

Stigma of Addiction Summit

June 10, 2021

Perfected Transcript

OPENING REMARKS AND WELCOME VIDEOS

RICHARD BOTTNER:

Hi, I'm Richard Bottner, Assistant Professor of Internal Medicine at Dell Medical School and Director of our Support Hospital Opioid Use Disorder Treatment Texas, or SHOUT Texas program. I'm joined this afternoon by my colleagues, Aisha Salman and Matthew Stefanko. Aisha is a Program Officer at National Academy of Medicine and works on the NAM Action Collaborative on Countering the U.S. Opioid Epidemic. Matthew is the Director of National Stigma Initiative at Shatterproof.

On behalf of the National Academy of Medicine, Shatterproof and Dell Medical School, we extend a sincere warm welcome to the National Stigma of Addiction Summit. Stigma and its many forms and manifestations creates so many barriers for people with substance use disorders and addiction to receive appropriate timely evidence-based and patient-centered care. Despite this, there is a relatively limited amount of research, resources, interventions and activities dedicated to dismantling the stigma of addiction in our society and in the context of today's conversation in our healthcare system. That is why we are all here today. Aisha?

AISHA SALMAN:

Great. Thanks so much for that introduction, Rich. Over 4,000 people have registered to be a part of this monumental discussion today about what stigma is, how it manifests in our communities, and most importantly, what we can do about it. Attendees at today's meeting represents a range of industries from government to academia, non-profits, health systems, payers, community organizations so much more and include everyone from senior leaders to people providing direct patient care, individuals with lived experience and everyone in between. This event has been almost a year in the making. And we are so glad to be collaborating between our three organizations to bring this event to you today. Special thanks to our planning committee, whose names are here on the screen now. They met biweekly for several months and have curated a fantastic and diverse group of experts for our program today. With that, I'll go ahead and turn it over to Matthew to kick us off.

MATTHEW STEFANKO:

Thank you, Aisha. We have a terrific agenda for today's summit, but we want you to know that the conversation does not end today. As you tune in for the remainder of the program, think about action, consider what you might do differently as an individual moving forward, and this is importantly, think about how you might need change in your own organization and in your own community. The Stigma of Addiction Summit has been built specifically to be action-oriented in this way. We'll talk more about this towards the end of our day together. We're going to go to the next slide. I will kick off the event. I'm pleased to present the leaders of the National Academy of Medicine, Dell Medical School and Shatterproof to share a few words through this opening video. Please roll the video.

VICTOR J. DZAU:

Welcome. My name is Victor Dzau. I'm the President of the National Academy of Medicine and the Chair of our Action Collaborative on Countering the U.S. Opioid Epidemic. Today's

summit is focused on how stigma against those with addiction manifests across the health ecosystem, and importantly, the actions that are needed to combat the stigma and deleterious impact. Our Action Collaborative is so pleased to be collaborating with Dell Medical School and Shatterproof on this really important effort today.

We all know the recent CDC data shows that more than 87,000 Americans have died of drug overdose in a recent 12-months, in a 12-month period that ended in September, with synthetic opioids being the primary driver. This surge of mortality represents a 30% increase. And it's the greatest yearly toll of any year since the start of the opioid epidemic. Well, we are seeing maybe a reversal of the progress that's been made in recent years and underscore the need for focus efforts to address the addiction crisis.

In 2019, the National Academies produced a consensus report named Medications for Opioid Use Disorder Save Lives. In this report, we identify stigma as a critical barrier that prevents people OUD from accessing lifesaving medications that they need. Stigma of addiction affects access to care, treatment outcomes, and broader health system factors. The impact of stigma across health system has led to the marginalization of patients with SUD. So, making headway against addiction crisis will require addressing barriers related to stigma and discrimination.

So, we all know the stigma is the result of complex and powerful social processes. Stigma against those with addiction, materializes as discrimination that arises from structural and individual factors. Stigma of addiction is rooted in the historic separation of addiction treatment and financing for mainstream healthcare. Structural stigma is then reinforced by individual biases from clinicians and members of the public. Certainly, we know that patients with OUD report stigmatization attitudes from professionals within the health sector, further undercutting access to evidence-based treatment and care.

Furthermore, evidence demonstrates that social stigma contributes to public acceptance of discrimination against those with addiction and public willingness to accept punitive and less evidence-based policies. So, calling attention to stigma and building individual structural competency within healthcare can be the stimulus to drive the needed change.

There is, in fact, historical precedents for national efforts that have profoundly reduced stigma, several ongoing individual initiatives are underway, efforts that use patient centered strategy and advocate for transformational changes in health system and across the nation. However, in addition to these individual efforts, there's a need for a comprehensive course health system strategy to effectively address entrenched stigma. I think it's time for individual clinicians, healthcare organizations, payers, and health systems to commit to working collaboratively and leading the way for a cohesive evidence driven effort to eliminate stigma against addiction, to better meet the needs of those with SUD and turn the tide of this crisis. So, I hope you have a great meeting. And thank you for your attention.

S. CLAIBORNE JOHNSTON:

So, welcome, everyone. It's wonderful to have you virtually here at Dell Medical School at the University of Texas at Austin. And it's wonderful for us to be a part of such an important event. The stigma of addiction is long overdue as a topic for discussion and research and action. So, we're really thrilled to be a part of it.

One of the studies that I'm most proud of that no one knows that I even did was on doing a deeper dive in what the NIH funds and basically plotting NIH disease funding, you know, how much is funded by disease versus that burden of disease for the United States. And it's pretty straight as a line. You know, the more common things are, the more burdensome they are, the more funding is received by NIH. But there are a few things that are well below that line. And each one of them is a condition in which we blame the victim. So really interesting, like liver failure as an example, where we don't feel like we need to study it as much because we blame the victim.

And obviously, there's stigmas associated with those same conditions, the way we approach people and the way we approach their disease and the way we talk about them and care for them. And so, nowhere further off that line is going to be overused in addiction. And I think it's long overdue that we had a conversation about this and long overdue that we began to study and discuss how to make this front and center in an efforts to address what is one of America's most important problems. So, thank you for joining us today.

GARY MENDELL:

Welcome, everyone. My name is Gary Mendell, and welcome to the first ever Stigma of Addiction Summit. It's my honor to be partners with Dr. Dzaou in the National Academy of Medicine and Dean Johnston in Dell Medical School, for what we all believe is so vitally important. My son, Brian struggled with addiction for eight years and tried so hard. However, in October 20th, 2011, I was woken up in the middle of the night by my cell phone ringing. My son had just died. He was 25-years-old. Equally tragic, it wasn't just addiction that took my son's life. It was the feeling of shame he had every morning when he opened his eyes, all day long feeling like an outcast that caused him to wake up that morning, research suicide notes, write a note of his own and take his own life alone.

And when my son died, he hadn't used a substance in 13 months. So, why did he take his own life? I've never, I've never had to wonder. He told us this suicide note. "It's about not being treated like a human," he wrote, "especially one who has worked so hard to get back to normal." My son didn't see a world, where as a young man, he could develop a disease, get treated in our healthcare system, get better and live a full and fulfilling life.

As we all know, the addiction crisis is destroying families all across our nation. And so, many have responded with wonderful initiatives in prevention, treatment and recovery. However, what has been missed, what has been missed is one of the most important causes of this devastation to end the stigma associated with this disease, those afflicted with it and the medications that treat it.

Recognizing this, Shatterproof work alongside leading experts develop an evidence-based plan to end addiction stigma. Our plan is rooted in social science and patterned after the most successful social change movements in our country's history. We are excited to present today's summit, leading experts, unite leaders, and showcase the importance of addressing stigma and highlight the promising initiatives that are taking place to end the shame and social isolation that is touching so many, so worldly.

I often think about the last time my son came home for a visit, four months before he died. And that last night, we're sitting on the back porch talking. He looked at me and he said, "Dad, I wish that someday people would realize I'm not a bad person. I'm a good person with a bad disease. And I want you to know, Dad, I am trying my absolute hardest." Brian's wish

has been way too far off into the future. So, for the sake of the tens of millions of Americans who are struggling with this disease, let's drag addiction out of the shadows and into our hearts. I can't imagine a more perfect expression of humanity. Thank you.

THE PERSONAL IMPACT OF STIGMA

MATTHEW STEFANKO:

Now, I'm honored to introduce today's opening session, which will display the vital importance of including people with lived experience and the work we are all pursuing. As advocates, policymakers, health care providers and more, the experiences of those impacted by our actions is too often ignored or forgotten. However, for people who use drugs and for those in recovery, this exclusion can be an incredibly intimate experience. Hearing the stories of those with lived experience is vital. I am happy to present today's panelists, all three of which are incredibly accomplished women with lived experience.

And now I'll introduce the moderator for today's session, First Lady Burgum. Kathryn Burgum became First Lady in 2016 when her husband, Governor Doug Burgum, was sworn in as the 33rd Governor of North Dakota. As First Lady, Kathryn priority is supporting and developing initiatives to eliminate the shame and stigma of the chronic disease of addiction in North Dakota. In long term recovery for 19 years, she shares her personal experience and encourages others to do the same to help normalize the conversation around the disease of addiction. Kathryn plays an active role in supporting the Office of Recovery Reinvented as the chair of their Advisory Council. First Lady, welcome, and I'll leave the conversation to you.

FIRST LADY KATHRYN BURGUM:

Thank you. Thank you so much, Matthew, for that kind introduction and for all the hard work that you and the other organizing committee members have put into making this summit a reality. And thank you to the over 4,000 of you, wherever you are, wherever you're watching from today for making the stigma of addiction a priority and for engaging, learning and discovering the ways in which you can make a difference. At this time, I'd like to introduce the other panel members. I'm thrilled to introduce the first panelist of the section, Melissa Anderson.

In meeting Melissa, I quickly understood that she is a powerful voice for ending stigma who is rooted in humility and empathy. Quipping that the credentials behind her name are the result of way too much formal education, she embodies what it means to be an advocate because she has walked the road through addiction and recovery herself. As a director of public policy and advocacy for BrightView Health, she brings a unique perspective of understanding addiction treatment as a payer, provider, and a patient, and has had an all too intimate view of how pervasive stigma can be in health care, especially in a health care setting. Please help me welcome this inspiring face and voice of recovery, Melissa.

MELISSA ANDERSON:

Thank you. First Lady Burgum. It was an all too kind introduction. I am thrilled to be here today with everyone, all the panelists and all of the registrants. I think stigma is the most pervasive and the most threatening issue facing turning the addiction epidemic around and actually becoming successful in helping others into recovery.

FIRST LADY KATHRYN BURGUM:

Thank you, Melissa. Next, I'd like to introduce our next panelist, Laurie Johnson Wade. When you have the opportunity to connect with Laurie, the first thing you come to recognize and appreciate is her infectious spirit for change. Laurie is a woman in long term recovery for over 30 years and a passionate builder of recovery communities. She co-founded her own

Recovery Community Organization, Lost Dreams Awakening in New Kensington, Pennsylvania. Laurie is a much sought after advocate in the field, being named the Pittsburgh Recovery Advocate of the Year in 2020, serving on the national faces and Voices of Recovery Board, and serving on state committees with the Pennsylvania Department of Drug and Alcohol Programs. She's a big believer in using your lived experience as a peer support specialist to eliminate stigma and help others in their recovery journeys. Let's welcome Laurie.

LAURIE JOHNSON WADE:

Thank you, First Lady Burgum, that is such a wonderful introduction and also to my colleague and peer here, Dr. Anderson, I want to thank NAM, Dell Medical School, and Shatterproof for the honor to participate on this panel and talk about this very important issue and the personal impact of stigma. Thank you so much.

FIRST LADY KATHRYN BURGUM:

Well, I'm going to ask both, Laurie and Melissa to give us, like a five minute overview of kind of your background and why this issue is important to you. But before I get started, I just wanted to say a couple of things. When I became the first lady of North Dakota four years ago, I can't believe it's four years ago now. I said right away that I wanted to shape my platform around eliminating the shame and stigma that surrounds the disease of addiction. I think for many people, they were confused why a first lady would choose such a topic when others had tackled things like children's literacy, food insecurity, and a host of other worthy topics.

It wasn't until my first interview as First Lady that I basically shed some light on why this topic was so important to me. The reporter looked at me and said, "Addiction, that's an interesting initiative for a first lady. Why are you so passionate about this?" I took a deep breath and with the quiet assurance that I was doing this for the right reasons, and just maybe my story can help one person, I said, "I'm very passionate about addiction because it affects me personally. I've been in recovery from alcohol addiction for 15 years." At that moment, I felt like 100 pound weight had been lifted off my shoulders. My struggles with addiction and joys of recovery had been a secret to most everyone outside of my closest friends and family. 15 years of silence, of shame, of wondering if I could ever talk publicly about this, had basically disappeared into thin air.

Today, I'm grateful to speak to you all as a person of over 19 years of recovery. And I have been actively working on this issue of stigma for the past four years in my role as first lady. Wherever I go across the state or around the country, I always maintain the belief that storytelling ends stigma. The stories create connection, help us understand that we are not alone and encourage others to reach out for help. So I model this by sharing my own story. I started drinking in high school as a way to cope with anxiety and social pressures that I faced every day. I experienced my first blackout when I was in high school, which led to a long road of 22 years of blackouts, embarrassing drunk episodes and hopelessness. I battled through a cycle of relapse for over eight years, and finally was able to find a sustained recovery because I was completely willing to do whatever it would take. And I had the courage to reach out for help from my team leader at work, of all places. Her compassion and understanding and support was one of the most pivotal catalysts to my recovery journey. I could never have imagined that telling my story publicly would have opened so many doors. It started a state wide movement in North Dakota called Recovery Reinvented, where we reach thousands annually through an inspiring one day event. We've launched stigma ending

initiatives in schools and in the workplace, and we've hosted a shark tank like Recovery Innovation Competition. We empower people to reach out for help and connect to resources. And we launched one of the first statewide stigma's surveys in the nation to understand the baseline of stigma in our state. Stigma is one of the most challenging barriers to seeking help in finding recovery. So as we move throughout today, I challenge all of you to think about where you see stigma and how you can help normalize the conversations around addiction by sharing your own stories and experiences. Now, I'd like to ask Melissa to give us a little bit of information about your background and why you're here, and why this topic is important to you?

MELISSA ANDERSON:

Absolutely. My name is Melissa Anderson. I am a girl that grew up in rural eastern Kentucky. I try to tuck in my accent, but it will sneak out from time to time. My journey, I've always worked in the health care setting. Started out working as a clinical pharmacist at a children's hospital in Lexington, Kentucky. Decided I wanted to dive a little deeper, so while working as a pharmacist, I completed medical school and began an anesthesia residency. In my anesthesia residency, there were a lot of external factors that contributed to my experience, the first consumption of opioids, and then developing an addiction that I tried multiple times to treat myself because I knew what seeking help would mean. And when I finally did seek help as a physician, your options are very limited. You're told where you can go and how long you will be there. MAT or other forms of evidence based care is not an option.

So I went, I completed my four months of non-evidence based treatments, came back, jumped through all the hoops and whistles, was not allowed to interact, obviously back into an anesthesiology residency. I can see it now that would have not been the best setting for me. However, that was devastating at the time. So I decided I want to do something, I want to make others pathway a little smoother. I can do anything to prevent others from walking the path, or if they have to, make it a more direct and more evidence based path.

So I worked in the industry developing medications for opioid use disorder and did that for five years. And recently, I fell in love with interacting with payers, public policy because you can have the best treatments, but if they're not accessible if they're not affordable, if they're not reimbursed, it never makes its way to the patients. I want addiction here to look like any other field of medicine where you have research. Research drives evidence based policy and those policies are reinforced are payer reimbursement, and checks and balances.

Unfortunately, that's still not the case. So I joined BrightView Health, which is based in Cincinnati, Ohio in March. And now I am the director of Public Policy and Advocacy. I can speak openly about my personal lived experiences, the first that I have been able that's actually been a positive, which when you're a patient that's the voice you need to hear, that's voice you want to hear. You don't want what someone's read in a book. You need someone that says, hey, I've been there. I know what you're feeling, and I'm living testament that you can get past this as well. So this is my first opportunity to do that, working with payers, working with state federal officials to drive policy and make sure that patients are treated with dignity and respect and have access to all forms of evidence based care.

FIRST LADY KATHRYN BURGUM:

OK, thank you so much, Melissa, for sharing your information, and it's so important that you're part of the conversation today. Laurie, would you like to share a bit about yourself and why this topic is important to you?

LAURIE JOHNSON WADE:

Sure. Thank you, Kathryn, and thank you, Melissa, for sharing that. It takes great courage to come out of the shadows, come out of the closet and live your recovery out loud. That's one of the mantras that I believe in, that I recover out loud. I put a face and a voice to my recovery. In my 20s, I had suffered a loss that emotionally I could not navigate. It was a traumatic experience for me. And so I had sought to self-medicate with opioid stimulants and what occurred out of that is it led me into the criminal justice system, because when you do that on a regular basis, it becomes a hefty task. And it's an ugly taskmaster. Addiction is an ugly taskmaster.

I was introduced to the concept of treatment by the criminal justice system, given a diversion opportunity that I took and I went to treatment. And what I know is that treatment works, prevention, treatment and recovery, they work. And when I got to treatment, I heard something that changed the trajectory of my life, that you have a disease called addiction, that it's a treatable disease, that you're sick, not bad. And it was like the heavens opened up and the hallelujah choir sang. I said, oh, my goodness, there's hope for me. And so then I just took that in, I ran with it.

And not only me, but my husband is also in recovery. And so together we co-founded a Recovery Community Organization as the direct amends to our community, as a way to be a light to our community because if we could recover, anybody could recover. We started a recovery community organization using the gold standard of the Association of Recovery Community Organizations, Faces and Voices of Recovery. And we wanted to start something that our community could benefit from. So we started a 501C3 non-profit. Our mission was to promote the right and resources to recover through advocacy, education and demonstrating the power and proof of long term recovery. We envisioned a world where recovery was understood, promoted, embraced and enjoyed and where everybody seeking recovery could have access to support, to care, and the resources needed for long term recovery.

We had this kind of Pollyannaish view of what things would be like, not taking into account that everybody was not going to be as happy as we were, and that stigma was going to be one of the things that we would overcome. But I'm going to tell you, the living proof is a stigma buster. Let me see, I have first lady Catherine Burgum on here and Dr. Melissa Anderson and Laurie Johnson Wade. And they told me in treatment, you are the least likely to recover. Black woman, you are the least likely to recover. And I said, not so. I'm going to do this thing. And so I am so excited to be here sharing the reality that we can and we do recover, that we have value and that stigma needs to put outside of the house. Thank you.

FIRST LADY KATHRYN BURGUM:

I am with you. Yes, put it out of the house. No more stigma. Thank you so much, Laurie, for that awesome information and for all that you do. I think I'd like to start and send the first question to Melissa. Melissa, one of the core services that BrightView delivers and is a big advocate for is the use of Medication Assisted Treatment, or MAT to treat opioid use disorder. For many of us in the camp of recovery advocacy, we view MAT as necessary and a useful tool to provide support and treatment for those who are struggling.

But in many places, including our own state, North Dakota, there was initial pushback for MAT, and a misinformed belief that it enables substance users by simply substituting one drug for another. Has BrightView had to work to combat stigma associated with MAT, and in what ways have you worked to educate the communities that propagate stigma toward this type of treatment?

MELISSA ANDERSON:

Stigma, absolutely. We've had to work diligently and continuously. I believe stigma is evident in policy, it's evident in our community, it's evident at the payer level. It's evident the fact that legislators produce that first level of clinical treatment paradigm. At BrightView we treat opioid use disorder, but we also treat alcohol use disorder, any form of substance use disorders. So we have patients from multiple avenues coming into our doors. And when they come in, we offer abstinence based, we offer medication assisted with agonist pharmacotherapies such as buprenorphine or methadone. And then we also offer the antagonist pharmacotherapy, Vivitrol. We do not force one pathway on any of our patients.

We basically present them with all pathways and allow them in the decision making process for their own recovery. I think if you want to see success, it can't be forced. No one can be forced into recovery. They have to be an active participant and given that respect to do so. So I think that just having that approach, having all pathways approach. And then we continuously participate in state and federal meetings, federal advocacy and outreach. Our leaders and different members of our team are always participating in every opportunity to speak to our mission, to speak to what we do and speak against stigma.

FIRST LADY KATHRYN BURGUM:

Great, thank you. Thank you so much, Melissa. Next, Laurie, I'd like to ask you a question. Lost Dreams Awakening utilizes recovery coaches and peer support specialists in the services that you provide. This is something that we find crucial in North Dakota because our state is 50% rural and we're never going to have all the resources and services we need to help all those people that need treatment and services. But peers with lived with addiction and mental illness can be amazing resources in helping people find recovery. How have peers transformed the work within LDA, I'll shorten Lost Dreams Awakening to LDA? And how does the shared bond of experiencing the disease of addiction reduce the stigma of the person who is seeking their pathway to recovery?

