NCAPPS National Center on Advancing
Person-Centered Practices and Systems

Transcript: "Exploring the Intersectionality of Peer Support and Person-Centered Planning Across Disability"

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>> ALIXE: Thank you everyone and welcome to today's webinar.
I would like to get everyone -- thank you for joining us today.
And I will just introduce myself and we will get going.
My name is Alixe, I am one of the codirectors of the national Center
on advancing person centered practices and systems.
Together we are enjoying this afternoon for most of you
to get together to focus on exploring the intersectionality
of peer support and peer centered practices across disability.
I will be running through a few of the logistics.
This webinar is sponsored
by the administration for community living
and the centers for Medicare and Medicaid services
and all NCAPPS webinars including this one are free and open to the public.
Briefly, I will say for the logistics
participants are muted during this webinar.
You can use the chat feature in zoom to post questions and communicate with hosts.
Toward the end of the webinar our speakers
will have an opportunity to respond
to questions that have been entered into the chat.
The webinar is being live captioning in English and Spanish.
To access the Spanish captions, I am going to put a link
in the chat box
which can be followed.
Hang on a second.
And we will --
and you can follow along with the English version of captions.
This alive webinar does include polls and evaluations
so please be prepared to interact during polling times and
in just a minute I will be asking for one poll to be brought up.
One of the thing I wanted to say is that our speakers for the most part
are joining us panelists,
so we are
for the most part
going to be hearing from our panelists here today.
With that I will ask honor if you can pull up the first poll for participants.
This question is in what roles do you self identify,
and if you can please select all that apply, this helps our panelists know who
we have with us here today.

Okay, people have had a chance to respond and
perhaps we could share the results.
Terrific, thank you.
So for the most part it looks like the highest number
is social worker, counselor, or care manager, and terrific.
Thank you for all of you that are here,
and you can see everybody who was taking a look at the poll results.
We have people representing a broad range of experience
and knowledge that are coming to this webinar together.
Thank you all for joining, and with this
I would like to turn it over to NCAPPS codirector, Dr. Bevin Croft.

>> BEVIN: Thank you Alixe, the other NCAPPS codirector.
I am really excited to be here and excited about this webinar.
It's a topic near and dear to my heart
and I am really looking forward to a rich discussion today.
As Alixe mentioned, you can access the slides
and also a fantastic handout that Martha Barbone created.
You can access both of those, the link will be in the chat and Connor Bailey,
one of our project coordinators will put the links in the chat so you can be sure to have those,
and these will all be on our website as well.
For those of you who are familiar for the national Center of advancing person centered practices or systems, NCAPPS,
you know that our scope is very broad and we are somewhat unique
and that we are a center that cuts across disability centers, and across age
and we are really interested in services and supports for all people
regardless of disability identity and regardless of age,
regardless of what system you are accessing.
And we also have a big network.
So we really see ourselves as community builders,
Bridgers, pollinators, and the goal of these webinars
that we have every month, if you are new to these,
is to showcase innovations, best practices,
with the idea that we might spark some inspiration for you, our community.
So today we are hoping to
explore peer support
which we really see as intrinsically person centered
and really embodying the values and principles of person centered thinking, planning, and practice.
We have three peer supporters who are here to share their experiences
and we have asked them all to reflect on how peers promote
person centered thinking, planning, and practice across disability experiences and identities.
We don't presume to represent all of the different types of peer support
on this webinar. Rather we are hoping to get a conversation

and get everyone thinking about how the peer support movement
can be a foundation for strengthening person centered systems
regardless of the diagnoses of the people who are served by that system.
So that is really our goal today.
Without further ado I will get started and what I would like to do to start
is invite our -- each of our panelists
to share a bit about themselves, their story, what brought them to peer support.
We will start with Martha Barbone.
She has worked as the director of certified peer specialist training
and has provided peer support on an inpatient unit, in a peer organization,
and facilitated groups in the Veterans Administration, so lots of different settings.
And currently Martha is the interim director of the national association of peer supporters,
some are the let's begin with you and spend a little time telling us about your
peer support journey.

>> MARTHA BARBONE: Thank you Bevin,
and I am so happy to be here today
and be able to share this with everyone.
And if I could have my slides please.
A little bit about me,
I did not grow up thinking I wanted to be a peer specialist, imagine that.
My first love and career was as a veterinarian
and I was in the Air Force for about 12 years, long before I got
sidelined with emotional distress and diagnoses.
And really for about the next 20 years
I was a professional patient
in the mental health system.
And although during that time sometimes I heard the term person centered,
I honestly cannot say that I ever experienced person centered planning.
So that is much the reason why I am here today.
I was introduced to peer support about 14 years
into that journey, and I believe without peer support
I would either still be stuck in that system
or even possibly not here at all
because it was peer support that first gave me hope
that I could live a full life instead of a limited life.
I really love the quote that is in this first slide,
and I like it so I'm going to read it.
It's amazing what you can do when you set your mind to it,
especially when you are no longer supposed to have one!
And this really resonates with me because
like within three weeks into my initial treatment
on an inpatient unit in psychiatry
I was told despite the best efforts of a multidisciplinary team,

she has failed to respond to treatment.
And that was followed by it is unlikely you will ever live on your own, raise your children, or work again.
And at that time I believed that
because that fit with what I was telling myself.
I had gone for help because I felt hopeless and helpless and worthless
and now I have a doctor that confirmed all those things for me.
And you know, I became a recipient of services,
not a participant in my treatment.
I received treatment, I was a good compliant person,
and it did not help a lot for many years.
Could I have the next slide?
So it's interesting because when we talk about person centered planning
often people in the behavioral health system aren't really into two what that is
and people outside the behavioral health system aren't either.
In the first thing we talk about his recovery, and I have the SAMHSA definition here,
that substance abuse, mental health services, administration, and of their definition
is that recovery is a process of change through which individuals improve their health and wellness,
live a self-directed life, and strive to reach their full potential.
Nowhere in that definition does it say
we reduce or eliminate symptoms
or that life is limited.
It's really open and it's open so much because
it is self-directed. It is for me to choose what I want in life
and find out what kind of support I need to get there.
And we also approach this from what we call
a recovery focused approach.
And a lot of research has been done
that has shown that people can live full lives
even in the presence of symptoms.
Whereas before we used to be in sort of a maintenance model
where we are going to maintain, you are going to reduce stress in your life,
you are not going to take risks, and you are going to take often a lot of medication
to just maintain.
And we are no longer satisfied with maintenance.
We strive for everything, to get back in touch with our hopes and dreams
and find the supports we need to live a full life.
And I must say since I was told all of those things that I would never do,
I have worked full-time for the last seven years, I actually raised all three of my children on my own
as a single parent, and they all went to college.
And I owned my own house and now I happily lived in a house with my son
and his wife, so I was really glad I got to the point

