vary from state to state. Often the real focus is on either coercing a PAD, withholding a PAD, or concealing a PAD.

I just want to briefly touch on a Duke University study on PADS which I think is really instructive on the way that people with mental illnesses use PADS. Ninety-four percent of people who were involved in the study said they did give advanced consent for at least one medication. Seventy-seven percent also
rejected at least one medication. And then they listed – the vast majority listed side effects (inaudible) particular medications and what to do about that.

So I think what this really shows is that the instructions in these folks’ PADs are really based on their past experiences, which really supports their credibility. And if you think about it, I’ve got an end-of-life directive, and it discusses my wishes regarding ventilators and so on, but I don’t really know what those are like, so I’m kind of guessing. But a person who fills out a PAD often is basing it on past experience and they really know what they’re talking about. So it’s an interesting contrast that I think really lends a lot of viability to a PAD.

One last thing I wanted to mention is PADs are getting a lot of attention in other kinds of legal proceedings. For example, if a person has an effective, valid PAD, and hopefully with an agent, that could prevent the need for guardianship. A PAD could affect the outcome of a court’s decision about forced medication. For example, in Minnesota if a person has a valid PAD, a court looking at a medication issue has to enforce it. And the PAD consenting to hospitalization could possibly prevent commitment.

So there are many advantages to a PAD that go beyond the instrument itself.

And Marie is going to talk more about drafting PADs and some of the things to consider, so I’m not going to spend any more time on those. And I am going to turn it over to Marie.

MARIE VERNA

Thanks, Pat, and thank you for being a disability lawyer, dedicating your career to people like me who manage behavioral health conditions.

So we talked at the beginning about the experience levels that all of you feel with PADs, and now I’d like to get your opinion on something else. And Melody, I’m going to hand it over to you for that.

MELODY RIEFER

Sure. Thank you, Marie. What we’re going to do is revisit our poll again. But the question is subtly but importantly different. Rate your comfort with developing or implementing a psychiatric advance directive. So this is different than asking about your knowledge, but in this we’re – how comfortable are you with the idea of developing or implementing a psychiatric advance directive? This is a personal question, and one that you can – there’s not a right or wrong answer. So feel free to make your selection by clicking on the radio button in the poll section. Just a couple more seconds to allow everyone to respond.

It's interesting. The results are much more evenly split on this question. So we have a wide range of comfort levels with this idea of developing or implementing a PAD.

So Marie, I’m going to turn this back over to you with the knowledge that there is a mixed approach here in terms of people’s comfort level.

MARIE VERNA

Thanks, Melody. So I think the poll was important for me because it justifies and validates both our feelings about experience and comfort. I’ll let you all know that I was the Director of Advocacy in New Jersey when we passed our PAD about ten years ago, and so I was the consumer who was answering
questions from all other stakeholders about why – why – why do we want to do this? And as we tried to understand the value of it, we often heard from people that there’s just something about legal stuff. And we have to get over that obstacle. And in the process, we also needed to hear from all stakeholders that are involved in this. If you’re a strong consumer advocate, you know that sometimes you feel like you really have to be loud and strong to be heard. But in reality really good policy involves hearing all stakeholders.

So the first one that I want to talk about is there was hesitation from practitioners. First of all I think there’s this assumption that a PAD applies only in a crisis. And that was something that we really had to get over that one, too, because our PAD is designed to help somebody understand that they can determine competence. I personally decide I know that when I can’t remember which drugs I took, or whether I took them, or did I – I don’t know, was it the morning or the afternoon or whatever, that is when I invoke my PAD, and that’s what it says legally in my PAD is that my husband is now in charge of giving me my medications. So that’s way, way, way before the crisis. And that’s the point. And it’s in writing, and it’s legal.

The other hesitation that was valid, very, very important, is the fact that it put practitioners in risky situations in terms of their liability and their medical malpractice. And, again, we accommodated that with, as Pat described, immunity because we were going to start with the assumption that everybody is working toward the same goal.

Practitioners and drug care workers are sometimes afraid that they’re going to be reading something that they cannot provide. And so, again, we wanted to stress that the PAD is not designed to be adversarial, and it is not a wish list. And we know that.

Again, with practitioners, the notion of informed decision making, or shared decision making, may be a new concept. A lot of people who work in our field really feel some strong responsibility for making choices for other people, and of course we’re working toward something a bit more of a compromise. But if the person isn’t used to that, if the practitioner is not used to that, it’s going to be hard, at first, to understand the value of the PAD.

And then finally this was just this logistical thing that I had to learn about was that typical healthcare professionals have documents that are – they’re standard and they’ve been using them for years. The chart has certain things in certain order. And they really hesitated to have to read one more thing. And I think anybody who has ever had to use mine is probably really, really, really sorry that I did one because I write certain really important things in every single section to make sure that no matter which part of my chart you’re reading, you’re going to see the things that I really, really feel strongly about.