LAURIE JOHNSON WADE:

One of the critical roles that peers play is providing a therapeutic value to one person with lived experience helping another. And I need to tell you, that's still unmatched. In one of the recovery pathways, there's a saying that the therapeutic value of one person with addiction helping another is without parallel. And I can tell you that is true. That is appropriate at every level of the recovery oriented system of care starting at the emergency room. So one of the places. If somebody is at the emergency room and has experienced an overdose and there is a peer there, if you have that peer go and speak to that person, the likelihood of them going to treatment, accessing the treatment that they need is elevated terrifically because you can speak in their language through your experience. I've been where you're at. I know what you're going through. This is something that you need to consider at this juncture or you may not survive the next one.

And while a physician or a nurse or some other paraprofessional could speak to that, not with the authority that a person who's experienced it can because there's a transference that takes place when you know that I know what you're going through. And what I would like to say is that I would like to see systems within the recovery oriented system of care. I would like to see professionals use peers more. They are a tool in your hand that can help the person fulfill their treatment plan, that can help a person take your directives in terms of prescriptions.

So those are people that are walking with you along the way that make you feel safe. You believe them and it just cannot be spoken of enough. And I think one of the things that I'm going to advocate for is compensation along with that. I would like the people that I work with day to day to view the value of peer support as important as any other part of the system of care.

FIRST LADY KATHRYN BURGUM:

Thank you so much, Laurie. Such great wise words of wisdom. Back to you, Melissa. You mentioned a little while ago you talked about multiple pathways to recovery. In North Dakota, I have the privilege of collaborating with one of the most innovative, I believe, one of the most innovative state behavioral health teams in the country who continually find evidence based practices to implement in our communities and most importantly, maintain committed to the belief that there are multiple pathways to recovery. One of the things that stood out to me about BrightView is their commitment to personalized recovery plans for the individuals they serve. How does BrightView carry out that philosophy that there are multiple pathways to recovery? And do you find this helps reduce stigma by not forcing clients into one specific treatment plan over another?

MELISSA ANDERSON:

I think first and foremost, we meet people where they are. We work hand in hand with our criminal justice system, with the probation and parole officers. We work in the emergency rooms through peer support members in all of those avenues. Basically meeting people where they are and then treating them with respect. Presenting them this is what you're struggling with and this is something that can be treated. Present all the options on the table, and then clinician and the patient make that decision together. Instead of it being a punitive or a paternalistic approach forced upon them. As humans, none of us would like that. None of us would succeed in that type of model. So I think just by meeting people where they are, giving them all the options, allowing them to participate in that choice, that empowers the patient from the beginning.

And I think it reduces maybe the stigma in the recovery community that the more times, more examples we can show people recovering in different pathways, maybe it'll be a different atmosphere. The recovery community sometimes can be the most stigmatizing, unfortunately, because there's still a belief that if this is how I recovered, this is the only way. So I think the more times we can show success in multiple pathways, it will reduce that stigma.

FIRST LADY KATHRYN BURGUM

Absolutely. Sounds great. I'll toss this over to Laurie, this next question. One of my closest mentors is William Moyers of Hazelden Betty Ford Foundation, and he always challenges people. And he says that storytelling will help eliminate the stigma of addiction, which I strongly believe. And that is why I tell my story and ask others to do the same and be a face and voice of recovery. But he also says we need to celebrate the success stories of recovery wherever we can.

And one of the creative ways that I've tried to do this in my own advocacy is through this Recovery Reinvented event. We create an opportunity to stand publicly at that event and be recognized for their recovery if they're comfortable doing so. I've also done this at business events like the Chamber of Commerce, or I also ask people at an Amazon Web Services event to stand if they were in recovery. What are some of the creative and intentional ways that we can celebrate the successes of recovery to help eliminate the stigma and normalize being proud and excited to share that, that we are people in recovery?

LAURIE JOHNSON WADE:

OK, thank you, Kathryn, for that question. One of the ways that I think is the most inclusive way to celebrate recovery, and one of the things we like at Lost Dreams Awakening is we do a lot of celebrating. We do a lot of celebrating. We celebrate every milestone that a person makes. We celebrate the fact that they got out of treatment or that they went to treatment. We celebrate the fact that they've reached one day or 30 days, whatever it is, that they went to their medical appointment, that they got their children back, that they got off parole or probation, or that they got a college degree. My husband obtained a PhD. My word, we were running around like chickens with our heads cut off, and to think that somebody could do such a thing. And he will have 30 years in recovery. So we celebrated every opportunity. But when we can collectively celebrate, I love National Recovery Month. And this year 2021 theme is Recovery is for Everyone. I love that because it's inclusive.

And the more you do that, the more you participate in recovery walks, the more you get your representatives involved in these type of events where they can come and celebrate with you. It's a collective effort. And I agree wholeheartedly with Melissa to make it a culture. The more pathways, the more ways we recover, the more it's in our general society and it's celebrated. I can be in a room where nobody else is in recovery but me, and I'll say I'm celebrating 30 years in recovery and everybody will start clapping. So it's a natural response. I think it's in all of us to celebrate one another. So I hope that that's the greatest stigma buster, living proof. There's nothing else to say, put a period right there. Living proof that's the stigma buster.

FIRST LADY KATHRYN BURGUM:

Absolutely. I completely agree. So, Melissa, I'll ask this next question of you, and I'm going to give a little bit of an intro to it. In North Dakota, we often talk about that the disease of addiction does not discriminate, as we all know. It is one of the most inclusive diseases impacting people across every gender, ethnicity and tax bracket. It also affects people of every age range, particularly the youth of our nation. One initiative we created in our state was called Youth Ending Stigma, and it was a challenge, otherwise known as the Yes challenge. Through this, we granted 17 middle and high school groups across the state a \$1,000 if they could lead a student driven initiative to help eliminate stigma in their school and in their community.

I get emotional thinking about it because it was such a cool thing. We saw everything from resource fairs, a school website built to provide comprehensive support for students, and a powerful video that I was actually able to get to the Surgeon General, the US Surgeon General, which he thought was awesome. So what role do you see youth playing in eliminating stigma? And what are the ways that parents, educators and community members can empower the next generation to be leaders eliminating stigma?

MELISSA ANDERSON:

I believe we have to begin where the exposure, where that first substance use and problematic substance use begins. I was a product of the Bayer program. Basically, the only thing I was shown was an egg in a frying pan. Basically, don't do drugs. That was the entire education, the entire message. And if you did, you were a person without morals, not a person with an illness. So I think by reaching out and educating students younger, the earlier the exposure, the better. In rural Appalachia where my family still remains, nearly one third of my high school graduating class is dead from opioid overdose or some complication thereof. And the poverty is palpable. The devastation there is palpable. And there's a generation that feels there's no way out. So I think in some of these hardest hit areas, we've got to get in there and show these kids that it's possible. It's possible to get out. It's possible if your parents have passed away, it's possible, if your parents are in the criminal justice system. There's still an opportunity for you. And then just I think it empowers them when we involve the youth. Again, instead of employing a paternalistic approach.

FIRST LADY KATHRYN BURGUM:

Absolutely. That's such great advice. I'm going to do another little intro and then, Laurie, if you want to respond to this. What we know that the disease of addiction does not discriminate. It's no secret, it can disproportionately affect certain populations more than others based on geographic barriers.

Hopefully, everything's going here. It's no secret that disproportionately affects certain populations more than others based on geographic barriers, lack of adequate services and disparities, and insurance coverage. In North Dakota, we have a sizable Native American population, and the data from the National Survey on Drug Use and Health shows that substance dependence or abuse is the highest among this group. Among Native Americans at 15%. This further is complicated by high rates of poverty, lower life expectancy, increased risk of disease and challenges accessing quality health care. We will continue to find ways to collaborate with tribal governments in our state to provide support and solutions. In what ways maybe have you sought to promote equity and recovery support? And what impact does this have related to the shame and stigma disadvantaged populations face when accessing care?

LAURIE JOHNSON WADE:

Thank you, Kathryn. That's a big question. However, I do know that at LDA we try to be diverse, equitable and inclusive in our approach to recovery. It's no secret that there are disparities in access to care. That has been an ongoing issue. I know it is a huge problem in the African-American community where traditionally addiction has been criminalized rather than treated. So then you get into layers of stigma. You have these layers of stigma that it almost seems impossible to climb out from under. That's why it's so important that I put a face and a voice on recovery. That I provide living proof not just at the recovery level, but culturally as well. And absolutely, my indigenous brothers and sisters that suffer from rampant rates of alcoholism and mental health issues and other things. There's other issues that are going on as well. And so part of the solution that I see is that when you come to the table, you bring the leaders from those communities, the recovery community, place them in leadership roles. They're not just backfill after the agenda's already predetermined. Let's make sure that they're part of the decision making process because there's a myth among folk that say that the recovery community does not know how to act in its best interests. And that is not true.

You get those leaders from the tribes, you get the leaders from your faith communities, from your various pathways to the table, so that then they have an authentic voice about what's really going on with that community. You can't come from the outside in and think you're going to solve internal things. Some things have to start internally. And so having value for the leadership of those within the recovery community, that can be change makers within those places. The Native American people, the African American people, the LGBTQ folks, those folks that are using MAT and stigmatize, you get the leaders that are doing it the right way. When I say the right way, they're recovering. They're in the recovery process. When you bring those people to the forefront, you create this dynamic where people are more apt to lead and that there again, the power of peers. Thank you.

FIRST LADY KATHRYN BURGUM:

Absolutely. Great stuff. Well, this has been super informative. Laurie and Melissa, you are both heroes out there doing incredible work in the community and across the nation. And I just want to say thank you so much for being courageous faces and voices of recovery, and for all the work you do to help eliminate stigma and foster supportive cultures for recovery. Lived experience with addiction and being able to share personal stories of finding the road to recovery is one of the most powerful tools we have to end stigma.

So as all of you continue today through these sessions and the opportunities for learning and growth throughout the day, think about the ways in which you all can help move the needle on stigma. Whether you've struggled with this disease personally or someone close to you has or someone you care for on a daily basis is impacted, keep sharing your stories. Eliminating stigma does not only create opportunities for people to reach out and find help, it saves lives. Thank you to everyone who watched this session. And I will now turn it over to Richard to share some more information to you all as you move on to the next session. Thank you so much.

RICHARD BOTTNER:

Thank you so much, First Lady Burgum, Laurie, Melissa, for that incredibly impactful and important opening session.

SESSION 1.1 - STIGMA OF DRUG USE, TREATMENT, AND HARM REDUCTION

RICH BOTTLNER:

Well, hello everybody. And welcome to concurrent session, 1.1 Stigma of Drug Use, Treatment, and Harm Reduction. Apologies for the brief delay, we were just having some technical challenges. Our moderator, Dr. Kim Sue, will hopefully be here in just a few minutes, but I'm going to go ahead and introduce the rest of the panel to you, I get us started here. Monique Tula, is the executive director of the national harm reduction coalition, Michael Pond, is a psychotherapist and author, Dr. Yngvild Olsen, is the medical director of the institute for behavior resources and reach health services in Baltimore city, and Dr. John Giftos, is the medical director of addiction medicine and drug user health, at project renewal, a non-profit organization that provides health, housing, and jobs to people experiencing homelessness. Thank you all so much for being here and fantastic, Dr. Sue has arrived. All I've done so far, is introduced the panel, so now I can introduce our moderator, Dr. Kim Sue who is the medical director at the national harm reduction coalition, and an instructor in the program of addiction medicine at Yale school of medicine. And Dr. Sue, thanks so much for being here to lead this panel, that take it away.

KIMBERLY SUE:

Oh, thank you so much. Sorry for the, I was in a limbo breakout, a waiting room. And it's my pleasure to have these amazing people to talk about this really important issue. This is something that, we all have been thinking about and dealing with in all of our work. And as we push for systemic change from both the clinic level, to syringe service programs to, you know, federal and state advocacy, we know that stigma has so many effects on people. So, again, this is the breakout where we're going to talk about the stigma of substance use, treatment and harm reduction. And we're really going to focus on many of the current systems failures, but also ways that we can do better. And we hope that we have, you know, some really great discussion with you all. So, to get started, we going to start off with Monique. And Monique, if you could introduce yourself, tell us your story, what work you do, and where you're focusing on right now, it would be great. And Monique is my colleague at national harm reduction coalition and our fearless leader.

MONIQUE TULA:

Thanks Kim. Yes, I'm the executive director of the national harm reduction coalition. I've been there, five years, it'll be five years in August, which feels a little unreal to me. I've been a practicing harm reductionist for going on 25 years now, also feels a little surreal. But about six years or so, I read the book by Johann Hari, called chasing the scream. And I think it's part of his book tour. He did a Ted talk, where he talks about what he believes to be the cause of addiction, any kind of addiction. And I have to say the way he sort of, you know, the stated his argument really helped me see things in a very different way in terms of addiction and recovery. So, according to Hari, the cause of addiction is actually the lack of human connection. He says that human beings have a natural and innate need to bond with each other. And so, when we're happy and we're healthy, we bond and connect with each other. But if we can't do that because we've been traumatized or isolated or beaten down by life, we'll find something to bond with, that gives us some sense of relief because that's our nature.

So, how he believes, and I believe as well, that the opposite of addiction actually isn't sobriety, the opposite of addiction is connection. And, you know, we all know that societally, we have a really long way to go in terms of embodying this belief, but we are making a bit of progress. About 10 years ago, SAMHSA worked with a variety of community stakeholders to

develop their definition of recovery. So, they say that recovery is a process of change, through which people improve their health and wellness, live a self-directed life, and strive to reach their full potential. And there's about, there's four major dimensions that support this life in recovery, including health, home purpose and community. So, health overcoming or managing disease or symptoms, and making informed and healthy choices that support wellbeing, home, obviously is stable and safe place to live, purpose, meaningful daily activities like the job or school or volunteering or something creative to do, and the independence and income to support ourselves. And then lastly, community. Positive connections and bonds with other human beings. So having social networks that provide the kind of support and friendship and love and hope, that every person on the planet deserves. That's how I think about recovery.

KIMBERLY SUE:

Great. Thanks for framing that introduction. So, next we're going to go to Mike Pond, in Vancouver. Hi Mike.

MICHAEL POND:

Hello everybody. Can you hear me okay? So, yes, I'm Mike Pond, and I'd like to thank the national academy in medicine and the Dell school of medicine and shatterproof for inviting me to this, what I believe is a really important event. So, I'm a psychotherapist on Vancouver Island, BC, Canada. And I specialize in addictions and trauma. I'm also the father of three sons, I'm a grandfather times six, and I'm really trying to slow down and work per time so I can actually immerse myself in this stunning part of the world where we live. Spirit bay on Vancouver Island, where there's orcas out in the bay, and whales, and dolphins, and Eagles, and sea lions, and salmon, and crab prawns, it's just amazing. So, I built a pretty idyllic life in British Columbia is Okanagan, which is Canada's wine country. Not an easy place to get sober. I had a thriving practice with four associates, and as my sons grew, I got sucked into working even more. And there was such a need.

I had school board contracts, and contracts with law enforcement, with our first nations and from critical incident stress management to the downstream effects of Canada's Indian residential school system. Although we didn't call it that back then, I lived with a lot of vicarious trauma. I began to drink a lot more and when I found myself trying to stop, I just couldn't. The more I tried, the deeper alcohol took its hold on me. I repeatedly tried AA and I was never able to quite work the program and make it work for me. Eventually my business contracts all slipped away. My employees quit. My wife told me to leave. And after months of living in seedy motels, I took a crayon bus to Vancouver and I ended up homeless and destitute on Vancouver's notorious downtown east side. From there, I began a downward spiral, through rundown recovery houses, rehabs, hospitals, and finally prison. I lost everything. I lost my home, my practice, my family, and my dignity. But again, some stunning insight. As a professional, pretty well, everything I knew about treating substance use, was wrong. And most of all, it was my own complicity in the shaming of my substance-using clients. Telling them to go and get sober first before we could even begin therapy. Stigmas everywhere.

So, here's a few samples from my stigma highlights reel. In the medical system, I was routinely stigmatized and humiliated when I sought treatment. I counted at least 31 trips to the emergency department, seeking help, and got instead from doctors and other medical staff, "Mr. Pond, don't you know they're real sick people here? I don't want to see you in my again. What part of this aren't you getting? Oh, you're one of those bleeding heart, liberal

social workers from the 80s!" I really liked that one. And I often left with nothing more than an Ativan and a bus pass. None of this treatment made my substance use disorder better. In one recovery house, the social worker in charge says the following things to me. "Oh, so you want to off yourself, do you? Well, come on, then let's go. I'll buy a rope; I'll drive you to the bridge." And from that same guy, I heard a camera's snap. I looked up and he was taking a picture of me, and said, "I'm going to send this to your kids, Pond so they can see what a sick fuck you really are."

And when I went to my bank and went to assess the status of my accounts to tell them I'm in grand show and publicly cutting up my credit and debit cards. Then there was cold glares and combined with the look of disdain on the face of the secretary in the medical monitoring office, where I attended random urinalysis checks for two years. I spent 29 days in intensive care, near death from a bacterial lung infection. One evening, the night nurse quietly whispered in my ear, "You know, you brought this on yourself, don't you?" And in prison, how many times did I hear, "This is where it takes you jails, institutions and death." And how that stigma impact me? Well, I was humiliated, I felt excluded, as Monique said, alienated, disconnected, isolated, bullied, and compounded by my already deep levels of depression and anxiety and PTSD. I eventually slipped into psychosis and was actively suicidal. I felt hopeless, of course. And I wanted to just drink more.

And for people with no money, this kind of punitive approach is pervasive in treatment. Laid people off and uneducated was the only skill as being sober themselves, often run the typically 12 step abstinence-based programs. It works if you work it, you're not working hard enough, that's the perspective. And the system realize mostly an untrained non-professionals to provide treatment for a complex bio, psycho, social and economic disorder, or sick, and that's so wrong. I was a privileged guy until I had no money left. Most stigmatizing of it all is being sent to prison for a mental health condition. I served 30 days from a drunk driving related conviction. Yes, there's no question, I broke the law and I endangered people, and I deserved some punishment. But what would have been more effective, would have been sentencing me to treatment. When I was in prison, I did a rough poll of my fellow inmates, and about 75% of them were in there for petty crimes related to substance use. This experience truly opened my eyes. If I got out of there alive, I was determined to try to change the system.

And how did I finally get well? When I shifted my focus to not relying on the system to help me. As my own willpower, resilience, motivation, and support from others. And I get well despite the system. And I get sober the best way I knew how, it actually got better, not necessarily sober. I got a job as a psychiatric nurse, a field I had worked in 20 years, and I kept it through a medical monitoring agreement. I threw myself headlong into fitness, gym, yoga three times a day, and new healthy relationships. And then I met my partner currently, Maureen, on fish. And on her first date, I came clean about almost everything, especially since I couldn't drive for three years. She said she wasn't sure she wanted to date me, but she sure wanted to write a book with me. So we did, we wrote the book, (INAUDIBLE), and we made a documentary for the Canadian broadcasting corporation about my search for evidence on based substance use treatment.

So, we had lots of success doing media speaking at conferences, and then came the backlash. And some were pretty horrible. Sometimes threatening emails from those I thought I disrespected in AA. Maureen was called codependent and enabler, and much worse than that, threats to her life. Members of the traditional recovery community accused me of being a

shell for big pharma because I advocated for medications to help with the treatment of substance use. I was invited to speak at the Western Canadian addiction's forum. And my invite was rescinded when several of the abstinence based so-called medical addiction experts threatened to boycott the conference. I was asked to take part in the Vancouver committee on homelessness, but my feedback was disregarded because I believe in low barrier housing. In too many shelters, you can't get in if you're using, and if you do use, you get kicked out.

I found the mainstream abstinence-based treatment industry in Vancouver, which got pretty savvy about using harm reduction to window dress traditional rehab. They have a big conference every year called recovery capital, and usually headline the conference in day one with a big star of the harm reduction movement. But the other 90% of the conference promotes the same old players with the same old solutions (INAUDIBLE), just get sober, just get clean. There's so much to fight back about. And we found the process exhausting and we burned out. I found myself to be a voice in the wilderness. Now I truly am in the wilderness, and I'm super happy about it. Still fighting stigma everywhere, I can, but not letting it eat up my life. We've got lots of young people taking up the challenge. So, my practice focus now is harm reduction, any positive changes down in big side, and psychedelics.

My final thoughts, we must adopt a harm reduction approach where you don't get kicked out of treatment. We must decriminalize drugs for personal use. Substance use is a health condition and needs to be folded into modern healthcare. In Canada, that means covered by the Canada health act. Community-based primary care reforming the system, develop a path to healthcare reform. And use this same philosophy across the board; easy access, clear entry point, one-stop shop. We need to get real about public policy in alcohol and other drugs. And the industry has made tremendous gains in the last decade, pushing back against regulations. We need a public education campaign to counter the flow of messages from the alcohol. And the five words and phrases upon which so much stigma is scaffolded: alcoholic, addict, junkie, drug abuser, codependent, and a neighbor. Yes, we even shamed the people who want to help us, the people who love us.

KIMBERLY SUE:

Great, thank you so much. That was really like, it's incredible to hear your journey and your thoughts on how we can be better. And you know, it's wonderful, you know, to see, you know, be in community with you. Well now we'll go over to Dr. Yngvild Olsen and you know, I do think building on what Monique and Mike have kind of laid out, we're gonna transition to how it is to provide that care, and to advocate for a more compassionate, respectful, and dignified, "treatment" of people who use drugs.