where I did not believe what I was told initially,
and that is what I tried to do in peer support, is to empower others.
And we also believe that not only is recovery possible, but probable.
There is no diagnosis that says you don't recover from that,
or no trauma that says gee, you can never recover from that.
We always approach this from Hope.
Can I have the next slide.
And this is just the definition again of SAMHSA peer support.
And peer support goes by many different names.
It is most commonly in the behavioral health system
with people that have what we call lived experience of either mental health diagnoses
or substance use diagnosis.
But it can occur, and it happens more and more now in primary care.
The original version of peer support was mostly voluntary,
the thing we are most familiar with are things like the 12 step programs
where it is the classic peer support in a totally voluntary nature,
but for the last several years we have seen more and more employment opportunities
for those in peer support.
And one thing I would say about that employment,
it is often looked at, you can get a job doing peer support as part of your recovery
and a pathway to something bigger and better.
And I really want to dispel that myth.
One, the first thing is this pathway to employment,
peer support is a tough job.
We spend our days with people who
sometimes are in the worst moment of their life.
They might have trauma, they have other things going on,
they are homeless often, they have food insecurity,
they are not employed.   And we deal with all those at the same time
often sharing our own experiences of those same things.
And it is often taken for granted
that well, if you are a peer, you share your story.
And a friend of mine had the best come back to that,
because we gladly share our story when it is relevant to support someone,
but often when you are on a multidisciplinary team
you are asked could you share your story with the team, and this person said sure,
shared the story, and then turned to the room and said who else here would like to share
something very personal,
maybe even traumatic, with the rest of us right now?
And I sure that because I don't want people to take for granted
the work that P specialists do.
And we also don't want to grow up necessarily to be case managers
or social workers.   We do peer support because
that's what we are passionate about and being able to connect to people

through that lived experience is what helps me have purpose and meaning in my life.
Could I have the next slide.
So how does this all relate to person centered planning?
In these next two slides
what you see on the left is
the principles of person centered practice
that come from the NCAPPS person centered thinking, planning, and practice,
a national environmental scan of definitions and principles.
And they link to that is here on the slide and I think Connor is also going to put that in the chat.
On the left where you see the focus on the person, and then the definition
also comes from that document.
And then on the right what you see are the national guidelines
for peer support.
And I have tried to match this up, so you see focus on the person and the peer support guideline
is that peer support is person driven.
Peer supporters are open-minded and peer supporters are empathetic
and they really match up very well.
And then the next one, for the person centered planning,
the focus on choice and self-determination.
And for peer support, peer support is voluntary and supports choice
and peer support is equally shared power.
Whereas in peer support it is about the relationship.
It is not a relationship where one person is receiving support all the time
and one person is giving support all the time.
It is a back and forth, it is mutually shared.
The next one on community inclusion,
a lot of what that says is embraced in the national practice guideline
of peer supporters are respectful.
And that is treating people with dignity and respect
and making sure we acknowledge that they are part of the community of their choice.
The next one, availability of services and supports,
the approach from peer support is always strength focused which we also see in person centered planning.
It is not about what is wrong but it is helping someone to find out where the strengths are
and what skills they have and what skills they would like and how to get them
and what supports they have and what supports they would like to have and how can they get those supports.
Can I have the next slide.
And we will move on here.
And to go on, person centered planning, that people should have information
in a clear and meaningful way in order for people to understand
their options and make informed decisions.
And in the comparable for peer supported is that we are honest and direct and transparent,

and a lot of what we do often is
sort of serving as this translator to take medical terminology and information
and make sure it is presented in a way that the person feels they have
all the information to make a decision themselves
and to support them to make that decision and support them,
and even to ask questions about what they don't understand.
I am going to skip to the third one on this
which is positive expectations.
Peer supporters are hopeful and we facilitate change.
And this change comes about both withdrawing to facilitate systems change,
as well as supporting a person in change if that is what they are trying to do.
The reason the other two don't specifically lineup,
the coordinated supports on the person centered planning side
talks about support between different providers, different services,
which definitely in peer support we definitely believe in that.
It is just that the guidelines are directed more about what do peer supporters themselves do
so that is why there is not a matching one.
And then finally on the bottom you see peer support is mutual and reciprocal.
And I am really not aware of any other profession
that really has this idea of
mutuality, and what we mean by mutuality,
it is not like if I support you for 20 minutes, I expect you to support me for 20 minutes.
It is more we both are making this relationship
and we both contribute to the relationship.
And sometimes I might be more in a supporter role,
but I also get from this relationship, the relationship is meaningful to me
and it helps me as well.
Can I have the next slide.
So my focus actually came from
reading this article that is referenced on the bottom.
This article was published in 2012,
and of the principal author was Janice [can't understand]
in the top 10 concerns about person centered care planning and mental health systems.
This article is actually what my handout is based on.
It is 10 concerns about why person centered planning can't work in mental health,
or does not happen in mental health.
And I look at this from 2012,
and I look at what goes on today,
and I see much of the same thing.
When I am not experiencing person centered planning,
it is because of a lot of these concerns.
And I think peer support can help bridge those concerns.
Because in peer support one of the challenges of having recovery oriented
person centered planning is

concerns about risk management and professional liability.
Well, what if I let this person make a decision
and they don't choose well?
That's a risky, and what is my liability.
And another one is that the health care system,
when you go to the doctor or a mental health provider,
it is often what's wrong, what brings you here today, what is wrong.
And it is all about medical necessity, but in peer support our focus is not on what is wrong,
it is on what matters to you and how can I help you with what matters to you.
And also a term I like is this medical paternalism.
Who really is the expert in the room?
Is someone an expert because of their education and their degree
and even their years of practice,
or is someone an expert on their own life because they have lived it
and it is about a collaboration of the two.
It is not about one person knowing what is best for the other.
It is how do we work together to have a better outcome.
The last is respect for autonomy and self-determination
in the presence of stigma and discrimination.
It really is discrimination that is associated with mental illness and substance use.
And this still comes up and unfortunately
this stigma about diagnosis is really prominent in the health care system.
It's increasingly difficult for someone that has a mental health or substance use diagnosis
to actually even access good physical health care
because it is often related to their mental health
or the substance use before it is even investigated
as a physical health concern.
And what I did in the handout is take these 10 concerns
from the article and then put how peer support helps
bridge those gaps, how peer support, the filler in there.
They are legitimate concerns but peer support can help allay those concerns are bridge those questions.
So with that I would like to turn it over to you, Bevin.