Now the hesitation from families I think most consumers can at some point understand that for our loved ones, our family, our friends, this invokes a lot of fear. It’s very, very difficult. But I notice that from families as well there’s also the same assumption that this applies only in a crisis. So when family members tell me, Oh, my God, it will never work, he’ll change his mind, I know that what’s not tracking is that we’re actually going to write this when we’re really healthy. When you’re in crisis or anywhere near crisis is not the time to be doing anything remotely legal.

So then family members and loved ones often feel well, the provider won’t listen. So, of course, Pat described lots of parts of the law that gives, you know, a legal and financial incentive to listen and to try as hard as you can to adhere to it.

Again I think some families aren’t yet on board with person-centered care, especially for their adult children who have been struggling for a while, and from their perspective continue to make unhealthy choices. So the idea of empowerment, and self-empowerment, and I’m driving the bus, might be something that family members, loved ones and supporters have a problem with. And then, I think, for me, throughout my life, I was diagnosed in 83 with bipolar disorder and anxiety disorder, I think I’ve had to just come to terms with the fact that mental illness sometimes just puts us in situations where people just
don’t trust us anymore. And obviously in recovery we’re trying to heal that, and for a lot of us that happens. But there’s got to be some awareness that that’s happening, and a lot of times it does.

Now for people like me and probably many of you on the call, we’re actually managing these issues. And of course my job was to find the voice of the consumers in New Jersey, and find out, yeah, so why would this be a good thing. And, of course, again, I saw this hesitation because it sort of doesn’t make sense if you think of a PAD as only something that you would create during a crisis. Or that all of a sudden during a crisis is when you’re actually going to try to do some type of future plan of any kind.

So, again, the education about – the person who determines competency is you, so when I know that I’m becoming, you know, I don’t feel balanced as much as I like to, or if I, again, this thing with the meds, the meds, the meds all have names that start with X and Z, and, you know, I’m losing my ability to keep all these details straight, that – I’ve learned over time like that’s my – that’s when I know that I take all the stimulations out. And consumers know these things about themselves. That’s kind of what we’ve been doing throughout our recovery is we’re trying to avoid crisis more than anybody.

So the reason we asked the comfort question at the very beginning was because of all this stuff about it being a legal document, and this feeling that, oh, my God, if I put it in writing, somebody, you know, who wants to do that? What if things change? What if, you know, they come out with a new drug that I want to take?

The PADs can be extremely overwhelming. There are very few people in our world who actually like reading a lot of dense documents of any kind except people like Pat, which is really why I thank her for being a disability lawyer.

And then sometimes it’s very traumatic to think back to relapse or crisis. I guess because I had such a leadership role in the formation of our law, I actually researched my records from all the hospitals I had ever been hospitalized in, and I found that to be very difficult. I mean, now in person-centered care, people try to write treatment plans or recovery plans with the notion that we’re reading them, too, you know, we’re here. But sometimes reading the lingo really takes you right back to it and kind of creates anxiety in and of itself.

And then I really want to point out, at least for myself, consumers sometimes just lack trust in themselves. Many, many consumers will tell me, well, you know, what if. And that’s just, again, something that means, that you don’t do a PAD willy nilly. It’s not something that you do in one group, in a partial or acute partial hospital program. It’s not like that. It’s just like a will where you think about it in advance. What really would have made it better? And that’s one of the key points that I want to bring out.

So there was this hesitation, it was a new animal, but very, very important, and I’m sticking to that story. That’s my story.

So one of the key things that answers all this hesitation for every stakeholder is understanding that what you’re putting in the PAD is really a preference more than a demand. And the preference can be explained. And once it’s explained, it makes sense to most compassionate caregivers, family members, supporters, and loved ones.

So what we try to help people with is why do you prefer X, Y, or Z. So why medication. So in my advance directive I say clearly that the FIDIC medications have worked well for me, and I know there are others that are more powerful, but I consent to a series of a combination of more powerful, higher doses, and maybe even different chemicals, however, there are certain ones, like the second-generation antipsychotics that I want to get off of immediately. As soon as I stabilize I want off of them.

Alternatives to hospitalization. Here in Jersey we have some respite centers. We can do a webinar on what those are later. For me, hospital preferences, I’ve been in urban hospitals, I grew up in the country, I live in a cute little country town. I don’t like urban ERs. They scare me. There’s too many people.
Everybody is screaming. So I tell my husband I want to go to the average general hospital, you know, near our house, and I expect him to do that. And I know he will because I trust him.

ECT. Many, many people just need to refuse it. Just not there with accepting it.