YNGVILD OLSEN:

Thank you. And both Monique and Mike, especially Mike, that's just an amazing story. And, you know, I think part of what your story resonates with me is really just the advocacy and the anger that I feel as a healthcare professional, who is really trying to, you know, also kind of make things better. So, I'm Dr. Olsen, I'm an addiction medicine specialist and an internist, in Baltimore. And where I work and what I have been doing for the past 20 plus years, is really focusing on providing comprehensive quality care for people with opiate use disorder, all substance use disorders in a safe, non-judgmental space, that really seeks to minimize harm and promote health. You know, the American society of addiction medicine where I also have been very active, we have a definition of addiction as a complex chronic treatable medical disease, that involves complex interactions between brain circuits, genetics, the environment and an individual's life experiences.

So, all of those things that Monique and Mike, you both been speaking to I think get encompassed in that definition. And you know that complexity, I think unfortunately is not the way that our systems are built. It's not the way that our healthcare providers are educated, it's not the way that we finance the systems. And at the root of much of this is really stigma and discrimination, I would say it's, you know, stigma is kind of the attitudes, then discrimination is really that what people experience. And, you know, just to start, I have lots of examples that I can cite, you know, in my work from my patients, my people that I have been trying to help, but there's one that really sticks out, I think kind of that's relevant to this conversation. And then we can talk more about, you know, how we really change things.

And that is, I had an opportunity that many years ago, I was the deputy health officer for a local health department in Maryland. And we as the health department funded a long-term recovery house, a long-term house and recovery program for people with substance use disorders. And we also happened to run an opioid treatment program through the health department. And so, we provided methadone, that was really kind of the medication at the time that we had access to. And I had a young man in his twenties, late twenties, who had been struggling with an opiate use disorder for about 10 years. He had been in and out of residential treatment settings. Similar to your experience, Mike, he had been in drug court, he had you know, been in and out of various different house of outpatient settings, intensive outpatient. And every time he was not able to sustain the abstinence, I think that the treatment programs and that all of his health professionals, that was what they told him he had to, he had to get to.

He came to our opiate treatment program, very ambivalent about methadone. Not necessarily sure that he really wanted to take this, his father you know, was very supportive of his recovery journey, but also was not very sure about methadone. And but he started, cause he said, you know, nothing else has worked. I got to do something different, and he actually stabilized fairly quickly, but he really wanted more wraparound services, He wanted more support. And so, the halfway house, the recovery house, that we funded, we thought, oh, he would be a fair fantastic (INAUDIBLE) all of their criteria. So we referred him and he was soundly rejected. And the reason for the rejection, they said, "No, you know, we just don't take people on methadone." And I remember calling the executive director and just, you know, really saying, "Look, we fund you, we fund a third of your total annual operating budget. Like this is not, this is discrimination." And he said, "Well, no, we just have a policy, we don't pick people on methadone."

And I called our health officer, I called the state, we had a meeting with their executive committee, we, you know, talked with them. With the head of the behavioral health administration at the time where their funds originated. And the answer still was, "Nope, I don't think we're going to take him." And eventually, the health officer and I met with their board of directors, we did a big presentation on the disease of addiction. What happens in the brain, medications, how they work, what the evidence is for reduction, significant-reductions in mortality, morbidity, increases in quality of life. And one of the board members, I distinctly remember said, "You know, we thought this way about antidepressants 25 years ago, we really didn't like, we didn't take people on antidepressants 25 years ago, and now we do. So, maybe we can change, maybe in 25 years, maybe we'll think differently about methadone, but I doubt it." And they decided to reject the 90, the tens of thousands of dollars that we were giving them. And they elected not to take it, rather than have to take patients on people on methadone.

The young man, he was, you know, he was devastated, but not surprised, because this is, he was had been hearing kind of from friends and family. And you know, he ended up moving in with his father and continued on, coming to us for services and treatment and including the methadone, but after a while he stopped coming. And it just breaks my heart, we lost track of him and it just breaks my heart knowing that, you know, I don't know what happened to him and that the discrimination that you know, he faced because of a medication. But you know, we wouldn't, we don't think this way about insulin pre-diabetes, we don't think this way about any other medication, but the discrimination and the advocacy that it really takes to make sure that we're not only discriminating against people who are using substances, have a substance use disorder, but even the treatments that we provide, we need to do something different. So, I'll end there. Thanks.

KIMBERLY SUE:

Thank you so much. And, you know, I'm not sure when you were talking about that particular instance, but I'm, you know, very, you know, aware and we're all aware that those are still, you know, happening to our patients and friends today. And we'll go to Dr. Giftos, who is one of my former colleagues from Rikers, and he, I think he's been in the thick of it in the last year, thinking about stigma in his new position at project renewal, in New York city and the ways that it affects the care of people experiencing homelessness and indoor using substances. So, we'll go to you. Thanks.

JOHN GIFTOS:

Thank you, Kim. It's really a pleasure to be here on this panel with everybody and to hear my co-panelists stories. It's very inspiring, and I think, so, just to kind of start, I'm John Giftos, I'm a general internist and an addiction medicine specialist. I currently serve as the medical director for addiction medicine and drug user health at project renewal. As Dr. Sue said, a homeless service, non-profit in New York city that provides housing, healthcare and jobs for people experiencing homelessness. I'm sort of new to this position, I started right before the pandemic actually. Before taking this position, I worked for four years in correctional health, on Rikers island, overseeing diversion harm reduction, treatment, and re-entry services for incarcerated people who use drugs. A big part of the work for me, was serving as the medical director of the opioid treatment program on Rikers island, which provided methadone or buprenorphine to patients who were incarcerated.

And what Dr. Olsen said about stigma against methadone resonates very strongly with me given some of the work that I was doing at the time. At the time, you know, one of the, there was a lot of Rikers had one of the few methadone programs, jail-based methadone programs in the country. But despite having a program, there was still stigma against the medications in the jail system and not as many patients access it for a variety of reasons. So, a big part of my work there at the time was expanding access to methadone and buprenorphine. And we were able to improve treatment rates from 25 to over 75%. We reduced post-release overdose risks by over 80%. And there wasn't a single in custody overdose deaths. During the years that I was working in that program which is a real Testament just to the efficacy of the medication when it's only made available to people who need it. It really should be the standard of care in all settings. So, my current work is involving a mix of office-based addiction work. I manage a large panel of patients on buprenorphine and treat hepatitis C, along with a cohort of providers working in integrated medical clinics that are inside of shelters or transitional or supportive housing or a mobile medical van that serve people on the street. I also oversee what are called low threshold licensed addiction treatment programs. Some of them are

outpatient, that provide counseling groups, occupational therapy, recovery support for people experiencing harms from their substance use. I also oversee what are called residential crisis programs that serve people struggling with chaotic substance use, many living in the New York city shelter system or on the street. I've been part of an organization over the last year, that's worked really hard to protect people living in congregate settings from COVID. Many of our clients living in our housing programs got relocated in the hotels across the city, many in neighborhoods that historically hadn't welcomed people experiencing homelessness, people who use drugs, and they experienced a tremendous backlash. And I'll talk about that briefly.

Many of our patients have a history of complex trauma, that is to say longstanding exposure to violence, abandonment neglect in this treatment that impacts how they access services. For many that includes incarceration as a form of trauma, but it also includes traumatic experiences with service providers, including the very programs aim to care for them such as hospitals, clinics in our treatment programs. But I work in a city that has no shortage of services. So, it's a service rich environment. And so, the availability of services is relatively high. But what I've come to really appreciate it, and this has really resonated in Mike's story, that just because something is available doesn't mean that it's accessible to you or acceptable. So, a big part of the work that I do, and it's a real long journey is really focused on improving the accessibility. In other words, is the care there for you when you need it? And do you know how to access it? And the acceptability. Does this place accept me as I am? As my whole self? Do they respect my dignity as a human being? Do I feel comfortable in this space?

So, the accessibility and acceptability of care in a city where services are otherwise relatively available as compared to other parts of the country. And a big part of that is really working to kind of build programs that are warm and welcoming. Something that I think we all we don't appreciate walking into spaces and not being greeted warmly, but many of our people struggling with chaotic substance use are treated terribly, even when they're accessing services. And so, spaces that are warm and welcoming telling people that I'm glad you're here, it's good to see you, I'm happy that you came to us. And to think creatively about safety, so we struggle a lot to think about how to really think about safety, holistically. Sometimes people often are programs for using drugs. So, how is that safer for anyone to be discharged to the street than to work with them while they're in your program? That accepts people as their whole selves, creating space to see people's strengths.

I think so much of our work tends to be deficit focused, and that really kind of limits people to their struggle. And I think there's so much strength in a lot of our other people who work with and creating space to see that. That are trauma-informed of course, that we really work hard to reach from (INAUDIBLE) retraumatizing people. I think so much of, so many challenges really retraumatize people, and then incorporate in respond to client feedback or concerns. So, we really kind of making programs that are for, and by the people that are served. So, I'll close, cause I look forward to kind of the moderated discussion, but I just want to close by saying that sort of valuing these things is really just the start, and it doesn't mean that your organization or your program will immediately reflect these values and practice, you know, crafting policy, training and supporting staff, managing competing pressures from regulatory bodies or funding sources, or community sort of aggression like we experienced in some of our relocations of our guests into hotels.

The way that they were treated by the community, the way they were described by the community. I had several of our clients overdosed publicly and had their pictures blasted on Twitter, or were told that they were, you know, used all the sort of awful words to describe them publicly, followed around with video cameras et cetera, you know, this stuff put pressure, you know, it ended up putting pressure on our mayor to actually relocate the clients themselves. So, we had to sort of respond to that. So, balancing all of these competing pressures to kind of do right by the people we serve is challenging. But I think we do a tremendous amount of harm when we aim to serve but fail to deliver on these values. And so, I look forward to continuing to learn from others as we try to move the work and the field forward. So, thank you.

KIMBERLY SUE:

Thank you so much everyone. And we're going to move into our discussion, and please don't feel shy to type in any questions you have for any of our amazing panelists while we start the Q&A. And the first question that I have is for Monique, Mike and John, but anyone really can jump in if you feel so moved. And really reflecting on how people have experienced the harms of the current treatment, and existing social service system in north America, we can even say to extend to our Canadian colleagues, is there a way in which you think that harm reduction as a philosophy, as a practical strategy can do better? Or supplement augment, expand the ability to provide compassionate care as opposed to traditional treatment or abstinence-based strategies? Monique, do you want to go?

MONIQUE TULA:

Yeah, sure. You know, I think, I mean, I think about this an awful lot, Like I get paid to think about that. And although we, as in harm reductionists are often seen as sort of the agitators who are on the total opposite and the treatments back a spectrum. There's plenty of us who embrace the pursuit of a life in recovery. But the reality is that recovery is not, it's not for everyone, it's just not for everyone. So, thinking back like kind of comparing the dimensions of recovery, with harm reduction principles. Both sets of principles are people centered, they're pragmatic, they take into consideration, really important social cultural factors like race and poverty, stigma, and social disapproval of drugs and the people who use them. So, rather than seeing harm reduction, being on the treatment spectrum, instead, we see treatment as part of a broader harm reduction framework. Where chaotic use is on one end, and abstinence maybe on the other end. But there's a whole lot of room in between those two variables.

And harm reduction interventions that we often talk about, so, things like; syringe service programs, safe consumption spaces, medication for opioid use disorder, Naloxone distribution, you know, all of these interventions can be pathways to personal responsibility and autonomy, because they put the power of choice in the hand of people who use drugs. So, they're all examples of really pragmatic and person-centered harm reduction approaches, and they can be extremely successful obviously reducing infectious disease transmission, overdose, and then linking people to treatment and recovery. So, you know, so for me, and for harm reductionists, these kinds of people first approaches, really helped to create the kind of space that relationships can be built in, spaces that should be free of judgment, anyway. Harm reduction really demands that we view people as whole human beings who are worthy of, you know, not just basic human rights, but love and acceptance.

YNGVILD OLSEN:

If I could just maybe add to that. I think that the way I guess, I also kind of think of harm reduction very much as that larger concept and that treatment and cause I think for a long time there have been these silos, right? So, silos between, you know, even prevention, harm reduction, treatment, and recovery, and it's really, it's a continuum it's all kind of blended together because addiction as a chronic disease, much like, and there are people who debate, whether that's, you know, that concept, but if you kind of take that at least that there's a chronic illness component, that there's a kind of it's not, it doesn't go away after seven days. And you don't give people an antibiotic for addiction like you do with pneumonia. And it doesn't kind of go away quickly. There is this just this continuum and that things kind of the approaches to me, it's really about kind of the approaches and the principles of kind of respect and dignity, understanding where people are coming from.

And we do that in other parts of medicine. So, I think to me the analogy, like, I love the analogy of diabetes, because, you know, we don't blame people, but we shouldn't be blaming people, you know, kind of for the fact that they have very high sugar levels in their system. We don't say, you know, kind of, "Oh, you're taking insulin, you're such a, you're like a bad person", as I think Mike was spoken to, and that when we talk about minimizing harm, and promoting health, we do that in lots of other areas of medicine, without kind of questions. And so, you know, why we have kind of created these very separate silos within the you know, substance use addiction space, doesn't do anybody any good and we can, you know, we can argue until the day is long about the why? And the what?

But ultimately, we're all kind of committed to, and we should all be committed to the same thing, which is really helping the people who are affected by this and whether that's on the street, whether it's in a house, whether it's in the hospital or the emergency department. And so, I think it's unfortunate to me that we still are really living with a legacy of looking at addiction as a moral failing, looking at substance use as this kind of bad behavior, and then it makes you a bad person, and then there's something just very wrong, and morally deficient with people that are using substances. And people have been, you know, humanity has been using substances for thousands and thousands and thousands of years, this is not something that all of a sudden kind of started. So, yeah, so I really appreciate Nick's comments and everyone's coming.

KIMBERLY SUE:

Mike, do you have any particular thoughts on how you've developed your strategies as a therapist using harm reduction that sort of can, you can give based on your experiences, both as a patient in these hostile systems and give us some, some tips about how you think about this with your patients and yourself?

MICHAEL POND:

Well, of course, given what I went through and through that process, I emerged from it with a pretty profound sense of empathy. As I said earlier, I was pretty judgmental, and I had my ideas and they were wrong. And then I was given the opportunity to experience it, to be on the other side, so to speak, and experience what a person goes through when they don't have the resources, and they're struggling. Healthcare and the recovery community intends to, traditionally intends to treat addiction as binary. You're either an addict or you're not, or you're an alcoholic, or you're not, or you're clean, or you're not. And abstinence is the measure. And I don't use that as a measure, necessarily. It's on the continuum, but when I'm

working with people, I tend to work more with people with alcohol use disorder, because that's my story and that's what draws people into my work.

And I just say, "Well, where do you want to go with this? What do you want to do with this? Do you want to be abstinent? Do you want to look at moderation management?" And so yeah, meeting the patient where they're at, and working from that, and having them directed and I say, who has the most wisdom about you? Who has the most wisdom about you? And they can't look at me, and then eventually as well, of course you do, I do, I have the most wisdom about me. I know me very well, what a concept? Although the DSM five now uses SUD on a continuum of moderate or severe, you know, the traditional model gives it lip service and I'm not here to disrespect AA at all, but that's the program that most of our treatment is based on at some level.

And it demands abstinence, and most rehabs train you as that's the go-to aftercare, the mutual social support is AANA that's 12 step programs. By the way, do you know, today is the day Bill Wilson, Bob Smith founded AA in 1935? Amazing. Most rehabs kick you out for laps, and you're yet punished if we're when you return. And when you do return, then you're probably on close observation and in a side room. And when I was kicked out or we have her drinking on a pass, it was the group consciousness that voted me out of treatment. These are my fellow clients, fellow patients, actually kicked me out of treatment. So, there's this degree of kind of lateral bullying or discrimination that happens, right? There's a pecking order within that system. And the director (INAUDIBLE) informed me that I could return at 30 days if I stayed sober.

So, I was put out in the street again, with all my belongings, which were in two plastic garbage bags, and you guys call them trash bags. It was the worst snow storm in 75 years. And I almost froze to death while I was on the street. We have a recovery day, we have recovery week, we have recovery month. And we celebrate being, you know, I'm an addict and I'm clean and I'm sober and I'm proud, which is fine, but what is that message giving the public? (INAUDIBLE) yell to the rooftops, you know, in term of sobriety, which is fine. I went into one AA meeting in White Rock here in British Columbia, I just happened to walk in and it was an individual's kick. And he was getting his second 20-year kick. So, in 40 years he used to get drunk one, on one weekend. And that was the focus of that meeting. I'm going, holy cow, you went 40 years and only, only drank once or used once.

So, there's a lack of, (INAUDIBLE) people don't get well that way. I was accused of taking an easier, softer way because I was prescribed Dymetrol. And quite frankly, it saved my life. It's based on a white Protestant male model. The war on drugs is not that it's a war on drug users. A colleague of mine was a lawyer with one of the largest health unions here in Canada, and he says he advises the union members to not disclose to their employer, because there's going to be inevitable repercussions; it's going to be judgment, discrimination, punishment, discipline. My experience, our healthcare judges and discriminates against us. But most judgment and disdain is reserved for the so-called illicit drug users right off the bat, we have to wait so long to get into treatment, and we pay outrageous amounts of money for private treatment. Which means our problem, our lives are not considering an urgent, are not considered an urgent priority, even though most substance use disorders, if they progress, they're life-threatening.

I met an AA member, he was Vancouver police officer, 30 years of experience working in downtown east side. He says, I just stepped right over the addicts when they're lying on the

curb shooting up. We know substance use disorders are by definition, chronic, relapsed conditions, but often healthcare professionals get frustrated and impatient, but those who exhibit the very symptoms of the disorder. And so, yes, we relapsed that dreaded word relapse, which is kind of the defining, one of the defining criteria for, you know, with the diagnosis being accurate. "Were you (INAUDIBLE)." I know that. We can be very unsavory, but if you saw us displaying symptoms of bipolar disorder schizophrenia, you'd see us as more deserving of treatment. It's a deeply held belief in so many of us still that addiction is a moral problem, not a medical, social, psychological economic, cultural problem.

KIMBERLY SUE:

Thank you so much. You know, we only have about six more minutes, but I did just want to use my moderator's prerogative to jump in. And there's a harm reduction coalition had a like almost 15 or 20 years ago, had a round table on harm reduction and recovery. And many people didn't, you know, had many wonderful and eloquent things to say about it. And Kevin Erwin said at their core, both recovery and harm reduction are about resisting stigma and discrimination, building resilience, cultivating hope, supporting any positive change towards one's own self-actualization of health and wellness, and for those in our various communities. So, we in the harm reduction community don't, you know, are inclusive of all people and all strategies that work for people, including abstinence. And we really, again see and I talk to patients as well, about people moving on a continuum. And moving back and forth with different substances over time like that, it really is a complex reality that people have to different substances over time. And that's why as an anthropologist, you know, I think it's so fascinating and important to talk about.

One thing that we're having many questions, but one thing that I think is important for us to talk about is the stigma of addiction treatment, pain and pain treatment, harm reduction, and structural racism. And I think this has been on everyone's minds in the last year or so, as we've kind of culturally been shocked and horrified about the way that sort of racism and the war on drugs and criminalization of substance use really has led to the death of many Black people, and indigenous people. And so, if we can just, if anyone wants to get in on this part, I think that a lot of our audience members might be thinking about, this and ways that we can address this in our lives and in our work.

MONIQUE TULA:

Well, I have a lot to say about it, but you know, so I think about you know, we, we talk about cultural competency. We've been talking about cultural competency for a decade now, and we've had varying levels of success. But what I want to push us to think is, you know, what does it mean to be, to move beyond cultural competency, actually dismantling structures that sustain and promote oppression. So, for me, any kind of movement to reform a structure or a system, or institution or practice, any movement, that's focused in that area, that have a history of inflicting harm on the very people that were supposed to be serving, that movement has to have a critical orientation toward racial injustice. Because without it, you're essentially addressing the consequences and the systems of injustice rather than the root causes.

So for example, America's current obsession with white opioid users is evident, really evident in our drug courts, that often favor white over Black and brown defendants. And yet many advocates are shying away from the kinds of conversations about individual, and institutional racism in favor of easier, and short-term solution. Through this fear of confronting racism, risks building upon rather than dismantling the root cause of the problems that we're trying to fix. And so, I think of harm reduction as actually could be an innovative approach to expand

our thinking around how racism shows up in our day-to-day interactions and our fraud in our institutions. So, most of us who are familiar with harm reduction tools, we use them to try and mitigate the harms of drug use rather than focusing fully on treatment or abstinence. But since the beginning, Black and brown harm reduction advocates have long seen the commitment, harm reduction commitment to health and human rights as a lens through which we can address the harm that has been caused by overarching, discriminatory, public health and criminal justice systems. So, advocates see, view that focus not only as reducing the harm that drugs cause to people, but addressing the harm that society inflicts upon them.