>> BEVIN: Thank you so much, my thought.
And yes, just a blog, in the link,
Connor and I at the same time reposted in the chat the link to Martha's handout which I think is awesome.
And we are pleased with it and you can also access the original article as well, Janice [can't understand] is an expert we work with a lot.
Awesome, we will keep rolling on.
Next I would like to hear from Ebony Flint.
Ebony is a certified peer specialist,
a peer group facilitator for alternatives to suicide and hearing voices network

and a wellness recovery action plan facilitator for adults, young adults, and trauma survivors.
She works with populations in the community
and in hospital settings and right networks for advocates Inc.
and she is the peer program coordinator for the living room,
a 24 hour peer run crisis alternative located in Massachusetts.
Ebony, tell us a bit about yourself and what brought U2 support.

>> EBONY FLINT: Thank you so much.
First I want to thank everyone for being here with us and sharing this time with us,
I appreciate you while, and thank you Martha for your presentation.
So I guess I will share a little bit about my journey
and hopefully you all can see into my worldview
and why I am involved in peer support right now.
As Bevin shared I am the peer program coordinator at the living room in Massachusetts
which is an alternative crisis space, it's 24 hours.
I am a trauma survivor, I guess I should start there with my story.
My story begins with childhood trauma.
I grew up in the projects in Massachusetts
looking out my window watching
cousins and family members and friends get jumped into gangs
and how I kind of avoided that lifestyle was that
my father took me to the Roxbury Boys and Girls Club every day after school.
But unfortunately that did not prevent other things from happening to me
and other traumas that occurred, and so from the age of eight or nine
until about 17 I suffered sexual abuse.
And how I dealt with that was via self-harm and running away.
And I did not just run away from home,
I ran away two different parts of the world, different states via school.
I got my praise and acknowledgment through school
and so I would join many different programs, all that I could,
and travel around and go to different schools and participate in different programs
and become a new person each time, every place I went to.
Avoiding and not even acknowledging the pain and the things I had experienced.
Fast-forward to my 20s,
and I had my daughter.
And that changed my life. I love her so much of course.
And it also brought back up all of the trauma that I had,
it made me very overprotective and non-trusting
and it also ignited
self-harm again which I had not been using as a coping mechanism
for a while.
Then when she turned three she was diagnosed with autism,
and at that point I was defeated, I felt defeated, I was like what is going on,
how am I supposed to deal with this, I'm a single mom, I have never heard of this, did I do

something wrong.
It took a lot of work for me to be able to
help her and help me.
But through advocating for her and fighting for her
because she came first for me, I learned how to advocate for myself.
And once she began speaking around the age of five,
she was nonverbal until she was about five years old,
I chose to take the time off of work.
I stopped working and I only focused on her and my mental health.
And I did that via different day programs.
I was never hospitalized but I was in many different day programs,
partials, and DBT, dialectical behavioral therapy
was something that actually in the beginning did not help me at all because I did not let it, I didn't want to.
But once I finally decided to do the assignments
and put the effort in, by the end of that time
I was running the groups and the facilitator said
you know, you should be a peer facilitator.
And I said what is that, what is a peer, what's going on?
They told me about the central Massachusetts recovering learning community, in central Massachusetts
and I went there and became a peer facilitator.
And I just engulfed myself in all of the trainings.
And although I was learned, I knew I was going to be learning these different things to help others.
I definitely started with me first.
When I came with my daughter F wanting to learn more about me first --
and when it came to my daughter I would always say if I'm not okay, she is not okay.
If I'm not okay I can't bring my best self to help others or her.
So I needed to be okay, and although I was wanting and using all of the trainings
to help others it was to understand me and help me first.
I did this with emotional CPR, wellness recovery action plan,
intentional peer support, it went on and on, all of the different trainings I did
to just learn more about myself and the engulfed in the peer movement.
And I love the fact that
the things -- my trauma and the negative things I went through
helps me to inspire and encourage others.
It can be so hard to because I still deal with my trauma.
There are still things that I do and that I don't do because of it.
And so to be able to feel rewarded
in helping others and showing them that they -- that there is some light,
that you can try, that there were things and people out there who can relate
and understand and encourage you brings me much joy.
And it is very rewarding.

In my time working in peer support,
I did have to take time off due to some physical limitations,
being that I am younger for needing certain surgeries,
I had to have spinal surgery, I have had a hip replacement.
So the stigmas and stereotypes of being my age
and needing a handicapped placard and having a cane,
the looks, and then you add on all of the different layers of meaning,
it is definitely arduous, and arduous task
to be me walking in this world, and yet I am still able to use that
to help and inspire others.
When I think of myself, I wrote down
all of these layers.
And so I am a single Black woman
with mental and physical challenges
raising a child with developmental disabilities.
That is a mouthful. [LAUGHTER]
and so many boxes were just checked off when it comes to
disadvantages, judgments, stereotypes, lower expectations,
of being productive in the world, and higher expectations of being a statistic.
It's definitely a lot to hold.
And I love that via this work I share that with others and still put a smile on their faces
and still help them walk through their journey with them, not for them, or telling them anything,
but beside them. I just can't stress enough how much I love this work.
I just do and being able to have that trajectory into this
and say that I do this is a job is amazing.
I guess I will end with my own quote
which I think basically sums up my journey,
and that is perseverance is my priority to assure my prosperity.
And I just try to live with that and walk with that, and thank you all for being here and listening to me today.

>> BEVIN: Thank you, Ebony.
Okay.
So next we would like to hear from our third panelist.
Sassy Outwater-Wright, Sassy is the Executive Director
of the Massachusetts association for the blind and visually impaired.
She has 15 years of experience in digital accessibility fields
and opening small businesses,
helping to make products and services digitally accessible
enter background is in project management and she specializes in multiple disability intersectionality.
Welcome Sassy and tell us a bit about your journey and your peer support expenses.