Emergency response alternatives. Consumers will tell me that in their PAD they want everyone to know we want the social worker to come in first, we don’t want the police coming in first. It’s too traumatic. So that’s the type of thing that a person can explain why, what happened. You know, yes, there’s no bed at my preferred hospital, but I will wait for that bed as opposed to going to another one because it has private bathrooms in each room and I have serious OCD and I can’t handle germs.

So once you hear the why, a practitioner and a family member’s response changes almost immediately.

Side effects. Most people want to talk about side effects. As the Duke study showed, allergies to medication, very, very important information for the practitioner to know.

Signs and symptoms. You’ve got to get them in there because they are the things that are going to be early intervention. So my husband has these things, you know, he sees them, he’s read it, this is what – it’s better to say Marie isn’t feeling well, let’s get to it before she’s got to go to the hospital.

So in my advance directive, in terms of who should be informed about my situation, I actually – I state very clearly that only certain family members are involved, and I base that on their understanding of mental illness. Not everybody has learned as much, but I specifically say things like, unless this really crashes, I don’t want you calling mom. I don’t want mom to know.

And then most people, they don’t think about it in advance, but as Pat said, most of us care about these other reasons not to go into a hospital, or not to, you know, we can’t actually ignore adult life responsibilities, and we can get that in a PAD.

So as a takeaway, I want to get to this thing about the comfort level having, you know, a thing so legal. For me it’s more than legal in that it provides what professionals in our field call collateral. Most of the time, even if they know someone well, you know, we don’t have a lot of time to talk with our providers, but we have a lot of time with ourselves. And the PAD lets us quickly explain really key information that helps them make a better decision. As I said, it gets to prevention and early intervention as soon as possible. And it also gives us that opportunity to take responsibility and with it the control of our destiny. None of us wanted this. None of us would buy a ticket for it. But recovery means responsibility and the concomitant control, and the PAD lets that happen.

So what I want to close with is something that I found myself thinking about a lot during the conversations with all of the stakeholders when we were forming our law, is that most people who care about people who are suffering don’t want to harm anybody. And like it or not, consumers will say that treatment, sometimes professional treatment as well as just the way people are treating you in life generally because you have a difficult illness, is harm and sometimes causes trauma. So if people know all of the gems that are in a PAD, then we can essentially like pick up where Hippocrates started, where let’s first do no harm. And in behavioral health I think it’s important to start there and to think about how a PAD positions all of us to get to that place.

I really want to thank you all for listening. I want to hand it over to Melody right now for Q&A.

MELODY RIEFER: Thank you so much, Marie. And Pat. Both of you. I tell you there’s so much interest and so much energy around this topic. I know that as presenters it’s hard to watch the participant chat, but folks have been really engaged and making some great comments as well as some wonderful questions. And so I’m glad we have a few minutes to respond to some of those questions.
One that I want to throw out there to begin is someone asked about where do teens or people who are transitioning from child to adult services fall in relationship to PADs and their use or their applicability? And Pat, I’m wondering if you can take a shot at that first.

PAT SIEBERT: I think really you have to look to the states’ laws regarding what services or treatment a teen can consent to. So, for example, in Minnesota, if you are 16 or older, under our state law you can consent to hospitalization for mental health treatment. So because as a competent teen you can consent, I think by analogy, you could also consent by way of a PAD. So you could develop a PAD. If you’re 13 and really, under our state law, can’t admit yourself to a hospital, then I think you’re viewed by the law as not capable of giving consent, and I think you’re going to have to wait a few years before you can draft your PAD.

MELODY RIEFER: And I’m wondering, and maybe you can clarify this for me because I always try to think about – I mean there’s the legal issue, but as Marie said, you know, the PAD is more than a legal document. That it’s also an opportunity to convey your preferences. And so I’m assuming there would be no reason that someone – that even a young person – couldn’t still convey what their preferences are even if it didn’t fall under legislative rule.

PAT SIEBERT: It’s my gut reaction that to me a PAD is essentially a communication document, and we need those tools when we’re not really feeling capable of a lot of things, not the least of which is communication. So it would seem to me that if you wrote it all down, you could notarize it, you could have it witnessed, and yes, it doesn’t have the full force of the law behind it, but it still serves as that amazing explanation of why.

MELODY RIEFER: I agree. And if I’m a provider, why wouldn’t I want to know what that 15-year-old has experienced and their understanding of what has worked for them?

Marie, could you tell us a little bit about how a PAD is different from the crisis plan as part of the Wellness Recovery Action Plan?

MARIE VERNA: Crisis plan to me says, “I’m in crisis.” But it also assumes – it’s sort of implicit that we’re going to drag in a lot of treatment providers, a lot of professionals. But I think one of the things that’s really freeing and liberating is that the PAD allows you to choose an agent who, if you trust the person, you give a lot of discretion to that person, and a lot of things can actually happen out in the community.