YNGVILD OLSEN:

What she said, I mean, I couldn't, I just couldn't agree more. And I think really the harm, and I think what everyone has really been speaking to, is the harm reduction principles, because they also are non-judgmental, and they put people first and they essentially demand respect, and dignity for, you know, kind of, no matter what you look like, no matter who you are, that it allows the space. I think also, to then have those conversations that for me, as a white privileged kind of, woman like can be also somewhat uncomfortable. But I think that being able to sit with that discomfort, and understand, that is discomfort that people have, you know, Mike talked about it, kind of being thrown out of a halfway house into a snow storm, it's such an important critical issue and one that we really need to spend a lot of time focusing on and it's not going to happen overnight, but I think until we kind of really get to... We change those doctors and change those systems, we're just going to keep circling around and around and around.

KIMBERLY SUE:

So, I think we're going to, our time is up, and I just want to thank all the panelists and the organizers; shatterproof national county medicine, and Rich and Alanna for this wonderful panel. And, you know, certainly the rest of the day is hopefully incredibly productive, and we hope to continue this work with you. We know that it's, this is a long, a long journey and all of us are doing our piece in our corner of the world to make this a better and safer place for people who use drugs and they can live in a world with dignity, respect, and compassion. Thank you.

SESSION 1.2 - STIGMA IN THE HEALTHCARE SETTING

MATTHEW STEFANKO:

Thank you for joining us for Session 1.2, Stigma in the Health Care Setting. We have an incredible panel of clinicians and health care providers to discuss specifically how stigma manifests during the provision of care. I'm really pleased to welcome our moderator, Dr. Alister Martin, and his faculty at the Massachusetts General Hospital Center for Social Justice and Health Equity at Harvard Medical School and he's also the founder of Get Waivered, a campaign aimed at transforming emergency departments nationwide into the front door for recovery for patients with opioid disorder. Welcome, Dr. Martin and the rest of the panelist.

ALISTER MARTIN:

Well, thank you very much, Matthew, for that generous introduction. I'm Dr. Alister Martin. And as Matthew mentioned, I helped to start a program called Get Waivered about five or six years ago now. And it was aimed at trying to convert our nation's emergency departments into the front door for addiction treatment by helping providers get their DEA X waivers, which allow them to prescribe buprenorphine, which is a medication that can be helpful for folks looking to get into long term recovery. So excited to be kicking off today's incredible panel here, focusing on the stigma in the health care setting. Today, we're going to be discussing how stigma of substance use disorders permeates into and through the health care setting. And we're going to be identifying stigmatizing actions, behaviors, language that exists within health care settings that hold us back, serve as barriers for us to truly take care of patients in the way that they should be.

I want to introduce my co-moderator, Matthew Stefanko, who you just heard from, is the director of the national stigma initiative here at Shatterproof and we are going to be leading a panel discussion with some incredible, incredible panelists. This is a little bit like the Avengers of opioid addiction treatment coming together here. I'm so excited to introduce them to you. Why don't we start off with Bill Kinkle, who is a nurse, trained EMT provider and also the founder of Health Professionals in Recovery. Bill, tell us about yourself. Tell us about your work, how you do it and what you're up to nowadays.

BILL KINKLE:

Those are interesting questions. Thanks for the invite and being part of this panel. It's a great honor. It's great to actually put faces, you know, to some of the names. But, yeah, my work's kind of my life has been a strange trajectory and, you know, if you would have asked me at 17 if this is where I'd be, I would have said, I want to believe you. But, yeah, I started my career early as a paramedic at 19 and then eventually became a nurse in my mid 20s. Primarily, I worked in the emergency department at the University of Pennsylvania. That's where I spent the majority of my career until about 2008, 2009. I developed an opioid use disorder or a substance use disorder, which really caused my career to come to a screeching halt, something I did not see coming. And that's really where my interest in this in this issue comes from.

But my over the past 10, 11 years or so, I've struggled with an opioid use disorder in and out of recovery. I've had periods of long term, five plus years recovery, three years, a couple of times here and there and over. Let's say the past three years about the past three or four years, I've spent a lot of time in the advocacy space and one thing that I that I realized is as a health care provider is how difficult it was to come out and say, I'm struggling a lot, I'm having a

problem and what I realized is that we have a culture of silence in medicine, that when we struggle, one, I don't think that in medicine it's commonly known that we actually are susceptible to developing a substance use disorder. I think the majority of health care professionals believe that it doesn't happen to us. You know, we go to work, we do our work, we go home, we're strong, and we have this sort of toughness about us. And that's essentially not true.

We actually suffer. Most likely we actually suffer more than the general population, but we don't talk about it. And so the reason that we started health professionals in recovery, myself and my partner, Sean Fogler, who's also a physician in recoveries, we wanted to try to break down the stigma and break down the walls and to create a place where people who are nurses, physicians, paramedics who struggle with substance use disorders can come and talk about their struggles openly without having any fear or feeling stigmatized. Because when I was a nurse working in the ER, I was silent. I didn't tell anybody. And that ultimately led to, in that initial phase, a three year period where I eventually lost my job, my career, my house, my license. I was homeless for three years. I was spent about six months incarcerated for a drug related offense where I was subsequently raped.

And so all these things could have been avoided had I, had there have been a culture in medicine where I went to my manager and said, hey, I'm struggling with drugs. And they said, it's OK, we have a place to go, come on, will come help you. And so that's where the focus of my work is, is to break that down so that we create a culture in medicine where when we struggle, we feel comfortable and confident to say I'm having a problem.

ALISTER MARTIN:

So powerful, so, so, so powerful. Thank you, Bill, for starting us off and we look forward to continuing to delve into some of the insights and perspectives that you as you bring such powerful perspective. Thank you Bill for being here. I want to introduce Dr. Hector Colon Rivera, who is director of the Asociacion de Puertorriquenos en Marcha. Dr Colon Rivera, tell us a little bit about the work that you do. Tell us what you're up to nowadays and how you get into it.

HECTOR COLON RIVERA:

Alright. So I was born and raised in Puerto Rico, right between San Juan and Vieques. I don't know you guys, you guys are familiar with Vieques was like a small island within the island, Puerto Rico its part of Puerto Rico became famous after the Navy left the island after 60 years of converting the island. So imagine growing up in a in a place that two third belongs to the Navy and you couldn't go to those two third of the land and only one third of the island was part was the community. Right. So you're living on that one third of the island. Our cancer rates were super high right now, 2021, there's no hospital on the island. Only the primary care physicians take care of the mental health and substance use disorders on the island. There's one high school and a lot of alcohol related disorders and opioid related disorder, but no one to be to treat it, right.

People have to take a ferry and drive over 80 something miles by land and sea to get treatment in San Juan, which is a capital of Puerto Rico. So I was born and raised in Puerto Rico and they moved to do my residency in Boston. Right now, I'm the medical director for APM. We call most of the social determinants of health is here in Philadelphia nor is Philadelphia. We treat African-Americans, Hispanic communities. That's about 85, 85% of our patients. We have two clinic for substance use disorders. We had three cases for mental

health. I'm a board certified psychiatry. My board certification are in addiction medicine, addiction, psychiatry and adolescent psychiatry. And that's what we do. I start seeing patients from the age of 10 to I think my oldest patients, is like 105, pretty strong, strong man for his age. So in terms of our community and what we do in a community, we have affordable housing. So we have a Department of housing.

We work with the state giving grants to patients so they get a waiver. If they're homeless, we have shelters and then we provide housing after that, we have a few schools in Philadelphia. So we have Education Department, we have a foster home with over 300 kids that have no parents, who have lost their parents due to trauma or other circumstances with substance use and we have a department that take care of grants and money and this works at a credit union for our patients. I also work for University of Pittsburgh doing research in access to MAT medication for assisted treatment for opiate disorder in rural areas, as you know. 90 something percent of the PCP, primary care physicians, are in urban areas so rural areas are left behind, especially in Pennsylvania, which is a huge state, and between Philadelphia and Pittsburgh, it's like seven hours of sometimes no treatment.

So what we do is we do research, we apply some apps technology, we do telemedicine for those four areas and trying to expand the use of MAT. I mean, access, as Bill mentioned, and someone that I understand not only your language, but are able also the cultural tradition is needed. I mean, someone to open that door for you any time anywhere. So that's what we do at UPMC. I'm a consultant for SAMHSA here in Pennsylvania and for Asociacion de Puertorriquenos en Marcha, which is kind of synonymous for SAMHSA for Puerto Rico. So that's a little bit of what I do. And I'm happy to be here. And thank you for your invitation.

ALISTER MARTIN:

Incredibly, incredibly comprehensive program and we're looking forward to hearing more about Dr. Colon Rivera. I'm going now hand it back over to my co moderator, Matthew, who's going to continue introducing the rest of our panelists.

MATTHEW STEFANKO:

Thanks, Dr. Martin, and really appreciate you taking the time. I know you have quite a busy day today. I'll next, introduce Dr. Hadland, we've two more speakers and then we'll move in to a question and answer session. Dr. Hadland is an associate professor of pediatrics and a pediatrician and addiction specialist at Boston Medical Center and Boston University School of Medicine. We've done a lot of amazing work with Boston Medical Centers. We're so happy for you to be here. We'd love to just a little bit understand your background of course you're bringing a unique perspective as a pediatrician as well. So would welcome a few minutes of your remarks. Thanks.

SCOTT HADLAND:

Yeah, thanks so much, it's really an honor to be here and thank you, Bill, for sharing your powerful story to get this really set off on the right foot. And, Hector, for helping us think through the ways in which stigma can be magnified for certain for certain populations of groups that have traditionally experienced stigma for a lot of other reasons in health care settings. That really becomes, as I said, amplified when it gets layered on top of the stigma that people experience when they have addiction. The lens I want to bring to this conversation is around stigma that youth experience in health care settings. So my background is that I'm a pediatrician. I am trained in adolescent medicine and in addiction medicine and so I kind of bring together these topic areas that aren't necessarily commonly

thought of, brought together. I work clinically in a clinic at Boston Medical Center called the Catalyst Clinic.

This is a clinic that takes care of teens and young adults between the ages of about 13 and 25 and we're delivering our addiction treatment here right in primary care. So if you're a young person that has struggles with anything from sort of marijuana and nicotine, alcohol, the more common things that we think of using all the way out to struggling with stimulants like methamphetamine or cocaine or heroin or fentanyl, we sort of address the full gamut of substances and we do it in a pediatric primary care environment. And so coming to our clinic, you not only can get treatment for your addiction from me and from our interdisciplinary team, that includes social workers and therapists and psychiatrists, but you can also have your medical health care needs met. And that's really critical because we know young people need immunizations.

Sometimes young people don't want to go see the doctor, but if that doctor is going to treat their acne, then they're excited to go see the doctor. And that's not just a hypothetical example. I have a number of patients who don't aren't ready or able to accept treatment for their substance use disorder, but they see me routinely as I treat their acne and make that better. And so it's a little bit of a different treatment model where we're really trying to offer addiction treatment in the same place that young people get all of their medical needs met. And I think actually this has important implications as we think about stigma, because it really is an unfortunate set up of our addiction treatment system but is so often siloed from other mental medical treatment settings. And so we're trying to bring things back together to make addiction just another medical and mental health condition that we treat in a patient's medical home by a pediatrician.

So I'll be happy to talk a little bit more about that. I think what I would love to bring to the conversation and happy to discuss more later on in this panel is thinking about the unique forms of stigma that youth experience. So we'll spend a lot of time unpacking stigma generally in health care settings. We've already touched on some of the stigma that people experience when they are in a health care setting and want to share that they have a problem when they're in a health care setting and are considering medications for addiction treatment, which we know often can set people up to experience stigma. But youth experience all of that and then some and that's because the pediatric workforce traditionally hasn't always, I think, done a very robust job of making sure that young people are treated with respect and dignity when they use substances.

And young people also experience a lot of a lot of stigma that sometimes can come from trusted adults in their own lives, like family members or community members who may sort of layer on extra layers of stigma that we have to work through. So I'll stop there. I'm happy to discuss these points and others when we get to the discussion.

MATTHEW STEFANKO:

Great. Thank you so much, Dr. Hadland. And last but certainly not least, I'm excited to introduce Dr. Lagisetty, Shatterproof has been doing some amazing work in Michigan with Michigan Open and we're so happy to have you here as both bringing your perspective, but also as a representative of Michigan too. Dr Lagisetty, like I said, she is a health services researcher and general internist in the Division of General Medicine and also the Center for Clinical Management and Research at the Ann Arbor, VA. She focuses on patients comorbid pain and substance use disorders similar to Dr. Hadland, Dr Colon Rivera and Dr. Bill

Kinkle. I love your perspective. You're unique perspective Dr. Lagisetty with the patients that you're treating, and then we'll move into the broader dialogue. So go ahead.

POOJA LAGISETTY:

Thanks so much, and I am honored to be here, especially with so many people that I admire. And as, you know, I would say that I wear a lot of different hats at the institution. I am currently a researcher, as you mentioned, an assistant professor at the Michigan. But I also work as a primary care physician and inpatient, tending both in internal medicine and also bond in addiction medicine. And my, I treat patients that span across the spectrum of having diabetes, have chronic pain, having addiction, and then also discussing patients that are specifically admitted for addiction related reasons. And similar to what Dr. Hadland said, I take great pride in the idea that we can offer treatment for patients with addictions, specifically in general medical settings so that they can potentially be treated in a less stigmatizing environment.

But I will say that one of the things that I really want to focus on today is a lot of my research really focused on this overlap between chronic pain management and it's really led me to kind of really think about how stigma is different and different for different patient populations. You know, for chronic pain, we often see stigma kind of manifests as disbelief or distrust in people's pain. Doctors may not think that somebody's pain is real or organic or physiologic. We use these types of terms to kind of assign whether pain is physiologic versus not. For addiction, as we've heard from a lot of our panelists today, there's this idea of addiction being a moral failing rather than being it being a chronic disease. And then we have this kind of underlying addiction around subsistent, particularly around opioids. Is it a legitimate therapy? And you know the recent kind of research has really led a lot of providers to just think that opioids it's not recommended.

And so all of the stigma around kind of pain, addiction, the substance in general, it's really complex and has really fortunately led to a lot of decreased health care access. And research by our team has shown that, you know, almost upward of 41% of primary care clinics aren't willing to even schedule an appointment for a person who might need opioid therapy for pain. And if we can't even get our patients in the door, it's hard to screen for substance use disorders, it's hard to address substance use disorders. And so I'd love to talk about that more in the Q&A and really think about how we really need to be kind of thinking about from all of these three different complex perspectives in order to improve health care access.

MATTHEW STEFANKO:

Wonderful. Well, thank you for that and as everyone attending can tell, we have such a great group with us today and I know that some questions from the audience are already streaming and I have a few questions just to get started. And Bill, I'm actually because you're one of the first speakers, I'm going to start with you. You have obviously this very unique perspective of both being a provider, where you are working with other providers who might have done stigmatizing things or had certain attitudes and then you've also sort of experienced that yourself and you mentioned that in the opening. I'd love to hear just that duality a little bit and what it's like from that unique perspective and how you see broadly how you're seeing stigma manifest from each side and what you're seeing out there today.

BILL KINKLE:

Sure, yeah, I mean, it's a really strange place to be, you know, I mean, I think the first thing, whenever we talk about stigma, you know, and particularly stigma, discrimination

surrounding people use drugs that we really need to acknowledge, especially me being a white male on that stigma and the reason that we hate drug users, it is it's purely rooted in racism, you know, in the American war on drugs is really where stigma has all began, which has been in pretty much operating in full force for well over a century. And I think she said that needs to be acknowledged front and center, that that's really where all this comes from, that the reason that we when we look at people who use drugs, we have that certain feeling in our gut of disgust and disdain and I was taught that way, as a paramedic and as a nurse, I was taught to that those people weren't really worthy of care, that they did it to themselves. It was purely a moral issue and a choice.

And they didn't deserve the same care. And I watched a lot of people be tortured and I watched people who were on long term methadone maintenance therapy be given Narcan just because they thought it would be funny to watch them suffer and things like that early in my career. This is the early 90s I'm talking. And so I had an opinion about people who use drugs from early on that was very negative. And so when I began to suffer with a substance use disorder, it was really confusing for me because it wasn't an overnight decision. For me, my drug use started with depression and every time that I have struggled with substance use, it's been from severe depression and my first experience with opioids really came from a I had a kidney stone in the mid, early to mid 2000s.

And I just remember the first time that I had Percocet had been given Percocet, that that really made me feel, you know, there was euphoria and things like that that came with it, but it was really how it made me feel in my place in the world that I sort of felt normal. I thought this is how everybody else must feel very comfortable in a crowd and things like that. And so when I when I suffered with depression, I pretty quickly found opioids and I found that they manage my depression much better than any other drug, you know, because when you're prescribed in any type of antidepressant, there's a long period until you get sort of any type of relief, whereas with opioids, it's pretty much instantaneous. But anyway, back to the original question, I found as a health care provider, the stigma that I've experienced has been horrific because it's not just the general public, the general public hated me, but also my colleagues. And it wasn't supposed to happen to us.

And I was pretty quickly alienated, not only just with my co-workers, but even, you know, once I admitted to the licensing board that I had this problem, I was put into a monitoring program which in nursing boards and physician boards they all most states had these monitoring programs. And most recently so I was in a program for about two and a half years. It was a three year program. And I was in the program for two and a half years. And at two and a half years is when COVID hit last year. And I was really starting to struggle with just the stress of COVID the death of multiple friends, by death of family members, a lot of different things. And so I spoke with my addiction medicine doc and told them when I was starting to have some cravings and I was working in in a neighborhood in a neighborhood of Kensington, which is kind of ground zero for drugs in Philly.

And we kind of came to the decision that it would be a good idea to start buprenorphine, so that would help manage those cravings. And so I started buprenorphine treatment last year. And like I said, I was two and a half years into this program. I had had all negative drug screens. I far exceeded every everything that this program recommended. And when I called the nurse monitoring program through the state of Pennsylvania and told them, I said, listen, I'm starting buprenorphine because I think that's the best thing for my recovery, I was immediately discharged from the program because they said that's an addictive drug and my

case manager actually said at one point, they can't, but we know everybody that take Suboxone abuses it anyway, and so it was discharged from the program and told that I would most likely never have a nursing license again, and so I didn't I don't just experience stigma from the general population, but I experience it from my own people as well, which makes it even harder. And then, to be completely honest, over the past year, that really thrust me into a pretty severe depression and I had struggled with substance use off and on through the past year just because I for the past three years I was had this hope that I would be able to practice as a nurse again, that I would be able to practice as a health care professional again, especially with the experience of having suffered with addiction. I thought that I would be able to bring that to the table and be able to take care of patients better and having had that ripped from me, my dream of being a health care professional again, a nurse again, that was devastating to me. And it really made me question just where am I going in life? What do I have if I don't have? You know, what is my identity anymore?

And so those that's the that's the severity of what can happen and why we need to change. And I think one of the reasons why I talked about it earlier about having a culture of recovery is I think if we did have a culture of recovery and a culture that that we do, we suffer, too. It would have been easier to ask for help. These monitoring programs would understand that buprenorphine is an acceptable medication just like any other and it actually would make me a safer, for a safe for provider safe for professional. And I think we take care of our patients better and for two reasons, one, like I said, it would make it easier for us to ask for help, but also, I think I think one of the reasons that we do such a core job of taking care of patients with substance use disorders is because we boot ourselves out when any one of us gets suffers with a substance use disorder or a mental illness in general, we're kind of alienated from the rest of the crowd.

And so there aren't many of us in practice. And so when patients come in, we don't really the people who are at the bedside generally don't understand it. And I'll just finish with, I think it will be extremely powerful if we did allow people who have suffered with substance use substance use disorders at the bedside because imagine this. Imagine a patient comes in who is just overdosed and they're their overdoses are reversed with Narcan and they wake up in the ER,, a place where they've been treated like crap every single time they've been there in their entire life. But yet this one time they wake up and the doc or the nurse walks in, they pull the curtain back and say, hey, listen, I've suffered with opioids myself or I've suffered with drugs myself. And I've overdosed 100, eight times myself. But I found a recovery. I know what that's like, this, I've been there if you want to talk. Imagine how powerful that could be.

And I think that's why we really need to change everything and how we look at substance, drug use in general, people who use drugs, people who are in recovery, all those things. I think I think we need to just change everything in the way that we look and think about it.

MATTHEW STEFANKO:

Yeah, Bill, thank you for that and I think we know we heard, you know, Dr. Anderson speak, you know, from her perspective this morning. And I think there is so much power in bringing that connection. I'd love to touch, you know, bring in some of the other panelists now, Bill, on one of the points you made really early on in your response, which is around the way that stigma and discrimination is disproportionately influencing individuals from certain racial and demographic backgrounds. And I'd love to hear from the other panelists as well about, where are you seeing that overlap manifest if you have some examples of specific groups and

Dr. Hadland you talked about some challenged you that in others? So just love to open it up to the group to hear a little bit more about that intersection between, you know, race, other demographic indicators and then and then the stigma of addiction.