>> SASSY OUTWATER-WRIGHT: Thank you so much, Bevin, for setting this up.

And thank you to everybody for being here today.
I am so excited to talk about this from the disability side.
We take a very different approach, but a very similar approach
to peer support issues of recovery in the mental health community.
When I was six months old I was diagnosed with a very rare cancer of the eyes
and when I was three years old I went blind, completely blind in both eyes.
And I came into disability that way as a fierce young advocate and cancer kid.
I learned from a very young age to talk to adults.
I learned from a very young age to speak my needs,
to prioritize my needs, to verbalize to the medical community
that I was being treated in what I needed, when I needed it, and how I needed it.
That was how you got care. But to the rest of the world
we oftentimes see people like me get labeled as noncompliant.
We get shuffled into a system or we are not supposed to verbalize,
we are supposed to let somebody decide for us and/or we are supposed to become compliant
to what somebody else believes we are capable of being and doing.
So I walked that line growing up in the educational system in the special education system
wanting things, wanting advanced classes, advocating for myself,
and then being labeled a problem
because I dared to self advocate and I dared to say I wanted more.
I wanted self leadership, I wanted self-actualization,
I want to self determination.
Symbol the term person centered planning got spun around me
it didn't feel like it was applying to me. It was person centered,
it was not person directed by the person who had the disability.
There was a difference between having a bunch of people in the room were not blind
picking what I could and could not have any is a blind person saying I could do this.
I could access this if I had a braille book, not an audio cassette.
Or I access this if I do it hands-on with graphics
that are tactile, but I can't do it if I don't have tactile things.
And so I walked through this constant
struggle of that until I was in college and got through college
and then started seeing it in my career and started doing it for other people.
And that led me in 2014
to a summit on aging and blindness.
And to the intersectionality of those two things.
Oftentimes those of us who are younger
who come into disability adjustment, and this is cross disability applicable,
we come into disability adjustment at a younger age and we learn the skills to self advocate.
We learn the skills to self actualize and get the things we want to.
But when you come into disability as an older adult,
you find yourself locked into the idea of the medicalized system.
We think of two systems when we think of disability.
We think of the social model of disability

where society has to build an accommodation for the body
because the body is not broken, society needs to accommodate us.
Or you think of the medical model of disability where the body is broken
and we need to fix the body and society does not bear any responsibility
to fix and inaccessible curb cut or an ability that someone cannot access.
So we at -- now we are seeing within age and disability systems and integrated model
where the medical model and the social model come together, especially for those who are aging
because they are both true.
Somebody who is 75 or 85 and experiencing macular degeneration are diabetic retinopathy
is going to have a tough time adjusting, is going to not know how to do with self-efficacy things
because they view disability or blindness or whatever disability community they're coming into,
they have you did from a medical model their entire lives because they never had direct personal contact with it.
So their journey through advocacy is going to look very different
than someone who is younger.
And there was going to be a massive mental health component.
We call that adjustment disorder or episodic depression
or it will appear as grief or anger.
And until you break through that,
they are going to struggle to adjust.
They are going to hit plateaus to adjustment.
So I got called to the summit in 2014
around aging and blindness and what we could do to help older adults
age into blindness and still find fulfillment by actualization
and recover and go want to do the things they want to do.
Just because you lose your vision at 55, 65, 85,
doesn't mean that you sit at home and isolate and become depressed and you fall.
It means you get out in the world and you still go do the things you want to do.
It means that there is no door that is closed to you.
And what came out of that summit was that
I became within nine months of the director of the Massachusetts association for the blind and visually impaired
which is the agency that Helen Keller started in 1903
to serve the interests of the adult blind in Massachusetts.
Helen and her group of cohorts at the time were angry at the government.
The government was telling us what we could and could not do with our bodies
as far as employment, as far as where we live, as far as houseguests,
but we were not institutional cases.
We were people that could live and work on around and earn our own wages and take care of ourselves.
And that was really one of the first organizations in the country in 1903
who went out on a national level who said blind people in the people with other this abilities deserve autonomy and can have it.

We challenge the government an inch by inch and decade by decade we won
until we are up to 2020, but we are still fighting to have minimum-wage.
We are still fighting to have the ability to live on our own independently.
We still fight those fights everyday and that is why we exist as a social service organization is to advocate for those rights.
But we brought in peer support.
We decided what we wanted at our organization was not a social worker
or somebody else dictating person centered planning.
We wanted somebody who is 85, losing the vision,
to have somebody who is 65 and losing the vision was a trained peer Maxim what specialist
who can walk into the room and say I am going through too, I get it, I am with you.
Let's talk about how you want to watch baseball because the Red Sox are on and they are good.
Let's talk about what you are experiencing with Covid because you can't feel the markers on the floor
when you go grocery shopping and you are not feeling sick to go out by yourself.
I have a couple of tips and tricks I show you.
Those practical things are what define peer support to us.
The idea that somebody was going blind,
new to it, scared of it, coming into a rehab system or social rehab system
with a bunch of forms and goals and told to comply to the goals.
And somebody else plan works and insistence as I've got you,
I have been through this, I hear you, I am with you, it is doable.
We run 37 supports groups throughout the state.
We have peer support specialists at a variety of levels.
We have younger ones were just losing the vision,
we have older ones who have lost their vision.
We have those who lost their vision as children and who had never had sight
and we have those who are just starting their journey.
They are all people who are blind and they lead.
They walk into meetings with people, they go into occupational therapy meetings with people, they meet with the optometrists with people.
They are not a buffer but a support system.
They are the people say I've got you and they teach self advocacy by example.
They teach self advocacy with support,
they teach that just because you are a disabled person does not mean that you are medicalized.
It means you are the leader in your own person centered planning.
Nothing about us without us, the old ADA adage.
It means user own experience and your own expertise
and that you learn for the first time when you walk into a meeting with social workers
and case managers that your voice is the loudest voice in the room
because you are the disabled person and you have the most experience with your own body.
I remember when I was 25 I was diagnosed with a second cancer.