So my husband knows that, you know, we’re both in this business so we both know that the capacity of our healthcare system today, but he knows, okay, it’s all in writing, Marie is going to bed for three days. I’m going to make sure she takes her drugs. I’m going to make sure she eats. I’m going to keep the dogs quiet. Move the phone, and all this stuff. So that, yeah, you could call it a crisis plan. I mean, I do – I feel like, yep, this is a crisis in the making. But it doesn’t have to come with that, you know, ICU/CCU feeling. It’s – the WRAP is an amazing document in helping people understand themselves and investigate themselves. But a crisis plan is different from a plan for you to take control of your life when you feel that you’re just losing a little bit of control over it.

PATRICIE SIEBERT: I’ve done trainings where people do a WRAP plan and a psychiatric directive together so the two documents fit together. And I like that because it really is like having a continuum of care. And it really makes people think through the whole spectrum of what they need when. So I think it’s a really good idea to look at those things in concert.

As far as legality, because, you know, I’m a lawyer, but a provider could technically disregard a WRAP plan. I don’t know why they would, but they can’t disregard a valid PAD.
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That's an important distinction. And that's a – and of course, the WRAP plan is so much more than just that one component of the crisis plan. So I can see where doing both and having that – what a great way to frame it – a continuum of care for one to communicate their preferences.

MELODY RIEFER: I was wondering, based on some of the conversations that have been taking place in the participant chat, if you create a psychiatric advance directive, and it's notarized, and filed with your agent, and with your care providers, does that mean you're stuck with it? That you can never change it? Because what if your life circumstances change?

MARIE Verna: Yeah, there's no such thing, to me, as anything that can't be changed. You know, after all, we change laws, and we change the behavioral health system. So I think it is a question that a lot of people have trouble with, and, you know, thinking about what if they come out with a drug that is better. We actually had that conversation many times. And the answer is you redo it. It is, you know, it's another “project,” and getting it to all your providers is a project, but I, over the years since 1983 when I was diagnosed, I've actually come to see myself as my broker. I broker everything altogether. And I guess I accept that responsibility because it lets me control a lot of it.

So most states allow revocation. Some at any time, some while you are competent to revoke and make a new one. Some circumstances that would be good times to amend your plan would be if you change insurance, for example, you might have different providers in your system, so you might want to take a look at what your PAD says about provider networks and hospitals that you can go to without being out of network. You'd be surprised how often that comes up.

Or if your situation with your family changes. For example, I saw something in the chat room about what happens if I have my husband be my agent but now I'm getting divorced? Well that's a good time to write a new PAD as well because you probably, at that point, may want to look at whether you want to change to a different person as your agent.

So there are a number of circumstances that really, I think, would mean that a new PAD or an amended PAD is a good idea.

PATRICIA SIEBERT: I also saw another comment that said they are good for two years, which I thought was really interesting as well. So in that case you’d want to do it when you change your fire alarm batteries or something so that you don’t end up with one that’s invalid because it’s more than two years.

I think it’s good to look at them regularly and just make sure they do what you want them to do.

MELODY RIEFER: That's an important distinction. And that two-year rule is for a specific state as opposed to a federal application.

PATRICIA SIEBERT: Right. I think that was Pennsylvania, I believe, as I saw the comment.

MELODY REIFER: I wish we had another hour because there are just so many great questions, but we're going to have to wrap up. I will take note, however, of the interest in this topic, and see if there’s a way we can work on providing more information.

I want to thank our presenters. Patricia, Marie, y'all have just been fantastic and have really opened up a lot of information for us. We are grateful for your time. I know that you all have spent a great deal of time preparing for this and we appreciate it.

We would like to let you know that there are additional resources available through the materials download, and so please do check that out and know that also the September issue of the Recovery to Practice newsletter addresses psychiatric advance directives. And so we’re trying to help make sure that we can get a bunch of information to everyone. So be sure and check out all of those resources.
If you’re interested in Continuing Education hours, please click on the link for a NADAC quiz here where you will be directed to a page with information that includes a brief survey, or rather evaluation, and then a quiz to complete. And you will be able to download a certificate of completion, and for many of you this helps you meet the expectations of Continuing Education for your different disciplines.

We encourage you to subscribe to the aforementioned quarterly newsletter produced by Recovery to Practice. We try to always focus on timely issues, bring current thought leaders to your attention, provide tips of resources. And if you’re not receiving this newsletter, you really do want to. It’s one of the better resources available.

Feel free to send us your thoughts and comments by email. You can reach us at rtp@ahpnet.com.

We really hope that you’ve found this information helpful and that you’ll be able to apply it in your practice and in your relationships with those you serve.

So on behalf of SAMHSA, I’d like to thank you all for taking the time out of your busy day to attend this webinar. We really appreciate your interest.

This concludes our call. I hope you all have a great afternoon. Thanks so much.