HECTOR COLON RIVERA:

I mean, we always talk about positive factors and negative facts, and when we talk about substance use disorders and some of the risk factors are, you know, your genes, you are your biology, where you grew up, I want to talk about social determinants of health, was it food on your table? And I mean, Bill examples is imagine a universe right where we have the freedom from discrimination and violence or social we all were or social in our society was inclusive and there was access to resources and we don't have that. We don't have that, especially in communities that are African-Americans or Hispanic or Asians and in some cases. Right. And, I mean, I think the story of Bill is so powerful. Even he said that he grew up thinking that people with a substance use already didn't deserve better. And we don't have that education. And I think we need to start that occasions from elementary school even before the elementary schools start at home.

So I think that's amazing as well. So I think that's where overlap and people that are not do not know don't go through the struggles are the ones making the decisions.

SCOTT HADLAND:

Yeah, I would add to there's an intersection here with you because I, I observed the differential treatment of people of color by our addiction treatment systems starts early. So, you know, I care for youth starting usually typically around age 12 or 13 and I you know in their data to support this national data and state level data to support this, that when youth of color are using substances or have other sort of mental health or behavioral problems, the approach that they're offered by our systems is typically one centered on punishment, on removal from schools, removal from classrooms, shunting to juvenile, you know, I don't like using the word justice, but juvenile justice systems I actually think can be quite unjust. Whereas many of my patients who come from, quite frankly better neighborhoods, from neighborhoods where the school systems are better resourced, where their neighborhoods are safer, most commonly neighborhoods that are populated mostly by white people and not by people of color are given opportunities when they use substances or struggle for mental health problems or behavioral problems to see a physician. And so I have families come from far and wide who have resources, who've come to see me and get the treatment that a young person should get. But they're most commonly the folks that are able to overcome those enormous access barriers are commonly not people of color and people who come from affluent backgrounds and from school systems in areas where they're afforded a lot more opportunities. And it starts at a really young age that starts right in elementary school, if not earlier.

POOJA LAGISETTY:

Yeah, and I would just add that we know that even amongst those who are offered treatment, so those that get through all of these barriers that we've just talked about to even get their foot in the health care door, that the treatments vary based off of your race. Our research has shown that, you know, methadone programs are predominantly located in urban, predominantly communities of color, yet buprenorphine or Suboxone, which has been around since 2000, while there's been growth in the amount of use of this medication, it's predominantly only been in white individuals. So even after we account for insurance differences or payment factors such as this, you know, white individuals are almost two times

as likely to be offered Suboxone. And I don't think that this is for buprenorphine. I don't think this is by chance.

This was, you know, when buprenorphine was initially kind of (UNKNOWN), less regulated, although we can argue about that which dated 2000 when they allowed buprenorphine to be used by general practitioners after getting trained. The way that this passed through Congress was individuals actually made the comment that we should have this other treatment for the suburban user for the less hardcore suburban user. And, you know, I think we can all we all understand what that that code word was for. And so there was racism from the get-go even around treatments. And so we've got to normalize even our treatment options and make sure that kind of being equitable when we're thinking about how we treat our patients if they even manage to get their foot in the door.

MATTHEW STEFANKO:

I think that's such an interesting point, and we've talked a lot about that in our work with stigma and that there's a lot of exciting efforts that are happening around anti stigma campaigns and better education for providers and being really smart about who gets that first and I think we see a lot of times that even though the communities are getting smarter around, you know, anti stigma efforts or anti-discrimination efforts, those first campaigns or those first efforts get pushed to communities that are predominantly white. And so, you know, we're years away from those even if they're even going to seep into certain communities of color, Black communities, et cetera, we're years away from that. So how do we ensure sort of equitable distribution of content or training and all these sorts of things. And I'd love to, before we get to the audience questions, I have one other topic that I'd love to dig into. And Dr. Lagisetty, I'll start with you, but certainly the other panelists, I love your perspective too as providers. We hear as at least from the Shatterproof perspective, we hear a lot about, from individuals suffering from chronic pain, about what happens when you reduce stigma around sort of recovery and how that sort of affects chronic pain patients who then feel like they're not being heard as well. So as providers, how do you think about that, that balance of making sure that you are there's a lot on your plate, right, appropriate prescribing, ensuring that you're providing compassionate care to those with chronic pain, but also compassionate stigma, free care for those who are trying to enter into recovery or who are in recovery? So you just talk about that interplay and how you think about it within your work that I'd love to hear other panelists to jump in as well.

POOJA LAGISETTY:

Yeah, you know, this is incredibly complex, you know, I think, unfortunately happening in the system is that as we are seeing this bailout between stigma and addiction, stigma and pain, stigma around opioids in general happen, you know, when we decrease health care access, we will decrease prescribing whatever that may be, even for chronic pain. What it ultimately leads to is a patient with chronic pain will start to make statements such as not an addict, my pain is real, you know, the hospital was treating me this way and they're doing this in order to get treatment. And they're doing this to like have somebody listen to them. But when we make statements like this, we're just further othering those who have addiction. Right. And so we're furthering the stigma against those who have addiction thing. I'm not, quote, an addict. And so when we make one system then, it inadvertently affects the other. And so I feel like, you know, when we're fighting stigma addiction, it can't operate in its own silo like. Right. We have to, you know, we act and we can't similarly just fight stigma and pain. Underlying all of this, is just a stigma around the substance. Right. And around the use, independent of what your diagnosis is. And so we've got to stop kind of one group against the

other because we often know that people have overlapping pain and addiction and really just start to break down the stigma around the substance use in general, whatever your reason for it is, depression, pain, addiction, you name it. We've got to break it down in its entirety.

SCOTT HADLAND:

I think this has become a really deep divide in medicine and in health care and actually we as health care providers have created it. We have we've created a system that pits one group of patients against another. And this is this is our fault and it's on us now to fix it. This is not an either or situation. All of us can treat addiction and treat people with pain. And we can treat everybody just as we were trained to do in medical school and in nursing school with compassion and dignity and respect. And I think it is rarely the wrong answer to just offer our patients a compassionate ear, to listen, to hear what they're concerned about, find out what's bothering them and address it. And I mean, I think a lot of attention is being paid nationally and, you know, in our in our hospitals across the nation to reducing excessive and unnecessary opioid prescribing. Look, I think that that's important.

I think that in the early phases of this national overdose crisis, it's clear that, you know, that there are ecological links between rising rates of prescription opioid prescribing and rates of addiction. But we're not in that era anymore. We're in an era in which people are predominantly using heroin and fentanyl and it's deadly and we need to be there to treat addiction. And there is, you know, to be very clear, like my read of the data and the read of many others who have read the national data are that when we cut back on opioid prescriptions now in an era in which heroin and fentanyl are readily available, all we do is drive people who would otherwise use prescription opioids because they may need it for pain to then use harder substances that are more dangerous for them to use. And so I do think it's important for us to be thoughtful in our prescribing of opioids and other medications that can potentially cause problems for people, but it's not the solution to this overdose crisis. And in the meantime, we're losing a lot of a lot of people who benefit from opioids, who function better when they receive opioids be it for acute or chronic pain and we need to make sure that in our in our attempts to improve our addiction treatment that we're not we're not losing those people. They're people that we owe dignity and compassion to. I'll stop there, but I have lots more to say on this, I just don't want to hog it from my fellow panelists.

BILL KINKLE:

And this is why it's a it's a great argument for safe supply. I mean, we really do need a safe supply to the contaminated drug supply. What I see in Philly, particularly over the past two years, it's gotten worse than I have ever seen. And I think that's really why we see the numbers just going skyrocketing of deaths. It's really bad out there. And I think there is a great argument for a safe supply.

HECTOR COLON RIVERA:

Yeah, I would just add that this is not new and this is started back, I mean, has been forever to start with the war on drugs and from the 70s, then Purdue Pharmacy minimizing the risk of using opioids in the 90s, then the pain mills in the same area and, I mean, we know buprenorphine has been around for ever since the 60s, but as a pain medication, not as a treatment for opiate disorder, it was known to the 2000s and the data 2000, as Dr. Hadland mentioned, that it was it was allowed to be prescribed and in the office space for as MAT for opiate has been around forever, I mean, since the 60s and for pain management. And this is, again, part of the stigma, I think. I think that we have to start talking about this since where I

mean, educate our kids, but also is not only the fall of the provider. Yes, we have some fault, but, you know, who makes the laws? Who makes the advocacy?

Who makes who is sitting on the Senate? I mean, we is the fall of all of Australia? And that's what stigma is created. I mean, society and we need to start educating our patients, our people and society in general. I mean, we need that. All the players.

MATTHEW STEFANKO:

That's great, really helpful conversation. I'm going to transition to some of the audience questions. We got about 15 minutes left. So hopefully we'll get through as many of these as we can. One that I thought was really interesting, I'm not a health care provider myself, but I think I'm certain that the four of you will have some strong feedback to this, but one of the questions that was asked was, how do we sort of eliminate the I don't know, stigma is the right word, but sort of judgment or feelings towards providers from other providers who do provide care to those with substance use disorders? Certainly that's something we think about a lot. At Shatterproof, how can we ensure there's better medical education, more people who are getting into the addiction treatment field? I can't speak to what that might be like from your perspective.

But when you are talking to other providers, other clinicians, et cetera, what kind of feedback are you getting about the work that you're specifically doing, especially when I think Bill, you spoke to this, but when you're sort of pushing the boundaries of what compassionate care is, it should be considered? What are you what are you hearing and how do you think we can do about that?

BILL KINKLE:

I mean, I think we need a... Just an enormously comprehensive education. I think we need to really rethink and redesign from the ground up really how we do how we talk about addiction, how we treat it, how we teach about it. Just, yeah, you know, from an anti stigma thing, I mean, we've people would pretty much have been bombarded their entire lives with a negative image of a drug user through media, through television, through magazines, pretty much any way that drug users have been portrayed throughout history, it's been in a negative fashion. So I think in the back of people's minds, we're already programmed to hate this particular subset of the population. And what I mean for well over a century, the way that we treated addiction was through a, you know, a religious type of mean, you know, through prayer and penitence and that type of thing has been, you know, really I mean, when we talk about treatment, that's pretty much still the if you go into a treatment facility, most treatment places you're going to go to are going to be a 12 step based treatment thing, which ultimately is based on prayer and penitence and doing the right thing and looking at all the harms you've done to people and that's how we treat addiction still, the majority of the time. And so I think we need to reorganize and re teach how we do it. And one of the ways that I think that we one of the things that we don't do is we don't teach a good, thorough history of drug policy. And the reason because the big question for me is when we when someone comes in and we have that negative feeling about a drug user, where is that coming from? How why do we feel that way? And I think that's one of the reasons is because of we've been programmed our whole lives to hate this subset of the population.

And a lot of that comes from our policies and just the way that we look at drug users. So I think that's one way that we that we can deconstruct this. And I think we need to understand, we need to look at also, you know, right now, the one thing you hear is it's a disease, it's not a

choice. And we've created this false dichotomy that it's either or it's either a disease or it's a choice. It's only one of those two things. When it may be neither, it might not be a disease and it may be a choice. It might be something completely different. I think there's a lot of trains of thought and a lot of other ideas out there about addiction and what it is, you know. Me personally, I didn't find the disease model helpful in my recovery. I found more like Maya Solove work and (UNKNOWN) their work. I found a lot more helpful in the learning model and that you can outgrow and that addiction is more rooted in being having some type of purpose in your life that you're going towards something that makes you happy and feel fulfilled, not necessarily some genetic or some, you know, mis-function in my brain. And so I think there's just a whole big there's just a lot more to addiction than what we think. And I think we need to start teaching people more about it from an earlier age. Like right now, the education that we get in either medical school or nursing school is just it's abysmal about addiction. And I think that directly transcend to the bedside of why we do such a poor job and treating people like me. And like I said over the past year, struggling again with this disorder, I can tell you that we haven't gotten any better. It's still horrific out there and the treatment that I've received over the past year, by and large, has not been the greatest.

The only place I can say that, the only place that I go, that I feel safe and the only place through my entire drug use, the time that I had to use drugs my entire life, the only place that I felt safe, where I was treated like a human being and got good, decent scientific treatment was the Syringe Service Program in Philadelphia prevention point. That's the only place that I can go or have gone that I felt treated decently. And that's terrible that I've suffered with all kinds of illnesses and different things and refused to go to the hospital because I was I knew how I would be treated or I was terrified how I'd be treated, that I've suffered kind of in the shadows and I know hundreds of people who still suffer in the shadows and refused to go see a physician in a hospital because of how they'll be treated. And I think all that's rooted in how we're trained. So I'll leave it at that.

HECTOR COLON RIVERA:

I would just say add to what Bill said about education and medical school and residency, I mean, it was not after the spike on overdoses as in 2013 2012 between 2013 and 2016 that we started caring about, how about adding a curriculum in substance use disorders in school medical schools. We're talking about medical school, future doctors. It was not existent. I mean, Boston Medical Center, it was, it. I mean, addiction was so high, so big in our patient that we were we were there. Right. But we take it outside. I mean, would say 95% of our programs didn't have that. Before that addiction medicine was fighting to fill their positions. I mean, addiction, psychiatry there were fighting to get residents. But no one was applying. And now it became a hot topic right when it was the problem was always there. So, again, I mean, as a society, we're not doing a good job normalizing that what is real right, when we're only talking about drugs, there's behavior addiction, there's sex addiction, there's gambling. There is all the stuff that we're not talking about. And we need to know is it happens to people. It happens to good people. It happens to bad people. It happens and it can happen to you, and that's the message I wanted to be sending.

POOJA LAGISETTY:

I think I would just add, you know, I I've been fortunate to help (INAUDIBLE) some of my curriculum for the medical students here at University of Michigan. And, you know, when I started to do this, what I found was they were getting a lot of curriculum around opioid prescribing, who it actually there was just so much fear around opioid prescribing, which I think, again, was potentially furthering stigma around any opioid use that way, any patient

that would present to the hospital. And so we really tried to rethink the curriculum to be more comprehensive around pain, addiction, stigma, and also talking about some of these policies, such as the war on drugs that's come to play. And I think when we started to change the system, one, we've got to be good role models for when people are starting their medical education or their health care training so that they see examples of people doing this. And, you know, the other thing that I think has really helped us most recently, one of the things that I try to highlight to our students, too, is our students are hungry to do something. They want to make the world a better place. They're also focused on social determinants and making care more equitable and one thing that I've really tried to highlight to them now with is a lot of the national dialogue around racism, two, is that when we don't treat patients, we are essentially sending them to the criminal system. So every opportunity missed to not treat a patient and health care system is an opportunity for somebody to be treated in another system. Bill mentioned, whether that's the criminal system, whether that's like a religiously based system, but these are not evidence based systems that we know work.

And so we we've got to embrace all substance use, whether that be for pain, whether that addiction, it's not our job as health care providers to deem somebody worthy of treatment or not. We're all worthy of treatment. And so, you know, I think one of these things that we really have to kind of highlight that enroll that at an early stage in some of these medical training.

MATTHEW STEFANKO:

Right, well, we just had one more question come in. I think it's really important, so I know we only have four more minutes, but this is going to be kind of rapid fire on a topic that I'm sure we could do a full panel about, but obviously there, Bill and others have mentioned the long history of racism and ultimately how we're responding to providing treatment and I think a lot of communities of color are responding and saying, OK, great that you're now showing up for us, but you should have been showing up for us for the last 30 years. So like vaccines and so many other things, right. There's this there's this inherent distrust of not just providers, but addiction providers, I think specifically. So when you are saying, OK, now we're here to provide that care, what is that conversation like or what are some ways that we can think about genuinely reaching out with care, recognizing that? And frankly, we've dropped the ball for a really big way for decades.

BILL KINKLE:

I mean, the first step is admitting it, not pretending it's not there. I mean, particularly like I said in the beginning, there's a white male. I think it's critically important for me to acknowledge that right from the beginning and to be proactive, to be anti-racist from the very beginning. And so we don't have time. I want to leave time for the other panelists, but this is something that I talk about very, very often and I'm very, very open about this and open about the differences between how we handled crack versus opioids. And really, they're the only reason that we're having this conference right now is because white kids started dying for opioids. Otherwise, this conference would never be happening. And I think we need to admit that.

SCOTT HADLAND:

Yeah, I just would second exactly what you said, Bill, I do find myself confronting it with patients and families, often in my work with youth and working with families who have experienced addiction over generations. And the approach that we take to young people now is so different from the approach that often their parents or even in some cases grandparents

experienced when they presented to the medical or other systems with substance use disorders. And I think the most important thing we can do is say like, hey, we got this wrong for a long time. I really am here right now to try to make this right for you and for us.

BILL KINKLE:

I mean, even the focus of this whole thing, I'm pretty much always spoken about as opioids were, there are a lot of other drugs other than opioids. Pretty much all we've talked about is buprenorphine, methadone, things that are for opioids and I think that there's a lot of racism even underlying the discussion that we've just had on this panel, that we really haven't acknowledged that there are other drugs and they're a big problem and all we talk about is opioids. And I think that is a big part of the problem, too, because it's not just opioids. There's lots of other problems out there.

MATTHEW STEFANKO:

Yeah, I think Bill you see that certainly manifesting at the national level in terms of where funding is being allocated. I think we see that a lot with a lot of these even Shatterproof, like with certain stigma efforts, you know, federal dollars being expressly allocated to do opioid campaigns and not necessarily being allocated for other efforts and campaigns. So it's really interesting, you know, where we see that, where that started. Right, with prescription medications and why there's been such a laser focus there. So I am I'm going to wrap up. I think we've identified probably a dozen topics for next year's summit that we can get into in much more detail. I'm certainly thankful for all of you to join. I hope we have the opportunity to have you back next year and certainly continuing to engage in this dialogue. I know I know that Dr. Martin had a lot of perspective that he was hoping to bring and sends his regards and I think he would have a really interesting perspective on this dialogue as well, but I just want to thank all of you for digging into this. I think we know that this is very early work that requires 100 times more work than what we've even discussed today. And so I think just beginning to unpack where the problems lie and where we can get into some of the solutions is so important. So thank you all. The recordings will be available to the for those who are watching later with transcripts and all of that available. We will be taking a 15 minute break and then we'll be coming back to 2:15 for another set of three different panels. If you want to be joining 2.2, you are in exactly the right place. If you're joining either 2.3 or 2.1, I'll be sad not to not see you, but also great options as well.

And so, come back in about 15 minutes. We'll get started again with another set of panelists. Thank you to everyone who joined today and really excited to see what's next.

SESSION 1.3 - STRUCTURAL STIGMA AND HOW SYSTEMS DISCRIMINATE AND INTERSECT

AISHA SALMAN:

Hi, everyone. Welcome to session 1.3. If you are in the wrong session, you can navigate to the other sessions through the tabs at the bottom of your screen. But again, this is session 1.3, Structural Stigma and How Systems Discriminate and Intersect. I'm pleased to introduce our expert panel who will discuss various intersections and stigma drivers and their impact. The session will be moderated by Dr. Helena Hansen, professor and chair of the research team and translational social science and health equity at the David Geffen School of Medicine at the University of California, Los Angeles. Thank you so much for joining us, Dr. Hansen. I will turn it over to you to go ahead and introduce our panelists, and then we can go ahead and get started.

HELENA HANSEN:

Thank you so much, Aisha. It's really a pleasure to moderate this distinguished panel. And I'm so happy for the attention to structure, social structures. I'm a social scientist, psychiatrist, cultural anthropologist, addiction psychiatrist, and I'm constantly talking with my clinical colleagues about the fact that stigma as a concept comes from social sciences. And a sociologist, Erving Goffman was really the one to most fully theorize what stigma is and the ways that it's created and sustained by institutions, including policies, not just individual attitudes.

So it's my pleasure to open this session, which is going to focus on how stigma manifests in policies and practices and creates barriers for treatment, recovery and safe use. And so I will, without further ado, open up the panelists so that they can each give a self introduction and give some background information about how they encounter structural stigma and structures that create sustained stigma around substance use disorder in their work and in their everyday lives. We're going to begin with Sheila Vakharia, who's deputy director of the Department of Research and Academic Engagement for the Drug Policy Alliance.

To be followed by Shelly Weizman, acting director of the Addiction and Public Policy Initiative at the O'Neill Institute for National and Global Health Law. And she's an adjunct professor of law at Georgetown University. To be followed by Myra Mathis, who's senior instructor of psychiatry and addiction psychiatrist at the University of Rochester Medical Center. And then we will hear from Morgan Godvin, who is a community advocate. And much more, we'll hear much more about her background in her self introduction. So please, Sheila. Thank you.

SHEILA VAKHARIA:

So good morning and good afternoon. I'm Dr. Sheila Vakharia and I'm the deputy director of the Department of Research and Academic Engagement at the Drug Policy Alliance. For those you don't know, Drug Policy Alliance is actually a national advocacy organization that is fighting to end the war on drugs by passing drug policies founded in science, compassion, public health and human rights. My role at the organization is to help my colleagues to ensure that our advocacy agenda is grounded in the best available research and evidence. But I've had a bit of a winding path that brought me to this work and to my current position.

I actually started off about 15 years ago with my social work degree working in a traditional well established abstinence only outpatient treatment facility. I conducted a diagnostic intake

assessment, facilitated our aftercare group and was our agency representative for our community going forward. A necessary part of my job is actually spend a lot of time on the phone with referral sources like Child Protective Services, the Department of Social Services, Parole and Probation, talking about client progress and treatment and the result for urine drugs screen that I often had to observe and handle myself.