I just went through my third neurosurgery two weeks ago to deal with this.
But when I was 2512 years ago that was a terrifying experience.
I was a blind patient with brain tumors that needed to come out immediately.
And the neurosurgeons had no idea how to help me, had no idea what to do with a blind patient
who now had multiple disabilities.
There was uncertainty in the room and when you are dealing with neurosurgeons
the last thing you want floating around the room is uncertainty.
There were a bunch of residents testing me and a bunch of nurses in the room
and a ton of sighted people in the room and I was the only blind person,
and the only person in the room with these tumors.
I flipped out and I lost it and I get angry.
I called the room to halt and I said everybody stop.
Nobody knows what you're doing with the.
I don't sense any expertise in this room.
Stop, I am so scared, none of you could possibly get what I'm going through.
And the nurse stepped forward and said yes I can, I've got you,
but you need to let us finish our testing.
And I said no, you can't understand what I am going through,
no you don't get it, how could you, you’re sighted.
She goes four years ago I had a really deep brain tumor removed that was a lot worse than yours.
So are you done yet?
And when she said are you done yet, my jaw dropped.
I did stop and I looked right at her and I went somebody else in this room gets it.
There is another brain tumor patient in this room.
There is somebody I cling to and identify with.
If there is somebody else I walk with you has been through this, I will be okay.
I hold onto someone's hand and I do this.
That's the culture we strive to put into place
with people are also disabled and who work with social workers and therapist to create an integrated model of health care.
Somebody who can walk in and say are you done grieving yet, I am ready to help you get to the next process.
That's the work we are focused on and we have found from an intersectionality perspective that it works.
It helps older adults identify and learn to self advocate
no matter where you are in the spectrum.
Older, younger, it helps to have somebody who has been there and done that
and leads through disability adjustment and we are the experts in our own bodies and we can help with that knowledge.
So with that I will turn it back over to Bevin.

>> BEVIN: Thank you, Sassy.

I am so enjoying looking at all of the comments coming in.
In addition to hearing the speakers, and one of them I just pulled out,
Susan says Sassy, you were the voice of reason.
That sums it up pretty well.

>> SASSY OUTWATER-WRIGHT: I will remember that when I [can't understand]

>> BEVIN: The voice of reason, everyone.
All right, so I have some questions for the three of you.
And I would like to start with Martha.
And everyone will have a chance to answer these questions.
We will take about a minute or less each to answer each question and we should be good.
And that leaves some time for Q&A from our very feisty
and active audience after.
I would like to ask first about
thinking across disability spaces, if you would,
what are the goals for peer support and how do we measure success for those goals?

>> MARTHA BARBONE: Thanks Bevin.
This is an interesting question
because for me, and again
I am only speaking my experience,
I am not speaking for all involved in peer support.
But often what measures success,
they are not relevant figures to me.
They are these metrics that can be pulled from a medical record
and what I experienced was about my symptoms,
and I would love if we could get measures that measure poverty of life.
I would love to see data on not only
is someone making their appointments,
how many people have moved on and they don't need a certain service anymore
or they have gone back to work, they have done this and that.
Often we don't get those numbers because once we start doing well
we are lost to follow-up.
So I think when we look at the goals,
it is so individual and to lump things in,
I come from a medical background, I believe in population medicine,
but I so often refer to it as herd health,
we do what is best for the individual and the individual counts.
And so many programs focus only on evidence-based practice.
There is great evidence-based practice but I have not seen any evidence
that it works for 100 percent of us.
So if we are relying on the evidence base, we are saying we don't care about the rest of you.
So I guess my goal would be can we measure

individual successes, and today it might be I got up
without being told to get up, or I took a shower for the first time this week.
There was a time in my life when that was my success to celebrate.
Versus now, I find purpose and meaning in every day
and every morning when that thought comes into my mind,
is today the day I am going to end it, no, I have all of these reasons to live.

>> BEVIN: Sassy, same question.
What other goals for peer support and how should we be measuring success?

>> SASSY OUTWATER-WRIGHT: At [can't understand] two thirds of them go through some lovely peer support
whether it's one of the peer support groups or individual counseling.
We do evidence-based quality surveys
but I truly measure the goal of peer support by two boxes on my desk.
One is my Kleenex box on the other is a box of crayons, 128 crayons.
I leave the box of crayons there as a reminder to myself
and to everybody who comes in my office
that what looks like adjustment for one person is a blind person is not the same for another person.
When I was a kid somebody made a little
braille labeled would think that held about 10 crayons.
The colors of the rainbow and a couple of others.
A friend came over who could not read braille and put the green crayon
with the blue crayon goes and I colored the sky green.
My thing as a child as I wanted to color in a coloring book like a sighted kid good.
My teacher praised me for doing a good job but didn't tell me I had colored the sky green
and I was out on the playground and my friend asked why is the sky green.
And my face crumpled and I got really sad
that I had made this mistake and I could not be like what the sighted kids could be.
But as I got older I realized there are many shades of blue
and many shades of green and I want access to all of them is a blind person.
And there are 75 or 85 people who want to paint and see the sky again
and they want to interact with things and my job is to sit and listen to them
and help them find a way to interact with things.
When people walk into my office and identify what they want,
my job is to get them access to it and that is the singular goal of peer support.
If somebody wants to access something, it is not my job to find the blue crayon.
It's my job to find out what they want access to and to facilitate that.

>> BEVIN: Thanks, Sassy.
Ebony, what do you see as the goal for P support and how do you think we should understand what success means?

>> EBONY FLINT: For me when you say that, especially
in the work I do at the living room,
I immediately think of options, more options and alternatives.
These zoom groups, helping people transportation
or going to them so they can access these supports during this time.
When I think of goals I just think of being even more accessible
and many different ways to get the supports that people need.
As far as how I measure success,
I would measure success -- I agree with everything Martha said
but I would also add to that for me it is what the person considers success.
What is success to them, what makes them happy.
And that could be a shower,
that could be going out in public,
that can be reconciling with their family.
It can be so many different things and that is what is so great about this work.
So for me success is whatever is successful to the individual I am helping.

>> BEVIN: Thank you.
All right, my next question is about
especially rooted in current times.
As we have been talking about it
in our NCAPPS webinars,
and as everyone is talking about it,
this summer in particular is marked by a national reckoning with racial justice.
People are paying attention to and attending to social justice
and racial justice in ways that
are unprecedented.
So with that in mind, I want to hear from the three panelists
about what the world of peer support is in advocacy for racial equity
across a disability and thinking intersectional he about the intersection of
race, ethnicity, culture, language, identity, and disability.
So I am interested in hearing from all three of you about your thoughts on that,
and Ebony, this time we will start with you.