Sadly, conversations with referral sources often resulted in people losing custody of their children, being cut off from benefits and getting violated and being incarcerated. I remember wondering how or why my clients could ever trust me when I was often going behind their backs and sharing what was happening in treatment with these external parties who are very quick to punish them for what happened in treatment and for not changing fast enough or the right way. And what I've come to realize is that our drug policies had actually made me an enforcer of the drug war, even though I thought I'd signed up to be a therapist.

And, you know, fast forward a few years and I found myself better suited for working in a harm reduction setting at a syringe service program with a harm reduction approach to care. I later got my PhD, and then was able to teach future social workers about the need for a harm reduction approach to services and why we needed to end the war on drugs in order to truly liberate our clients, but also to liberate ourselves. And, you know, back to these topics, stigma and how it manifests in policies that impact people who use drugs, I think we'd be remiss if we didn't start by actually acknowledging that this month actually marks the 50th anniversary of the declaration of the war on drugs as we know it by then President Nixon.

And what we all really know is that rather than it being a war on drugs per say, it's actually a war on people who use some drugs. And particularly people who are poor and low income from communities of color and who live at a number of other margins and inner sector. I would suggest that we actually refer to stigma as something else, the legally sanctioned discrimination against people who use drugs within the context of the drug war and criminalization. In the words of Zoe Dodd, a Canadian harm reductionist and advocate, it's important to differentiate between stigma and discrimination because we need to name and understand the actual structural and systemic problems in order to change them.

And while, of course, I believe that we must engage in micro and individual level work to reduce stigma, the day to day work of health care and (INAUDIBLE), there's only so much that this stigma distinction can do and that can actually occur at this level. As long as people who use drugs are still deemed criminals in the eyes of society at large and that they're ongoing or history of drug use, actually threatens the very supports they need for full and healthy lives, including being a parent, having access to social services, getting an education, having gainful employment and having a home of their own. I believe that we cannot separate the stigma and discrimination from other systemic and institutional isms, including institutional and systemic racism, sexism, classism, homophobia, transphobia, xenophobia, ableism and so much more.

And people who use drugs and then also live at these other intersections, actually these compounded systemic and structural harms. Because their drug use identity is actually only one of their numerous boiled or marked identities. And as a side note, some people speak of framing addiction as a brain disease or as a chronic disease, as a micro and macro strategy to reduce stigma both through language and how we provide care. You know, that if people only understood that addiction with a disease and a medical issue, that somehow stigma could be reduced. And I'm sorry, but as long as addiction is actually the only so called disease that's

also a crime, I don't think we can persuasively and truly reduce stigma.

Medicalization will not save us. And people who have benefited the most from this framing are already the most privileged people who use drugs. People are often white, middle or higher income and who've avoided criminalization altogether. So in closing, while stigma reduction is a valiant and important goal for our work, it'll never achieve its aims if we don't simultaneously work and the legal discrimination disenfranchisement of people who use drugs because of prohibition. We must work to decriminalize drugs and eventually legalize and regulate them. If we truly want to remove the stigma of drug use and end the legal discrimination against people who use them.

HELENA HANSEN:

Thank you so much. Shelly Weizman?

SHELLY WEIZMAN:

Thank you and hello, everybody. I'm Shelly Weizman. I direct the Addiction and Public Policy Initiative at the O'Neill Institute for National and Global Health Law. It's a health policy think tank at Georgetown Law Center. And we work a lot at the intersection of substance use disorder, public health and the criminal legal system to advance evidence based practices. We are also launching a new Masters in addiction policy and practice at Georgetown in less than a month. We're super excited about that. And I'm a lawyer. I'm an advocate. I'm a former policymaker. Before joining Georgetown, I worked for the governor of New York on New York's addiction and mental health and a policy and operations. So I have kind of an advocacy and a government perspective. And I'm also a person in long term recovery from addiction.

So I have that kind of personal experience, lived experience overlay, which, you know, the three of these together is pretty interesting. And, you know, and thinking about and preparing for this discussion, I mean, first really thank you to all the folks that put this together. This is such an important and critical conversation. And when I think about approaching stigma and in particular structural stigma, maybe because of the areas in which I work, I think about it in two ways. One is advancing kind of large scale policy strategies that address discrimination and bring issues related to addiction, recovery, drug use out of silos and weave them into the fabric of reform efforts, the fabric of society, and not just as a boutique issue or an acute issue that we treat one and done. It's kind of the first thing.

And then the second thing I think about is, how do we get more people involved at the policymaking table? That one understand the science and evidence related to substance use and substance use disorder, addiction. And many more people with lived experience with these systems to have a meaningful role in the conversations at the table. And just to touch on a couple of things, I mean, I feel like there could be so much covered here, and I'm really looking forward to this conversation. When I think about examples of ways that how stigma and discrimination kind of manifest, I also think about how this is starting to shift.

And it's conversations like this and all the folks that are speaking at this conference and other conferences like it, people that are listening in that are really facilitating, I think, an accelerated shift towards doing things differently, really taking a hard look at what's not working, that there are a lot of things that we do as a society related to addiction that are not working. Not only they're not working, they're kind of sometimes bringing us in the wrong direction. Two brief issues to highlight, and Sheila spoke about this as well, is jail. Basically

jail and prison. The use of the criminal legal system to address addiction. And, you know, it's interesting. We don't often talk about jails and prisons and community supervision and courts in the context of a discussion about health care.

But I want to urge people to think about that differently. That the carceral settings are huge providers of health care, and the largest providers of mental health care in the country. And we can't ignore this fact and kind of pretend that incarceration and the use of incarceration as a response to substance use somehow has no impact on our health care systems or the people that seek to get help through our health care systems. Right? And, you know, in the US we have the largest, highest incarceration rate in the world. And drug possession and drug related offenses, these account for a significant portion of this. And Black Americans are disproportionately impacted in these numbers.

So, you know, I think any conversation related to substance use and health has to include the overlay of the criminal legal response because people of substance use disorders cycle in and out of prisons, jails, the court systems, the child welfare system which engages in the courts. And we know that trauma and isolation and lack of social and economic mobility, all of these are contributing causes of substance use. Which, you know, are perpetuated in these settings and in these systems. So as long as we continue to use the criminal legal system as kind of a front line solution to address substance use disorders, we're just going to continue to perpetuate these challenges.

And, you know, I have one more minute, but I want to say we don't often even provide treatment in jail. So putting the whole question aside of whether, you know, that's the right or wrong way to address this, people go to these settings and don't get treatment, don't get evidence based treatment. So a real challenge. One last thing briefly about perpetuating the shift away from stigma and discrimination in our systems is really people, champions who are working to do these reform efforts, implement these reform efforts, who understand the science, particularly in the House of Medicine and also folks who have lived this.

And it started with our stories. We heard in the last panel a lot about folks stories and the experiences we had and families members that we've lost. But I think what this has evolved into is people with lived experience and expertise really meaningfully participating in the policy conversation. And we need more of that. Representation is key. I got more done working for the governor in New York in two years than I did in 20 years of advocacy. So, you know, I think more support for that is a huge part of what's needed. So with that, I'll end. Thanks.

HELENA HANSEN:

Thank you so much. And so, Myra Mathis.

MYRA MATHIS:

Good afternoon, everyone. I should say hello, depending on where you are joining from. It may not be afternoon where you are. My name is Dr. Myra Mathis. I am a senior instructor of psychiatry and an addiction psychiatrist at the University of Rochester Medical Center. And I spend my days working in an outpatient dual diagnosis clinic and opioid treatment program where I work with patients to think about how we can utilize medications to help them with their recovery or their mental health or both.

So this is my day-to-day work and my day-to-day practice. And in the midst of seeing

patients, I'm also thinking a lot about who makes it to the doors of the treatment program and who doesn't, who continues in treatment and who has lost the contact, who is discontinued from treatment for a variety of reasons versus who is maintained in treatment. And these questions bring me to the reality that the individuals who are coming into the doors are only a subset of the population of people who use drugs and who may want to engage in treatment, and that the subset of this population is skewed. And it is skewed along racial and ethnic lines, it is skewed along gender lines, it is skewed along the lines of class.

And I spend a lot of time thinking about why that is. Why is it that I'm only seeing certain people? Why is it that I'm only able, in the current practice setting, to offer treatment to certain individuals? And that brings me to this conversation and this discussion related to structures and how they discriminate and how they intersect. And I do want to come back to the definition of stigma that Sheila mentioned when she started this panel discussion in her remarks, that it is legally sanctioned discrimination against people who use drugs, and particularly some people who use some drugs. And so in my work and personally as a Black woman, when I think about the community that I grew up in and I think about the changes that happened in that community over the '80s and '90s, and I think about the family members who were no longer present for periods of time for a variety of reasons, these reflections are what led me to choose a career in addiction psychiatry to begin with, because I wanted to be in a place where my, not just my personal experience but also my expertise and my knowledge could be used to leverage through advocacy and systems change so that the conversation related to reducing stigma did not just apply to one group of people.

But the different the different face of addiction that was being seen contemporarily in a lot of in media portrayals that wanted to use a softer tone and maybe not to be more careful about the language and the description of individuals who use drugs. I wanted to be sure that communities of color and in particular Black people were not left out of that conversation. That that same degree of compassion, that the same degree of a de-stigmatization from both an interpersonal and a structural lens would be offered to those communities as well. And so that is what I'm particularly bringing to this conversation. That's the kind of thing that I bring to my work.

I recognize that even within my clinical setting, again, these structures impact who comes to the door. But once they get in the door, the policies continue to impact the way in which we practice. And so there are a variety of levels of regulation in terms of the policies that determine how I can utilize drug medications that could save patients lives. And as I work within these settings and I think about how counselors and other clinicians are thinking about engagement with patients who come into the door, I'm always questioning why is it that we are saying someone has to, say, percent or 30 days before they can be allowed to take some medication?

Or why is it that we're saying that a patient has to have a certain number of negative urine screens before we can allow them to have access to their medication on a longer term basis. This structures and policies that have influenced the way we think about substance use come from this lens of criminalization. And that same perspective then influences the way in which patients navigate their treatment once they engage in care. And so I am cognizant of this and I often am questioning, well, why is it that we are taking a more punitive stance even within our treatment settings as we engage with patients? And when is that more punitive stance being utilized? Because often it is also being utilized along those same racial, ethnic and gender lenses that prevent individuals from being able to come to treatment to begin with. So

I look forward to the rest of this discussion, and I'm very glad that we get to think about how to disrupt these systems that discriminate against patients who use drugs.

HELENA HANSEN:

Thank you. And now, Morgan Godvin.

MORGAN GODVIN:

Good morning, everyone. It's morning over here in Portland, Oregon. I began studying for my bachelor's in public health the week I was released from federal prison, and my graduation is this weekend. I am a community advocate, a writer and a researcher at Health and Justice out at Northeastern. Here in Oregon, I serve on the Measure 110 Oversight and Accountability Council. So we're overseeing Oregon's paradigm shift in drug policy, which is drug decriminalization. I also serve on the state's Alcohol and Drug Policy Commission. So before I talk about stigma, I want to talk about blending of systems of authority.

Sometimes I sit around and I think, how many cups have I been made to pee into? So whether it was the hospital or probation or prison or treatment or my Suboxone doctor. So many humans have handed me a cup with the firm instruction of pee in this while they either watched me or hovered nearby. So in my mind, the criminal legal system, especially when I was actively using, merged with the medical system. So this became like one broad overarching system of authority. And as long as drugs are criminalized, addiction is not confined to the medical sphere. One cannot be extricated from the other.

OK, so now on to stigma. People often refer to stigma as this like amorphous abstract social phenomenon. OK, but the history of my drug use tracks with some massive changes in drug policy in Oregon. And I'm a firm believer that stigma is the direct outcropping of policy. There's very little amorphous or abstract about it. So during my first heroin overdose, and now this is long before I ever had a substance use disorder, my boyfriend called 911 to save my life, which he did. Was it stigma that inspired the police to arrest him out of our bedroom while the paramedics resuscitated me? Was it stigma that caused the police to forward a copy of that arrest report to our landlords? Was it a stigma that caused their landlords to immediately evict us? Nope, that was policy.

Specifically, that was because Oregon at the time did not have a Good Samaritan law to protect him. OK? And then that changed a few years later. Fast forward, I got arrested for felony possession. They put me into drug court. Alternatives to incarceration. Right? My very first time in jail, I was sentenced to a seven day jail detox. I thought to be re-stabilized on my buprenorphine, which I had had a prescription for. Was it stigma that caused the jail nurse to laugh in my face and tell me under no circumstances would my medication be continued? Was it stigma that caused me to detox cold turkey in jail for seven days? No, that was jail policy.

OK, but I do understand that all these policies are both causes and results of stigma, OK? But the effect of policy on stigma cannot be excised. When I was 24 years old and hopelessly addicted to heroin, I middle mount a gram of heroin to my best friend Justin. Later that night, he overdosed and died alone in his apartment. The next day my apartment was raided. They called me a drug dealer, a stigmatizing term to be sure, and arrested me for delivery resulting in death for my best friend's accidental overdose. I could have got the mandatory minimum sentence of 20 years in prison. And if I were a person of color, I would still be in prison today. But I'm not.

I was released from prisons custody two years ago, right as the Measure 110 campaign was kicking off. Informed by my life experiences, I volunteered immediately, obviously, because criminalization is stigmatization. I know this because I lived it. And during the campaign, so perplexing, I watched many of the people who were advocating against Measure 110, against drug decriminalization. These were the same people that were talking about reducing stigma in this nebulous way, like, oh, we need to reduce stigma, but we will not decriminalize it because that is encouraging drug use. How disingenuous is that?

Society cannot condone de jure stigmatization on one hand and then reduce some abstract notion of stigma on the other. They are one in the same. But drug decriminalization passed. So now we're in the critical implementation phase. I'm on the Oversight and Accountability Council. I'm one of a handful of people there who operate on the philosophy of harm reduction. And I let all of my past experiences inform my current policy advocacy. I'm attempting to dismantle stigma by dismantling the policies that produced it. I do not think it's as abstract as they make it sound. Thank you.

HELENA HANSEN:

Thank you. Wow, what a really powerful statement from all of the panelists. But a very, very good place to hop off into the questions for this panel. And I have many. I see there are some coming up in the Q&A. But just to start, I wanted to revisit the larger picture of structural stigma, which may be a new way of thinking of stigma for some of our audience members. Because this is the United States of America, it's about the individual, right? It's about individual acts, individual attitudes, and we forget that individuals are very shaped and constrained by the institutions and policies that they're in. And each of the panelists has powerfully commented on that.

And so I want to start off by asking, what does the concept of stigma allude to different forms of discrimination that each of you and power and inequalities, the way that they're enacted. Each of you has commented on what does the concept of stigma, the way that we tend to use it and think of it in the United States and in drug treatment, drug policy circles, what does it highlight for us usefully, what does it hide? And to go along with that, the difference between stigma and discrimination, if there is any. And whether you think stigma functions as a determinant of health, whether and how stigma is itself a determinant of health. So on that note, I wonder who of the panelists would like to hop in? Feel free.

MYRA MATHIS:

There are many places to jump into the conversation here, but I think I would start by addressing possibly what stigma hides. And I think the larger conversation on stigma, as we discussed earlier, what it hides is the fact that the structurally marginalized identities of individuals who may not benefit from de-stigmatization. We talk more broadly about stigma as if it is equally applied to groups and individuals in the same way, but it is not. And de-stigmatization is not equally applied to groups and individuals in the same way as well. And so when we only discuss stigma in a broad sense, we are not addressing the structural marginalization of people of color, of gender minorities, the LGBTQI community and other groups and individuals who may not be as close to what society broadly thinks of as the norm.

HELENA HANSEN:

Thank you. Would anyone else like to jump in?

SHELLY WEIZMAN:

I'll jump in quickly. I think there's a kind of, sometimes a narrow approach to thinking about how to address stigma. I know I've been in rooms where there's a desire to do some anti stigma work or an anti stigma campaign, and the first suggestion is always a public information campaign. And I think, you know, taking a much broader approach that really seeks to identify what are this? Kind of getting down into it like looking under the hood. What are the specifics? And Morgan talked about this, you know, the kind of specifics of how this kind of stigma and discrimination drive in a cycle, and how does that manifest on an operational level? And what are the kind of systems and policy levers that enable that to happen, and could change that?

And I think we see it often, I mean, a great example is in the insurance and health care access context, right? And I'm talking about Medicaid, about commercial insurance, a lot of policies that have been implemented over the years that perpetuate barriers and challenges to care, regulatory structures like Dr. Mathis talked about, hoops that people have to jump through and really getting down to it and identifying what the what is and dismantling that step by step.

And I think we've seen some of that over the last few years, for example, with COVID and a relaxation of certain rules related to access to treatment and medication. And, you know, from my perspective, more of that, you know, more really kind of digging in and identifying what's blocking people from getting what they need when they need it. And what are these kind of structural barriers, and then meaningfully addressing them.

HELENA HANSEN:

Thank you. Yeah, I love that you're highlighting structural barriers. and I'm wondering, Sheila, if you wouldn't mind me calling on you because you brought up the idea of addiction as a brain disease, which I know from my clinical colleagues, is really an attempt to try to de-stigmatize by medicalizing addiction. But you alluded to some limitations of that approach. And I wonder if you could comment on that a little further and maybe even comment on social determinants as an approach, how that relates to stigma in your mind?

SHEILA VAKHARIA:

Sure. Thank you for the invitation after me making a very controversial statement, which will probably get me, if it hasn't already, gets me a lot of slack. Here's the thing. I think when we talk about stigma, we still talk about it as a feeling. Like it's a feeling, it's a negative feeling. It's one that we should be changing. And if you knew they were people, too, you would care about them. And, you know, and as Myra said and even as I said in my opening remarks, you know, like the intersectionality of people's identities and the fact that we know as a society, you know, we don't hear Black patients pain. We don't think they feel pain the same way that white patients do. We don't look at low income people and validate their need for health care. We think they need to get off drugs first before we can engage them in services.

So, like, I just wanted to kind of like reference back a little bit to this idea that what does stigma hide or like what does it reveal? It hides the fact that it's systemic and structural. But OK, so back to the brain disease question, though. You cannot just situate someone's experience or choice to engage in any behavior as being solely driven by the brain. And I think the biomedicalization, the individualization, and then making it about what's happening in your brain, actually, again, it kind of absolves our social and structural factors, which

makes some people's drug use more risky than others. And it actually creates a category of like pathologizing the vast majority of people who use drugs who actually don't have a problem, and who use it socially and recreationally.

So when we medicalise, we're also still medicalising in a way that is respectable, that almost says now like, you know, the ones who have a problem, you know, it's a brain disease. They need help. They need services. They don't know what they're doing. They've been hijacked by these drugs. And so it's still also feeds into a puritanical belief that we can still criminalize drugs because we need to criminalize drugs, because as soon as someone takes the drug, they cannot just engage in occasional recreational use. It's feeding to this idea that drugs hijack your brain, and that somehow you succumb to the reinforcing nature of a drug rather than the fact that drug use happens within the context of a human being, the human being's life and life circumstances.

Every time you choose to use a drug, you are choosing to use a drug because it serves some sort of function or has some sort of meaning in your life. To numb pain, to make a fun time even more fun, to deal with anxiety or depression that isn't adequately treated, to suppress and dissociate parts of yourself that you can't actually manage day-to-day and that you need to in order to survive, able to use drugs to manage. And so I think the medicalization of addiction actually perpetuates a lot of false narratives about drugs and drug use and who uses them.

It creates a hierarchy of respectable drug user, of respectable drug use versus not. And it does nothing to talk about the systemic and structural factors that make anyone's drug use dangerous, namely the fact that we have an unregulated drug supply that can kill a recreational user in the same way that could kill someone who shoots several times a day or who smokes several times a day. And so, again, we can't limit ourselves to these things. And I feel like there's more hazards than that.

HELENA HANSEN:

Thank you very much. Beautifully said. And I wondered, could I pivot Morgan to you because you spoke so powerfully about how policies create stigma. And you focused on criminal legal system and the fact that drug use is criminalized, certain kinds of drug use and certain kinds of drug users more than others. And I wonder if, in addition, expanding on that, there are other areas of policy besides explicit drug policy that come to mind when you're thinking about how policies create stigma, which could be a surprise for a lot of people on this call.

You know, often we think about stigmas individual attitudes that might add up to a policy change of some kind because of popular support. But, you know, I think it's really intriguing you're saying it goes the other way, the way that you have encountered it. So other types of policies besides the obvious explicit drug policies that you already mentioned.

MORGAN GODVIN:

Yeah, I mean, little things. And I had cut this for my introductory because I was running long. So like the very first time I went to detox and they made you wait 24 hours from admission to be first dosed with buprenorphine. I had last used the day before, and so I was sick upon intake. It didn't matter because the default assumption is that you are lying, and if I dose you with buprenorphine now, you will go into precipitated withdrawal. And so they made me wait until 24 hours, you know. By the time they finally chose to dose me, I was

vomiting so violently that the Zofran couldn't keep it down. I couldn't keep it under my tongue. And then they capped out the ceiling dose without knowing how much I had absorbed. So I MA-ed out. I was so terribly under medicated and sick. And so that is a policy. Right?

But then it looks, oh, there's the junkie who's leaving treatment early against medical advice to go score. And so that is perpetuating stigma on one level of the health care providers that I was interacting with, but again, that was a result of policy. OK? And so another time, you know, I was doing it at Home Detox because I never went back to detox after my terrible experiences and I would just do it at home because I didn't want to be under medicated and I could medicate myself.

And I was so dehydrated on like day five or six that I was fainting, my blood pressure was so low and I couldn't keep fluids down. So I went to the ED for IV fluids. And the nurse drug test me, and while she's out of the room, she comes back in and then immediately accuses me of injecting heroin while she was out. Why? I'm in active withdrawal. I'm withdrawing. And that was such a terrible experience that I left and never went back to that hospital.

Now, why did she do that? Was it policy? Was it stigma? Was it somewhere in between? The overlap, I think so often stigma is the result of policy. It is not the cause. But the interplay is just we just can't break up these things. But right, stigmas is abstract. OK, if I go to my friend who's still using and I say hi, I want to make your life better, I'm going to work on stigma, he's going to look at me like I'm crazy. He's like, I can't find a Suboxone doctor that takes my insurance. I can't get housing because I have a felony for possession.

What is stigma? I have tangible means. But yes, I am just a firm believer that the interplay is so strong, and it's not as abstract. Stigma is a tangible thing. There are written policies and laws and they're not always explicit. I mean, especially in health care. They're much more subtle. It's not, you know, in the criminal legal system we're clearly prohibiting drug use. You're going to jail if you have a positive (UNKNOWN) blah, blah. But in the health care system, the policies are a little more insidious. And I mean, god, how many cups do I need to pee in for y'all?

HELENA HANSEN:

Thank you so much. And on that note, I'm seeing Myra Mathis nod a lot. And given that she spoke so powerfully about the changes she saw in Black communities and the ways that different structures intersect, I wonder if you'd like to comment also on intersecting structures. Which structures have you encountered? How do they intersect, and especially in their impact on people of color who use drugs.

MYRA MATHIS:

Yeah. Thank you for that, Helena. I'm nodding because I agree the policies in health care are nebulous, right? And you don't really know where they're coming from, who has decided that they are a policy. So and of course, things vary from state to state. They vary from program to program. And as a patient, as someone who is trying to navigate treatment, you are completely lost because you don't know what policy you're going to encounter when you walk in the door of one treatment program or another. And so I just wanted to address that and Morgan's comments, because I find that even as a physician, as someone who is practicing, if I'm practicing in a different setting, I am thrown by the various policies and regulation.

I want to be, I want to implement harm reduction principles in a particular treatment setting and I am told by an administrator somewhere that there is a rule that prevents me from doing x, y or z in a clinical setting. And you're right, it is this interplay between stigma and policy that this stigmatizing beliefs about people who use drugs cause us to implement measures where we are looking at only the worst possible part of someone's behavior. That we have stigmatized people who use drugs to such a degree that we are assuming that they are being untruthful. We are assuming that they are engaging in some sort of nefarious behavior. And this is a result of criminalization and only seeing people who use drugs through a criminal lens.

So I'll just pause there and I'll come back to Helena's question in terms of communities of color and intersecting systems, in particular for Black individuals. And this is a little bit my personal journey, even in deciding to become a psychiatrist, right? So you go through medical school and you figure out what you're going to do with your life. And I wasn't sure what I wanted to do. And when I decided to become a psychiatrist, I framed even the stigma related to mental health within communities of color as stigma, right? I thought, wow, we really need to get our depression treated. We really need to get our anxiety treated. We really need to get our trauma related symptoms treated. And I wonder why people are so hesitant to go and see a counselor or see a therapist. I wonder why people are so hesitant to go and see a psychiatrist.

And then I started working in these systems and I realized it is not necessarily the stigmatizing beliefs of those individuals that keep them from engaging in treatment. It is the structural barriers. It is the bias and racism that they encounter if they overcome those structural barriers. Right? And this is particularly important for communities of color and poor communities of color. As we mentioned, health care, access, insurance. Access is not just insurance, right? Insurance is coverage. Insurance is who is paying for it. But there are so many other things that are included in that banner of access. There is coverage. There is accessibility. Where is the treatment facility? We mentioned that there wasn't a Suboxone doctor available.

If there is a treatment facility, is it anywhere where I can get to that? Can I even get to the treatment facility in terms of transportation? Once I get there if I'm able to and if I have coverage, will I have timely access to the services that I need? In healthcare and particularly in substance use treatment programs, there are so many protocols. You have an intake, you have a locator, you have x, y or z steps before you even get to an appointment where you're seeing someone for treatment, and that may be a counselor. And then you have another few more steps before you can see a prescriber. All of these structural barriers, certainly they happen for everyone. But the compounding effect on communities of color that are structurally marginalized, is even that more increased.

And if they overcome all of those things, who needs them when they finally get into the room? Is this a person who is going to be compassionate? Is this a person who is going to have a culturally responsive approach to their treatment? Is this a person who is going to have a structurally competent response to their treatment? All of these things impact the way people of color engage in treatment particularly for substance use, as well as other aspects of healthcare. But given the structural impact of criminalization, it is that even more compounded for substance use disorders.

HELENA HANSEN:

Thank you so much. So clarifying. And I'm looking at the time and there's an active question and answer box, and so I wonder if we could devote the last, what is it, seven minutes to responding to basically a number of different forms of the question from the audience of how can we effectively intervene on these discriminatory structures, these stigmatizing structures, and they mention combating criminalization. They also talk about Black and brown communities and the structural forms of discrimination, structural racism that impact them.

So I wonder if maybe I could call on Shelly Weizman first, because, Shelly, you mentioned that you felt you've gotten further in working for the governor's office, much further there in a few short months than you'd gotten in years of advocacy as a person with lived experience. And I wonder if you could talk about just very concretely, what are the ways that we can as health care providers, as clinical researchers, as primarily people working in clinical spaces, but perhaps in other kinds of spaces as well, that we can work at structural levels to combat stigma?

SHELLY WEIZMAN:

It's a great question. And I think, you know, the key is, and you just said it, is to get down to specifics. I think there are a lot of, I hear often, you know, we need to access to evidence based treatment, racial equity, but what does that actually mean day-to-day? How do you legislate that? How do you implement policies in a hospital ED that advances that? And so I think, you know, one real key is getting down to the specifics, having a real and focused, today's panel gave dozens of them. And I actually don't hear that very often, you know, kind of real nitty gritty.

I mean, I was talking to a provider the other day who was asking about a policy that that said something like if somebody relapses, you can't come back to detox without waiting 30 days. It's not a policy. It's a belief. It's the way things maybe have always been done. It's written nowhere. And there are probably hundreds of examples of that. Or things that are written down and how do they manifest in kind of day-to-day.

And so, you know, I think having a real concrete understanding of what are we asking to change and rallying around that. And I think it could take a number of forms. I'll say this now and even more strongly after working in government than before. The combination of litigation plus press shame to advance any kind of reform, there's nothing like it. Like that is the one two punch. And really understanding and raising awareness around what are the specifics that we want to see shifted. And we talk about kind of stigma discrimination. Discrimination often is a legal term. What kind of discrimination are we talking about? Americans with Disabilities Act. Are we talking about something else? And kind of connecting those dots.

And I think that's why what we've seen over the past few years is a real culmination of an interdisciplinary approach to advocacy, where you have the medical community, the research community, the legal community, advocates, people who've lived these systems, everyone kind of working in collaboration. That's where I think we've seen the most shift. And you asked about research. You know, one real plug I wanted to make was there's some amazing research going on out there. Is there a plan to translate it into actionable policy or is it something that's published behind a paywall that only a few people ever see?

So I urge folks who are doing this, who are collecting data, doing research in this area, think

from the front end, how is this able to be translated into actionable policy? Include people with lived experience of the thing that you're studying on the front end and all the way through to show alright, what are we going to do with this information? And that's what we need. We need all hands on deck.

SHEILA VAKHARIA:

I was wondering if I could jump in here for a second and just also add the qualification that while we see people with lived experience, we don't just mean people in recovery. And we mean people who are currently actively engaging in drug use, who are having to navigate these systems every day, who know they're called frequent flyers, who know that they're not believed, who deal with these actual policies on a day-to-day basis, and can tell us, you know, do I want them to feel better about me or do I want them to do x, y and z every time I come in so that I know I can leave and I have the help that I got, you know, the treatment that I wanted, right?

Because when you ask people who use drugs like they already know they've been stigmatized, they already know what people say about them, and many of them have sadly also internalized a lot of those feelings themselves, right? And so it's less about changing how people feel, and it's actually changing the policies that affect them and the behaviors and the access, right? And also to incorporate people who use drugs, not only in evaluating services and providing recommendations, you can all hire an advisory board and fund them and pay them. If people who use drugs stipends to tell you how programs are failing them, and then to help you evaluate whether they're working, right?

So bring them on board, have them have them in positions where they can actually evaluate things, and then pay them for their time and their value and their expertise. And just like many of us, I use my paycheck to buy alcohol. So getting caught up on whether someone's using their paycheck or the stipend that they're receiving to use drugs, is a bit hypocritical and doesn't acknowledge to the fact that, you know, we want people to feel validated for their expertise. And a lot of times the debit card, if you don't have a chip reader, I recently got a card for participating in a study, it didn't have a chip on it. I couldn't use it anywhere. You think about mailing checks to people, they can't use it. Give them cash in their hands. Right? And when we talk about research on stigma, we need people who use drugs to be part of our research teams, developing our research agendas, evaluating our findings, actually helping with data collection and analysis and interpretation. But we need to invite them as co-presenters on that research as well. And they need to be compensated for that. Because, again, stigma is more than just a feeling.

MYRA MATHIS:

I see that we are just out of time.

HELENA HANSEN:

Oh, yes. Please, please jump in with closing thoughts.

MYRA MATHIS:

The last I will say is that as we're thinking about these positive policy initiatives that we're putting forward; we need to remember those who are at the margins. Often policies help a certain demographic and they don't raise everyone up. So if you are advocating and you do not have people of color at your table, make sure you have them at your table. If you do not

have individuals from the LGBTQI community, make sure they're at your table. And make sure that their experiences are also included in the policies that we are shaping.

SESSION 2.1 - THE ROLE OF ADVOCATES AND FAMILIES

RICHARD BOTTNER:

This is Session 2.1, The Role of Advocates and Families. We're joined today by our moderator, Dr. Jennifer Potter, who is the Associate Vice President for South Texas Public Health initiatives, Vice Dean for Research, Office of the Dean, Professor of Psychiatry and Behavioral Sciences at UT Health San Antonio, the Joe R and Teresa Long School of Medicine.

Our panelists are Leslie McBain, co-founder of Moms Stop the Harm, Dinah Ortiz, vice chair of North Carolina Urban Survivors Union and a leadership team member of the Urban Survivors Union as well as an author, public speaker and independent consultant, and Ryan Hampton, founder of the Voices Project and speaker, author and advocate. Thank you all for being here. Dr. Potter, take it away.

JENNIFER POTTER:

Thanks so much, Dr. Bottner - and Rich. I'm honored to be here moderating this panel and I'm going to hand it over very quickly to the speakers that you're here to hear. But I want to thank the organizers for their efforts in bringing us together to discuss stigma.

So, I think I'm here in two capacities. The first is that I am, in my day job, the director of a program called the Texas Medication for Opioid Use Disorder initiative. We are a program funded by Texas Health and Human Services to expand compassionate, evidence-based treatment for opioid use disorder throughout Texas and we also provide training and technical assistance to programs. We have a suite of recovery support services and a lot of other programs working on this issue. And I'm delighted to be working on expanding that to substance use disorder more broadly.

But I think the reason I was invited to moderate this panel was that my life intersects in a couple of ways with some of the issues that you're going to be hearing about today. I am the daughter and parent of people who use substances and people in recovery. And during the course of their substance use, it became increasingly clear that stigma threatened their lives and how little, little, little I knew, even as a professional who works in the field, about people who use drugs and people in recovery, and the importance of advocating for the issues that you're going to be hearing about today. And it was a terrifying, humbling process.

I'm grateful to all of the advocates and people who use drugs and people in recovery who have taught me so much, who continue to teach a lot to me. And they're real champions for bringing these topics into the public sphere so that we can talk more openly about these issues and address the very serious issues we have in the United States with stigma on addiction.

So, without further ado, I'm going to introduce our first speaker. Our run of show is that each of these individuals will be talking for ten minutes from their view and perspective. And then we'll come back together. We'll have a moderated discussion amongst the three of them. And then we'll have some time for questions and answers from the panel for our audience. So, I am delighted to introduce Leslie McBain.

LESLIE MCBAIN:

Thank you, Jennifer. I'm sure that this has been pointed out at this conference many times already but the word stigma came from the same Latin root as the word stick, as in making a

mark with a stick - so, a marked person. And I'm sure that back in ancient times and not-so-ancient times, the person was marked with a stick because they - the community or the tribe - perceived the person as dangerous or too different to include. So, I think stigma exists today for a reason, that there's a direct thread from ancient times to now. And it makes me ask the question, have we actually evolved? In many respects, we have not.

My story is my son Jordan's story. He died from a prescription drug overdose at the age of 25 in 2014. He was my only child. The short story is this. In late teenage years, he was what he called over-partying, what I called problematic substance use. I don't know when the partying intersected with addiction but it did. It was sort of a black box at some point.

But when he was 23 years old, he was working on a construction site and he had a back injury. We live in a small community, so he went to our family doctor because he was in pain and the doctor prescribed - well, we call it oxycodone, OxyContin essentially, for Jordan's pain and didn't treat the injury in any other way. So, the doctor continued to prescribe oxycodone without treating the issue for seven months in ever-increasing amounts until Jordan was so addicted, he was barely functioning in terms of his work and his relationships and so on.

Jordan came to me and said, "Mom, will you come with me to the doctor? Because I'm scared, I need help. This is not good for me." And so, we went to the doctor and the doctor's reaction to Jordan's confession that he was addicted was to become enraged. And he became disrespectful. He said horrible things to Jordan, one of which was, "Well, I guess the fanatic's lips are moving. He's lying." That was one line I remember. And when I tried to intervene and say, "Hey, we came here for help." He said, "Hey, I don't need a social worker in here."

So, that was pretty bad. And at the end of that appointment, the doctor fired Jordan as a patient. He said, "Get out of here. I never want to see you again." With a concerted effort, we got Jordan into a detox facility where he stayed for about the usual 12 days. He came out clean of the drug, but still with the basics of addiction in his head and in his body as well. He relapsed. He then did some pretty successful drug-seeking behavior. He went to walk-in clinics and doctors prescribed him a compendium of drugs, in particular, hydromorphone, Xanax, Citalopram - I'm missing a couple here.

But he got on one benzo, which was probably the straw that broke the camel's back. One day he took each of those drugs in the therapeutic amount, which is whatever it was prescribed, one or two tablets or pills. And the combination stopped his heart. He was alone in his apartment listening to music, had his headphones on. So, his death probably wasn't agonizing. It was probably quite peaceful. And I do take some comfort in that.

So, do I blame the doctor? Yes, I do, in part. If he had been able to approach Jordan's issue with some compassion, with some information, instead of coming from a place of stigma and fear and ignorance, he could have helped Jordan. And I think that was a moment wherein Jordan might still be with me today. But who knows? We don't know that.

So, that was stigma with the capital S. And that's what eventually drove me into activism and advocacy. The group that I co-founded with two other women who had similarly lost their sons to drug harms is called Moms Stop the Harm. We initially gathered because we want to advocate for better, evidence-based, compassionate drug policies that support the lives of people who use drugs. We started with three of us. We have about 2,300 members now

across Canada and about a thousand of those are in my home province of British Columbia. We have evolved into support, as well as advocacy.

So, what do we see and what have we learned on this journey? Families face isolation, whether their child or their loved one is in problematic drug use now or has died. If a child has died, we experience people saying such things as, "Maybe it was for the best." Or, "He's in a better place." Or, "It was in God's plan." Things that only tear apart whatever heart you have left.

So, yeah, families experience isolation. Other family members often step back, not wanting to be associated with someone with a drug problem. Often, friends and family are fearful of the subject. They don't feel comfortable engaging in the conversation. And often, others just judge the family. Where did the parents go wrong? Why couldn't they control that kid? Or where were they when their girl was out in the middle of the night? You know, moms and dads carry enough guilt, enough anxiety, enough stress without the judgment of those who do not see inside a family dynamic. And so, the support families desperately need, the support they've counted on before - maybe before addiction happened - and thought they had, has been diminished. This is not always true but it's too often true.

The media also makes it difficult for families to rid themselves of the ugliness of stigma. Images of homeless people injecting drugs in alleys, people who have fallen on dire circumstances with severe mental illness, trauma, racism, poverty, do not represent all people who use illegal substances or are addicted. So, this makes it difficult for all groups across the board.

At conferences and webinars and in the media, we show photographs of our kids, our gone kids, who are generally white and middle-class. We didn't design our organization that way, excuse me, but we find that often, other cultural groups have even greater stigma within their cultures and communities, and don't want to out themselves. They may know about us, but they don't join.

We learned quickly in our organization that we needed to provide some kind of real support for families in grief, telling them no matter what, they can survive this. I don't know how many times I've said that, particularly to moms, "You will survive this." Because people do feel like taking their own lives sometimes, after the loss of their child. And we don't pull any punches. We tell the truth, that this grief will last a lifetime, but that we can go on in this new reality. We can soften the pain over time. And we may even find joy again.

So, we have two types of groups, Healing Hearts for those people in grief and Holding Hope for those people with a loved one still struggling with their substance use. We learned that this kind of support inspires advocacy. It makes people feel stronger. It makes people connect with others that have had the same experience. And somehow, they lose their fear of speaking out.

What we're doing to create more room for diversity is - and this is new, so we don't know if this project is actually going to work, but we have engaged people from our First Nations community and from the Punjabi community in our area to rewrite our training manuals for the people who facilitate the groups - who are peers, by the way - so that they might be able to start support groups in their communities that work for those communities in a culturally sensitive way. Like I say, we don't know if this is going to succeed, but it is worth trying.

We encourage people who have lost a loved one to write an obituary that includes the cause of the person's death. If it is a - sorry, I lost my place. If it is a death from drug harms, saying so may start a conversation. And more importantly, it may relieve the family from the burden of not telling the truth for years to come. In fact, the story that happened about six months ago is we saw an obituary in a newspaper in Saskatchewan, and it was a decade after this couple had lost their son, and they wanted to correct the record. And they said we didn't say back then what happened to our son but we want to say it now. And they brought it right into the public. And it was such a courageous thing to do. I mean, it wasn't somebody we'd talked to. They just knew they couldn't carry that burden any longer.

We give webinars and workshops on how to talk to friends, neighbors and families, on how to frame addiction - evidence-based and from the heart and our actual, real stories. And for people who have their loved ones still with them and in substance use, we provide not only support and information, but we try to find the scant resources available for their for their loved one in our community.

JENNIFER POTTER:

I'm so sorry. I want to continue, but maybe a final thought? I want to make sure - ten minutes goes fast, doesn't it?

LESLIE MCBAIN:

It's OK. I thought I had timed this. I guess what I want to say finally is that more people are dying in Canada from toxic, black market drugs than ever. We are advocating strongly for a safe, legal, regulated supply of drugs for people who need them. But many governments are throwing all their dollars into treatment facilities. And this is well and good, but it is not going to stop the deaths. Ultimately, that stigma is at the bottom of politicians and people in power, the root of their decision making. And, you know, shame and blame may work. So, we will use whatever is at our means. I could go all political but I guess I don't have any more time. Thank you so much for your attention.

JENNIFER POTTER:

Thanks so much, Leslie. Please take those thoughts and put them together and we'll loop back to them in the discussion. Thank you so much for sharing your story. It's a pleasure to meet a fellow Canadian. Dinah Ortiz, you're up next.

DINAH ORTIZ:

Wow, Leslie, thank you so much for that amazing story. And I really identify with parts of it and sorry for your loss. When you spoke about going to the doctor with your son, it brought me back to when I was pregnant with my daughter, who was actually stolen from me by the child - quote, unquote - protective system, and convinced my siblings to pretty much take her and adopt her while I was in prison. But I remember that I was afraid to go to the doctor. So, I spoke to the street doctors, the people that I had a camaraderie with, the people that had the answers that had been through it before. And what they told me was - this was 18 years ago. And what they told me was, you should get on methadone. Your baby will be born safe. It's a safe drug to use, and it's a very oversaw, weaning process, that she is sure to be taken care of.

And so, I did just that. I stopped using drugs and I went and got on methadone. And that's when I went in to see my OBGYN. It was an older white man and I'll never forget - crystal-clear blue eyes, gray hair, white jacket, just kind of stood out and stays out in my mind. And I

was so proud of myself that I had gotten on methadone, and that I had stopped using heroin because to me, that was going to kill my baby. And of course, I was very uninformed back then.