>> EBONY FLINT: For me our first goal is representation.
Having people that look like them, us, in these jobs and in these areas
for people to want to seek the support on their own
and feel like the people that are supporting them understand them culturally.
Understand the different things they are going through
and their lens and they don't have to explain so much to get that understanding and familiarity.
I also think we can help us peer specialists
by helping people advocate for their human rights.
We are all humans, so if we can start off there
and help people see that these are just things that I need and have the right to have

and access to because I am a human being,
I think that would be helpful in this time that is so --
it is just so hard, I don't even know what to say, it is so hard
and everything that we see and that we feel.
So yes, I think representation and helping to see that we are all humans.

>> BEVIN: Thanks Ebony.
Martha, what do you see as the role of peer support across equity.

>> MARTHA BARBONE: Thank you, and one thing that is pretty evident in peer support especially historically but even today
is it is largely white. And part of that is it was originally designed
by a lot of white people, and we are very welcome and opening,
but often what I find it is like come into this space that is comfortable for me.
You are welcome here and I am not asking what would make the space comfortable for you,
so it is about centering everyone's voice.
And if we don't see people represented,
how do we reach out to them.
What do I think that's good that is not reaching this community,
so how do I center the voice.
Instead of speaking for people or doing for people,
how do I support and center their voice.
And I will use the word token, where we get one person.
Well, you can speak for all people.
It happens, I have been that as the person with lived experience.
And I will talk to Ebony, Ebony and I are good friends,
and I know Ebony, and so we will ask Ebony that question.
And we need to broaden that.
We need to be so open that people are coming and sharing
and we are centering those voices.

>> BEVIN: Yes. And Sassy, same question.
What is the role of peer supported and advocating for racial justice and equity?

>> SASSY OUTWATER-WRIGHT: I have been deeply involved with the disability justice movement since 2005.
I didn't fit well into the organized line movement because at multiple disabilities.
I am raised Arab American, I am white but I am part of an Arab family.
So I strongly identify as that
and that gave me a lot of problems because the community of organized blindness
was very white.
So I found my place in the disability justice community
which is very LGBTQ, the idea of that was where I started my disability advocacy journey
many years ago.

What I found was this idea that blind people don't see color, quote unquote.
Racism is not contained in your eyeball.
Racism is contained in your brain.
So we have a long way to go.
We have started that journey, but there was a long way to go to make sure that people within our community, within the blindness community and the larger disability community make and hold space for people of various identities
whether it is gender, race, all of these identities need to be at the table.
So if you are a case manager, a social worker, a peer support specialist,
whatever role you take, look around the table.
Who is not there? Who is not leading?
Is an able-bodied person leading?
Stopped the meeting and put somebody with lived experience into the leadership chair because they belong there, period, amen.
And their leadership of their own disabled experience in their ability to self actualize
is what is going to shift this conversation.
We need to be given leadership as disabled people.
We are the ones entitled to be our own body experience.
The term sovereignty gets moved around a lot.
We need to now experience what stepping into power and sovereignty feels like as leaders of our own experience.

>> BEVIN: Thanks Sassy.
I'm glad we have a transcript of this call
because there are a lot of mic drops happening.
Also I want to remind everyone that the webinar is being recorded
and we will have a recording and a transcript and a summary of all of the amazing resources that are being shared in the chat, all of those will be on our website.
Next question, I will start with Martha again.
Now actually I will start with Sassy.
What does a leadership in peer support look like?

>> SASSY OUTWATER-WRIGHT: I just said it. Leadership looks like the ability to feel powerful in your own body.
One of the employment seminars that I teach,
I say stride into an interview like you already have the job
because you are the only one that has experience living in that disabled body.
There is so much ableism and discrimination that happened for employment interviews, because the person does not know how the person who was disabled will do the essential functions of the job.
You know your body and how you will get there and you know what technology you need.
Walking like you are the boss, like you are the expert, because you know what you need to do and they don't.
It flips ableism on its head when you walk in with that much power

and confirmation behind yourself. It takes a long time to do it,
it takes a long time to learn confidence like that,
but when you walk into a rehab meeting, to a job employment interview meeting,
when you walk into a doctor at this appointment, when you walk in as the leader of your own experience
because you had a peer support specialist teach you what that feels like
and Martha's handout is great for this,
when you walk in with that level of self empowerment,
that will change your entire disability experience for you.
But it takes having a peer support specialist was done a little bit of that
and supporting each other to get to that point.
So that is what disability leadership feels like.
It is peer support knowing that somebody else can help you get to that level of self-confidence
were you stride and as the boss of your own body.

>> BEVIN: Thanks, Sassy.
And next Ebony, I will take this question to you.
What does leadership in peer support look like?

>> EBONY FLINT: I totally agree with Sassy.
I think when I gained my confidence
and what I was dealing with and took control of my emotional wellness and regulation,
that really helped me in how I was present
in my different environments.
So yes, I totally second what Sassy says.

>> BEVIN: Thanks.
Martha, how about you?
Leadership.

>> MARTHA BARBONE: I would say ditto too
and to build on something I said earlier,
often people do get back to work in peer support.
And then move on to other things they want to do
and there lived experience gets lost, it is no longer considered important,
they no longer share it.
But lived experience is centered no matter what role you are in.
Even if you stay within, say, the mental health system,
if that is what you like doing and stay there, there is peer support at all levels of leadership
and it is honored by the lived experience.
The other thing about lived experience,
sometimes it is looked at as our lived experiences are what is wrong with us, it is our disability.
We bring all kinds of lived experience along with that.
We are parents, we are spouses,

some of us have been business owners,
we have been supervisors. Our lived experience
is extraordinary even with his lived experience that people called attention to you.
And that often gets overlooked.

>> SASSY OUTWATER-WRIGHT: I completely agree with that.
It's valuable, lived experience, disability identity are valuable things
that I want to see our systems and institutions treasure and not stigmatize.
I completely agree with that.

>> BEVIN: Great.
All right, so I am
at the last question before we go into Q&A.
So my last question is a forward-looking question
and I want to hear from each of you.
What is your vision for the future of peer support?
This time we will start with Sassy.

>> SASSY OUTWATER-WRIGHT: I run [can't understand] like a startup.
We did a pilot program with a peer support specialist and we started expanding it,
we have a blind social worker and various low-vision and peer support specialists,
but I want to see that become something that a lot of agencies run.
I want to see mental health and blindness adjustment, start talking openly.
I don't want to see mental health stigmatize within our rehab systems, our blindness systems,
and a rehabilitation system.
Mental health is going to be openly acknowledged if we will adjust to blindness
and it needs to be done with no stigma and with absolute support.
Peer support is the way to do it.
Blind people who are adjusted or who are adjusting and going through that process together,
that the future a blend is rehab but I want to see where mental health is acknowledged
and not stigmatize 10 people are allowed to adjust on their terms with other blind people
who can support them from a clinical and social perspective helpfully
and with less and less stigma and more and more intersectionality and disability justice.

>> BEVIN: Thanks, Sassy.
I will go to you, Ebony, what is your vision for the future of peer support?

>> EBONY FLINT: My vision for the future of peer support
is really just having it everywhere and available to everyone
regardless of what they are going through.
For me it makes me think of myself and my daughter
because we do some peer support work together.
We are part of the seven hills foundation
and they have a program called just us girls for girls on the spectrum.

We started with Jess
participating and she would do different events with the girls
and eventually it came to me helping and providing support as a parent liaison
and my daughter is now the mentor for the girls in her age group.
So when I think of the future of peer support I think of it like that,
in all ways, all ages, all disabilities.
My daughter says we are handy capable.
So just being handy capable and making this available to everyone in every way.

>> BEVIN: Awesome, thanks.
Martha, what is your vision for the future of peer support?

>> MARTHA BARBONE: I guess my vision is peer support of all kinds is available to everyone everywhere if that is what they choose.
And that the people who choose that as their life work
can make a living wage doing it.
That peer support movement, the recovery movement is a human rights movement
and sometimes there is benefit
in what we have in common, but there is benefit in
each and every one's uniqueness and how do we pull all of that together and move forward instead of move forward at the expense of someone else.
So the human rights movement is about equity,
it's about recognizing uniqueness and differences and having equity.

>> BEVIN: Awesome.
Okay, so now we have some time
to open up the Q&A from our audience.
Alixe, I will pass things over to you.

>> ALIXE: Perfect. Thank you to all of our panelists.
This is been such a rich, rich discussion and a great appreciation for all of you.
And to all of you who have been having a very, very lively conversation
in the chat, as Bevin said,
all of the chat -- we are capturing this
and this will be available along with the recording of this on the NCAPPS website as we move forward.
So I have been doing my best to follow along with the chat and pull out some of the themes.
Actually there are quite a few questions per se because people have been answering many of them
but there are some things I pulled out and I will put this to any of the panelists to respond.
One of the themes quite naturally that has come through
is the importance of relationships all the way through
and how important it is to get the relationship right
and then have everything fall into place.

I was wondering if US panelists could reflect on this
and also reflect on how peer supporters find the shared experience
that really resonates for people, that really gets to the place
where people can understand the lens each person brings to the peer support relationship.

>> MARTHA BARBONE: I will say one thing to kick it off and then Ebony and I will relate to this.
But it's important. We have a dear friend that is no longer with us
who would say is not about I know your experience or exactly what you feel.
It is I have not been in your shoes, but I have been in the shoe store.
And that is where our lived experiences about, it is about what are we feeling, not I have had that exact experience.
But I am challenged similarly, I have the same feelings, I have been hopeless,
I have been angry, and we connect about that.

>> SASSY OUTWATER-WRIGHT: When I was 19 -- this is Sassy --
when I was 19 I had to go through massive surgery for my cancer.
I went through a period of depression.
I was a college student, I was supposed to be working two jobs and going to college classes and here I am having stopped my young adult experience to go through massive bone reconstruction surgery.
So my mom who is large and the peer support movement,
so I grew up around social work and peer support,
my mom suggested that I match up with a peer support specialist to deal with some temporary depression around this.
And I did but the chances of them finding a cancer patient
for me to identify with or somebody who had peer support diagnoses that I felt like I identify with
wasn't really there, I didn't think it was there.
And then she showed up and she said I have HIV.
And we instantly bonded because it was not the same diagnosis
are the same disease, but it was sitting in the shoe store, in the same room.
It sitting in hospitals, being medicalized, being called noncompliant when you advocate for yourself.
We shared enough commonality were a few visits
and she had done what she needed to do and supported me
and I was able to face what I needed to face even though we did not have the same diagnosis or the same disease.
We had that commonality that mother referred to.

>> ALIXE: Terrific, thank you.
Ebony, did you want to add something?

>> EBONY FLINT: I was just going to say that I totally agree with that, and relating with the

emotion.
And that is actually what I do with the program that I was just talking about,
for the just us girls, because it is also the fact that people,
not everyone identifies. Whether you have that label or not,
not everyone is going to say I am depressed or I am clinically depressed.
But we all get down, we get said, we get angry.
And so connecting via that instead of trying to find a specific story
or experience is where I would stem from with that.

>> ALIXE: Thank you.
I want to take it to a different level.
There was discussions that you all brought up around
supporting people at the individual level
as they identify and then exercise their choice
through person centered models.
And then of course the comment that identifying is one thing,
but there has to be the opportunity to take action and to have the choice and something that he was important to follow through on.
I wanted to hear from you about what you think about your roles
as peer supporters in furthering choice both at the individual level
but also at the systems level.
I think you touched on it a little bit,
but how you see peer supporters in driving systems change as well.

>> SASSY OUTWATER-WRIGHT: I think it is one thing that you have a choice.
It is learning from a peer supporter, somebody who is been through more the system then you have
at least on the physical disability side, learning that
you are allowed to have a voice.
You are allowed to not just be a set of goals on paper and a plan or a medical report,
but you are allowed to Captain your team.
You are allowed to say something does not feel right.
You are allowed to walk into a case manager's office
or a social worker's office and say I just experienced ableism,
I just experienced inaccessibility, I just experienced a bad thing.
And that does not have to be something that is off the table does because you were working on a plan or goals that you are supposed to accomplish.
Setbacks that come from society or from your own mental health,
and setbacks that are not bad things.
They are things you work through together as a team,
but as you lose your sight as an older adult that is a process that a peer supporter
can help you learn to empower and facilitate and manage
because they have started it, they have been through it.
And that is where we really start, is learning those emotional self-efficacy and trust

so that you have a safe place to go and say I just got hurt,
I just had a bad moment, and those lead to good moments.

>> MARTHA BARBONE: Thank you, and what I would add is
we also advocate for more choice.
And truly informed consent.
So often, actually I worked with Bevin for little while,
and looking at behavioral health systems from the systems perspective,
one thing I learned about was the high utilizers.
Services were available based on how sick you were.
And at the top of that chain is the high utilizers,
and my perspective is as a former high utilizers,
I did start as a high utilizers. I became a high utilizers
because what I needed was not being done early on,
and I think in peer support we can bring that.
And it is not about where someone fits on an assessment,
it is where they are right now and what they think they need and how can we get them to have it.
And if it is not available in this system,
how can we give them access to it.
And I think self-directed care does that.
It's like okay, this is my money to direct my care.
If I need to buy a laptop so I go to school,
that is as important as going to DBT group.

>> EBONY FLINT: The only thing I would add is just to help others
find their voice and empower them to use their voice in whatever space they are in.
I also think asking -- just being genuinely curious,
likely talk about in certified peer specialist training.
Just asking people questions, not even so much for them but for us,
and sometimes hearing the response allowed will allow people to see and think in different ways.

>> ALIXE: Thank you, thank you all.
And again we have some comments and questions coming through
about person centered or perhaps person directed
is something that we really do need to focus on
in the directed part of things both for individuals and then taking it to the system level.
We had a few questions or comments that came through earlier in the discussion also
which I want to bring forward about how peer supporters
navigate in the world where they are working with
and alongside in some cases case managers, caseworkers, social workers,
and I would just like to put it to you from your experience,
how that works best. If you can think of examples of

when it works well when there are peer supporters working alongside
people and aware those boundaries fit best.

>> EBONY FLINT: For me the example I would use was when I worked in a [can't understand]
and what seemed to work was being a team. Even though I am the peer specialist
and I have this different set of ethics that I follow,
still helping to educate and share that knowledge,
being a change agent by example more than words,
not ridiculing or saying you should try this or why didn't you do this and instead
letting people see the result of my different approach.
And then being open and leaving the space to discuss that.

>> MARTHA BARBONE: Thanks, and I would echo that.
And in the theme of this I think if we could apply the person centered approach to the team
where every person has equal value, every person's voice is heard and respected,
and unfortunately often on that team
the peer supporter is still considered the low man on the totem pole.
Oh, you are one of them, and they even get asked horrible questions
like did you take your meds today.
And peer support, when it works well it is a collaboration.
What do we all do.
The person being supported, the peer supporter, the rest of the team, what do we all do for the outcome where everyone has an equal value and equal voice.

>> SASSY OUTWATER-WRIGHT: We have a variety of programs, occupational therapy,
volunteer services, quite a few programs that people may simultaneously be involved in.
The one thing we do is to make sure that nothing about us without us is a key preface.
So if you have multiple people like an occupational
therapist and a social worker who were working with the same person during the same timeframe
the person meets with the team.
We might meet quickly with the team behind closed doors
for a meeting, but generally we have the person there.
They drive, they are the leader.
And 90 percent of the time we say them [can't understand] for the peer support specialist
to be by the side to help them learn how to do that.
So the person should be the one who tells the peer support specialist to go first.
And we have the team and everybody rally around them.
But we see people reach for their peer support specialist as the one they want
being the liaison or the buffer, the highest person on the team.
And we respect that. If they ask for that, we respect that.

>> ALIXE: Thank you.

And one other question specifically about some of the questions
as it relates to recreation supports and recreation therapy.
Recreation therapy spaces and how that works in terms of
peer supports.

>> SASSY OUTWATER-WRIGHT: I will jump in quickly.
We run the largest team of blind runners and sighted guides for the Boston Marathon every year, team with a vision.
The peer support and the mental health boost we see people get out of that weekend,
we do a year of events but the -- this year because of Covid, we have done it for 25 years
and the mental health good feeling in the room
as people learn they can run, they can get out and exercise, it skyrockets.
Learning that you can move, learning that you can compel your body, recreational therapy is critical.
And all it takes is partnership and learning that somebody else has done it
and you can do it and it's a possibility.
Possibility is where we put peer support when we think of recreational therapy.

>> MARTHA BARBONE: I would just add, I think again
often it is presented in a way of
I think you would feel better if you ran, I will go running with you.
It's about finding movement that feels good to me as an individual,
whatever that might be. It is not someone is deciding what movement is good for me
or that a team sport would be good for me versus an individual sport.
One thing I have found with people, it happened to me,
I quit doing things that used to be meaningful to me
because I couldn't anymore, and once someone said to me --
there was a time when if someone said if you could do anything, what would you do -- no idea.
I just couldn't think of anything I wanted to do.
And they connected to me by saying what other things you used to do that you don't do anymore and why not?
Is it something you think about doing again?
And that helped me get back involved in things I enjoy.

>> ALIXE: Thank you, thank you all.
I really wish we could continue this conversation for a good long while
but I realize we are coming to the end of the time we have.
And please stay with us, we have a very short set of evaluation questions to include as well.
But before we get to that I wanted to be sure to thank each of our panelists
and particularly Martha, Ebony, Sassy, for bringing your authentic selves to us today
and to the discussion.
There has been so much gratitude that if you have not been tracking along
in chat, it certainly is there and this has really been
a great learning experience for everyone.

So thank you, thank you, and thank you.
With that I would like to bring up
a few evaluation questions and we would love to hear from everybody who participated.
You will see that there was a little gray bar
and you will scroll down to get to all six of the evaluation questions.
And we will be leaving the evaluation open so you can go ahead and vote.
I will also say that
there is more information coming out from the national center on advancing person centered practices and systems
on our upcoming webinars.
In September we are planning a webinar
on student directed IEP plans
and there are more great ones to come in the fall.

>> BEVIN: And real quick Alixe,
one thing we wanted to do is put into the chat
email addresses for the panelists in case folks want to get in touch with peer requests.
Connor, if you could put those email addresses into the chat.

>> ALIXE: Thanks, Bevin.
Also in chat we can drop in
our Facebook and Twitter names for those of you who are interested
in following along with NCAPPS.
Please go ahead and follow us.
And with that I would like to turn it back to you, Bevin,
if there is anything you would like to say to close us out.

>> BEVIN: Ali would like to say is that I would like to thank Martha,
who really worked with us to put this webinar together.
And introduced us and brought Sassy and Ebony into our lives
and into our community.
So just a heartfelt thank you to all of you.
It's been awesome, I learned a lot and clearly everybody else did too.
Have a great afternoon everyone.

>> EBONY FLINT: Thank you everyone.