And when I went and I explained to him that I had stopped using heroin and that I had enrolled into a methadone program - there was a lobby full of people. This was in Florida. So, back then, there weren't a lot of people of color back in Florida. And so, I was probably his only Black patient. And he screamed at me and the whole lobby could hear it. I swore that the building shook. And he basically scolded me and told me that my best bet was to go back on heroin because I was just supplementing one drug for the other and that I was doing the same damage to my child.

At this point, he stormed out of the office and I just left. I was left with all of these emotions and feelings, thinking that I had done the right thing, but clearly I hadn't because the doctors know best. And that I shouldn't have listened to the people that I listened to. And tears were coming down that I could not stop. I could not hide. And I walked out, defeated.

And so, I stopped everything. I stopped methadone. I stopped everything. And what happened was that I ended up going into labor and ended up having to have a C-section. And on the labor table, I remember that they were giving me all of these, you know, the epidural and all of the things to prepare me. But what I was going through the most was withdrawals, because I had stopped cold turkey. And the methadone, it had been over 48 hours since it was in my system and I hadn't done anything prior to getting on that steel labor table.

My former sister-in-law had offered me a Xanax and she was like, it could just take off the edge. And so, basically my daughter was born with Xanax in her system that was not prescribed to me. And that's why she was taken from me. But the entire time that they were cutting me open, I felt every cut. I felt every slice. I felt them pulling my baby out of me. None of the drugs that they gave me worked.

And it was the worst experience, what was supposed to be the happiest day of my life, because I have three sons and I so wanted my daughter. And what was supposed to be the happiest day of my life turned out to be the worst day of my life. And knowing that a couple of weeks later, I would have to turn myself into prison, I would not be able to bond with my daughter. I wasn't able to be left alone with my daughter. I wasn't able to hold her by myself. I was not - like, I had eyes on me from every angle. And so, I was never able to bond with my daughter the way that I wanted to.

The nine months that I spent picking out her name, only for her adoptive parents to then go to court and change her name completely and erase me from her life, and never tell her that she was adopted, was just too much for me to bear.

So, I did my time in prison and I left the state of Florida and I came to New York. And by this time, I was homeless. I had no support. I had my boys with me and I did not want to look back at Florida. I didn't want to look back at the family members that stabbed me in the back, that stole my daughter. I didn't want to look back at any of that. And so, I moved to New York and I came straight into the shelter system.

This was back in 2007. And I was married to this man that was on heroin and using heroin, as I was trying to get my life together and be a mother or the mother that they say you're

supposed to be to your children, right, which is no substances, abstinence only. Nobody had ever asked me why I began using substances. And I realized that throughout all the therapists that I've seen and all the people that I spoke with, nobody ever wondered or asked me why. And the truth of the matter was that it was trauma. It was me losing my mother, who I was very close to, at the age of 13. My father did not have a good relationship with me. He favored my older sister. And I was the youngest of nine siblings, five brothers and three sisters.

So, I left my home at the age of 16 and kind of just grew up in the streets. And so, I ended up marrying someone who was using drugs and he would hide it from me. Eventually I found out about it and the cycle just continued.

And I tried the 12-step programs. I tried all of these programs, but none of them worked for me. For me, the 12-step program, I remember that, one, it was all about the time under your belt, and it was all about, oh, I've gone 30 years clean, quote-unquote, and I've gone 25 years clean. And if you so much as drink a beer, you had to start all over again. And I was like, well, beer's not even my drug of choice. I don't really even like alcohol so much. So, it would drive me to test myself. And I would keep a case of beer in my refrigerator to test myself, even though I knew that that wasn't even my drug of choice. And eventually I just kind of saw through all the bullshit. When one of the married sponsors tried to assault me, I knew that I had to leave and I knew that that wasn't for me.

And so, in New York, what I found was a community of harm reductionists that embraced me and created a safe space for me and accepted me for who I was and met me where I was. And it was this feeling that I was just overwhelmed with the empathy and compassion that I was shown, that I knew that I found my place. I knew that harm reduction was where I needed to be and where I needed to continue to stay close to my community and continue to get involved on different committees - the Senate Opioid Task Force Committee, many other committees, just bringing the information from the community to these policymakers that were sticking to draconian policies, that were stigmatizing us more and more, and keeping us more oppressed.

And I just wanted to have my ear to the ground and stay close to my community and represent those that are the most marginalized, which are Black and Brown mothers who are afraid to come forward, because they will lose everything. They will lose their children. They will lose their families. They will end up in prison and they will have to end up starting all over again with the stigma that they are drug users or drug sellers.

And so, the advice that I give to people now is that go by the science - you know, MATs work, right? And there's a difference between chaotic use and functional use. And that doesn't mean that people are irredeemable. That means that people are in different places in their lives. And all 12-step programs are not for everyone and abstinence is not for everyone. Everybody has their vices. It does not mean that we shut them out. It means that we embrace people and we treat them with compassion and with empathy, and that we hire them and we employ them. It's not our business what substance they use or what they put in their bodies. It's our business how good they produce the work that they're in.

And so, it's just all-encompassing that we treat drug users as human beings and that we stop stigmatizing people. And that includes harm reduction organizations that speak the talk - they talk the talk, but they don't walk the walk - that will have you apply, but have you take a

urine test before you apply. But yet, they call themselves harm reductionists and harm reduction organizations.

I've learned so much throughout the many years that I've been doing harm reduction work. And the most important thing is that I keep my ear to the ground. I keep spreading the knowledge that I have. I keep listening to my community and what their needs are. That's most important to me. And letting my ego take a seat and knowing that this is not about me, but it's about saving lives. And we have lost way too many lives because people are not willing to listen.

And most importantly, that the drug war is a war on people. And it's a war on the most marginalized and the most stigmatized. It was treated differently when affluent, white people were experiencing and being impacted by losing family members and losing their children and all of that. And so, we're no different. We bleed the same color blood. And so, it's about treating all of us the same, and being able to employ us and being able to give us that opportunity to show that substance use is just a small part of our entire lives. We're mothers. We're fathers. We're professionals. We're advocates. We're activists. And we have so many more qualities. And so you can't really tell what type of person I am by the piss that I put in a cup.

JENNIFER POTTER:

Thank you, Dinah. That's a (CHUCKLES) great way to end. I keep thinking of what you said about nine months, picking out your baby's name. And it's a really good example of why we need to hear voices like yours, as we're talking about these issues with a national platform. Thank you. Ryan Hampton, you're up, about ten minutes.

RYAN HAMPTON:

Thank you, Jennifer. Dinah, thank you for that. And Leslie, thank you very much. My name is Ryan Hampton. I'm an author, advocate, community member. I'm a fiancé. I got engaged to a man that I am deeply in love with and can't wait to get married soon. I'm a brother. I'm a son. I'm a dog lover. I'm also someone in recovery from a ten-year - for me, chaotic use, heroin use. And I now am living in recovery.

I was listening to Dinah and I was getting fired up, right? Because I truly believe and I want to thank you for your work in the Urban Survivors Union, because in the last two years you all have taught me so much. And it really gave me a new view on what is it that we're advocating for, as a community - why do we do the work that we're doing? Because if we don't advocate strongly and loudly for people who use drugs, we are not doing our jobs. And I want to say that again, if we do not stand up and advocate for people who use drugs, we are all failing. And it's because of the work of the Urban Survivors Union that I have learned that. And I remain teachable through them as an advocate, and through the work that I hope to do every single day.

Leslie brought up stigma and where the word stigma comes from. For me, when I think of the word stigma - and I know that this is the stigma conference or Zoom conference, at least - I feel like stigma is just a really glossy way of not really saying what it is, which is bias. It is prejudice. It is systemic discrimination. It is wrong. And it is, to me, insanity that we are in 2021 and we still have to have this discussion. And quite frankly, it has gotten worse, not better.

And we need to look beyond just - I can't see how many people are on this Zoom call right now. Hopefully a lot, and people are learning a lot, but we think of stigma, and maybe some of you who are listening think of stigma, and we think, well, we look to the outside world. I have news for everyone. There's a tremendous amount of stigma within this community and people who are probably on this call right now. I'm sure there's people who are shaking their heads at some of the things that are being said. And I just want to call it out.

I'm a person whose life was saved because of MAT. I went to treatment multiple times. I finally got access to buprenorphine in 2015 when I went to a facility. Never had access to it before and almost died as a result of it. I was told in the beginning that I wasn't really sober if I was on it and was forced off of it, essentially. And thank God, there was a qualified recovery residence for me to go to. Thank god, I had a peer community that really embraced me because there were certain members of my community that wanted nothing to do with me because I was on MAT.

I have to mention this. I mean, stigma - I had a friend, a friend of many people who are on this call, Jesse Harvey, who was, I believe, murdered because of stigma. People say it was a drug overdose that killed him. No, it was discrimination. It was bias. It was the state hunting him because of what he was doing, which was ministering to those most in need in our community. Jesse had a belief, a radical belief, radical love that the last should come first, which is something that we all should have as a core principle when we do this work.

And people ask me, well, Ryan, like how? Like why, why do you do advocacy? How did you get into advocacy? I know that's kind of the theme and the topic of this panel. I consider myself, and I think many of us consider ourselves, accidental advocates. None of us were like, this is what we want to do. I have yet to find someone who does this work, who said this was what they originally planned to do with their life, was to make this their passion and their purpose. But that's where we're at.

And I don't want to spend too much time on my personal story, but I do want to tell a quick story. And it's when I realized that I needed to get into this work and I needed to jump in and that this was something I wanted to do. My advocacy, my work creating the Voices Project and Mobilize Recovery, and really focusing on community-based solutions from the bottom up, and a grassroots approach to combating the drug war, to combating the overdose crisis didn't happen as a result of my experience, which was a nightmare to me. Right?

I accessed treatment the last time through Medicaid. I was homeless on the street, on Hollywood and Vine in Los Angeles, California, begging for help and was turned away many times because I didn't have good PPO insurance. I didn't have someone who was writing a check for me to get into treatment. But I lucked out and I did get into a facility. And I did get into a recovery residence afterwards. And I was able to find a job through Uber because, again, of that discrimination and that prejudice, nobody would hire me in the beginning of my journey, because they wanted nothing to do with me. So, if you're an employer, I hope you're listening.

It happened to me when I lost my first really good friend and my roommate. It wasn't just any roommate. He was my roommate, somebody that I cared about, somebody that I got to know really well, a young man named Nick. And he was living in the house that I was living in. And I had a volunteer job of the recovery house. I had the volunteer job of being one of the peer leaders of the house. And Nick came home one day and he was using drugs again. He

was using IV heroin and he couldn't stop.

And he came home and he said - he made a beeline for me. It was like 7pm at night. He said, "Look, I can't stop using heroin. I've been using for a while. I don't know what to do. I have no money. I have no insurance. I can't call my job." He was working a construction job. "I can't call my job because they're going to fire me. I can't call my parents because they're going to want nothing to do to me. I'm terrified to tell anybody here at the house because I know they're going to kick me out. But I know that I have to find somewhere to go right now. I can't get into treatment. I don't know where to go. I don't know what to do."

And that was heavy on me. And we convened a small group of the guys who lived at the house. And we sat down with Nick and we talked to him for about three hours that night. And there was no 12-step meeting to send him to. There was no recovery community organization in our neighborhood. There was literally nowhere for him to go other than the street. And that was not my decision. That was the owner's decision, the house owner's decision. Under no circumstance was Nick going to be able to stay at that house that night and the owner really didn't care where he was going to go. It was up to us, his roommates and his friends, to figure out what to do.

So, we had this novel idea that there was a hospital about six, seven blocks from our house - and not just any hospital but one of the best hospitals in Southern California that receives hundreds of millions of dollars in endowments, that props itself up as a leader in mental health care in Southern California - to send him there. We go to the ER room and to tell the ER doctors exactly what he told us. Can't stop using heroin, afraid he may overdose, has nowhere to go, needs help, wants help, has a lot of questions, need support, has nowhere to stay that night. And the agreement was if Nick went there and at least got checked out and maybe they would hold him for a day, we bring him back to the recovery house.

Well, that's what Nick did. He walked over there that night. He wasn't admitted into the ER. He was triaged in and out, never seen by a doctor, given a piece of paper with a bunch of crisis lines on it that he could call the next day, if he was willing. And he died that night. My friend died and he overdosed that night, just a couple blocks from our apartment, from the sober-living apartment. And they told us the next morning what happened. And the owner of that house said - he opened up to tell us this by saying, "I just want you all to know that this is what happens, that some people have to die so others can recover."

That saying today, almost seven years later, for me is still complete BS. Nick didn't have to die so I could sit here and talk to you. There is so much discrimination. There is so much prejudice. There is so much stigma, whatever you want to call it, from all directions, from the government, from policy, from the failed drug war, from the medical community, from the education community, from the academic community, from policy makers. Probably to some people who are sitting on this conference right now, maybe you're realizing it. But it's my hope that we can combat that together by listening to each other, learning from each other and remaining teachable. So, you have to open your ears. You have to open your eyes to what is reality and what is happening in this country right now. Thank you very much.

JENNIFER POTTER:

Thanks, Ryan. I should take a breath. There was so much in what you just said and in what the other two folks, Dinah and Leslie, said. The reason I'm pausing is because my original question was going to be sort of a general - what is the role of families and loved ones as

advocates? And I guess it made me think, how do you guys feel about this idea of rock bottom? There's this idea that people need to hit rock bottom to be able to recover. And as we think about the role of family and friends and loved ones, I'm just really curious. And maybe I'll start with you, Ryan, given what you just shared and maybe you three could all speak to this comment.

RYAN HAMPTON:

I'll just say really quick, I mean what does that even mean? I mean I know that people use that term a lot and say you have to hit rock bottom. I will tell you, if somebody had said I would have had to hit rock bottom this last time, would I be here, even? I'll share a little secret with you. The night that I got called, that call to go into treatment, I was so over-everything. I had no intention to stop using drugs. I didn't. What I really wanted was a roof over my head. What I really wanted was a meal. I don't even know how to respond to a question around rock bottom, because I think that whole argument is just complete BS. If we wait for every single person to hit rock bottom, we're just going to kill people.

JENNIFER POTTER:

Anyone else want to weigh in on that? Dinah or Leslie?

DINAH ORTIZ:

Just very quickly, because I saw that Leslie raised her hand. I mean, rock bottom is different for everyone. And, you know, how low do they want us to go, right? Because it's really about embarrassing us and keeping us down. What happened to love and compassion and empathy and treating people as human beings with the rights that they were born with? Rock bottom to me is death and I don't want to die. And my community members and the people that we talk to, they don't want to die.

And so, that rock bottom bullshit is just a fallacy. It is something that people tell themselves so they can excuse their actions towards their loved ones or their family members or community members. But it's real bullshit. Rock bottom is death, right? As long as the person is alive, let's help them. Let us help them.

And recovery looks different for everyone. It does not always mean abstinence. It's not what you think that I should be doing. It is about what makes me feel comfortable in my recovery. And so, let's do away with that rock bottom shit and let's really embrace people and meet people where they're at and help them. And usually a roof over their head and a job, being employable, helps people to get out of chaotic use, right, and just be able to function. And that's really what we need to be focusing on, not about these terms that we just throw around, rock bottom and let's turn our backs on them.

RYAN HAMPTON:

Those are excuses, like people using the word rock bottom is just an excuse for failed policy. It's an excuse for policymakers. It's an excuse for people who want an easy way out. That's what it is.

JENNIFER POTTER:

Yeah, thanks to both of you. I think that's a really important message to keep hammering home on. Leslie, I know you raised your hand. I apologize, my computer crashed in the middle of this session and I'm on my iPad, so I'm with limited technology all of a sudden, Leslie. But I heard Dinah say you raised your hand. So, jump in here and then we'll go to

some audience questions.

LESLIE MCBAIN:

Rock bottom - as a mother, and for all the moms out there and dads, rock bottom is completely counterintuitive to a parent, the last thing - and people do it because they're told that this will work and it is bullshit. It is complete - there is no evidence that this works. I've encountered a few parents for whom it did work for their kids, but hardly any. Why would you let the person that you love the most hit rock bottom, which means removing love basically, removing support, removing anything that - take their phone away, take any grocery gift cards away, whatever it is that is helping that kid stay alive and in some kind of balance in the chaos - then it's wrong. And parents, like I say, they intuitively know it's wrong, but they're desperate. So, it's a complete failure of our society to ever say something like that.

JENNIFER POTTER:

Thanks, Leslie. I remember with my loved one, the stigma that I felt, that I didn't even know I felt as a professional, initially set me in a place where I wasn't able to talk about this with people I knew who could help. And then there became this point where I wasn't going to let this person die. I was going to do whatever I could with whatever I had. So, it makes a lot of sense. I appreciate that. We have a bunch of questions from the audience that I'd love to get to because I think they're important and relevant. A couple of quick ones for you, Dinah. I believe you said functional use. You made a distinction. What would you define as functional use when you used it in that comment?

DINAH ORTIZ:

Well, we got to stop with the clean and the dirty language, right, because I've never been dirty. We got to stop with the, you know, crackhead, dope-fiend language. There is functional use and there is chaotic use. And chaotic use is when you are pretty much like spending your last dime and just not really caring, because you've lost all of your support. Everybody has just pretty much said let them hit rock bottom, right? So, that takes you into chaotic use. And all you're thinking about is just getting high and numbing the pain.

Functional use is when you can actually use drugs, get up, go to work, help people, help your community, do what is your passion, whatever it may be, and still use drugs and come home and take care of your family, send your kids to school, whatever it is that gets you through the day. Everybody has their vices.

Nobody complains when the affluent people are using drugs in the comfort of their own home. It is only when it's the most marginalized, when they show those pictures of the ashy Black and Brown people with the chapped lips that - those are the drug users, those are the dope fiends, those are the crackheads. But the affluent people that use the cocaine in their house, in the comfort of their home, there are no police knocking on their door. There are no ACS or child protective services banging on their door. Yet, they go to work. They have executive jobs. That's functional use. We do it, too, except for we don't have the luxury of doing it in our own home the way that they do.

JENNIFER POTTER:

So, Dinah, can I just pick up on that a little bit and say one of the reasons for this panel was what can people do, that are family members or loved ones or concerned people. So, knowing what you know, with how strongly you feel about it in your experience, what do people need

to do if they know someone who they're concerned about? What do they do with this to change the narrative?

DINAH ORTIZ:

They have to continue to love them. They have to continue to treat them as if they weren't using substances, right? And be a support to them, right? Because if you lose all of your support, you lose all of your hope. If you are left to hit rock bottom, you lose all of your hope. And all that is waiting for you is death.

So, think about that. Would you rather let your child or your loved one die because you were trying to teach them a lesson? It's about compassion and empathy. I can't say that enough. We have got to embrace our folks because the laws are not doing it. The legislators and the policymakers are not doing it. These drug companies are not doing it. They're making money off of the losses of our family members and our loved ones.

But when it comes down to decriminalized drug use, then there are issues. We have to approach it from a place of love and compassion and just shut out all that noise and focus on embracing and meeting them where they're at. Right? And that's a start. It's not shunning them and shutting the door on them.

JENNIFER POTTER:

Thanks for that. There's another question. And Ryan, I'll start with you and then others jump in. Could the panel speak of the self-stigma and stigma in general related to relapsing, which is very often a part of someone's journey and rarely discussed?

RYAN HAMPTON:

Sure, I mean, recurrence of use is - it's part of any disease state, right? I think we have to get beyond this thought. That's like when I talk about the discrimination, the bias, the prejudice against people within our own community. I've seen situations where people I love have had a recurrence of use and it has killed them, because of the lack of radical love, the lack of acceptance, the lack of reality.

Recurrence of use is part of anyone's recovery journey, I believe - maybe not everybody. It certainly was a big part of my story. But we have to shed this old thinking and thought that it's a bad thing. I mean, is that what we do with any other chronic healthcare issue in this country, that is, as soon as someone has a flare-up of a disease or a recurrence, we shut them out? We stop talking to them, we shame them, we fire them, we take away their car - how does that help anybody? It doesn't help anybody.

But there's some great data I'll point, folks, particularly with recovery. Dr John Kelly at Harvard's Recovery Research Institute just published a great study a couple of weeks ago - there was a wonderful article on it in Stat - that talked about how many times - I think the average time is between three and four, that takes for someone to actually get in - if their goal is long-term recovery or abstinence-based recovery, recurrence of use is going to be a part of it.

And I just want to say one more thing and then I will shut up because I could go on forever on this topic. And I see everybody getting (CHUCKLES) - but I am in abstinence-based recovery. But every single morning that I wake up and I practice that abstinence-based recovery, it is a form of harm reduction for me. Right? Like that's my harm reduction. I

practice harm reduction. That's what I do every single day. And I think we have a scale of harm reduction and we need to realize in a sense, we're all harm reductionists, at least in my community, in one way or another. That's how I see it.

JENNIFER POTTER:

Just before we go, because I saw Leslie jump in, I wanted to just point out a language thing that you were doing, because I'm assuming it's intentional. The question came with the word relapse and you changed it to recurrence of use. Is that intentional? And why is that important when we talk about stigma? And Leslie, then you're up.

RYAN HAMPTON:

Language is everything. And yes, it's very intentional. It's very intentional. I think the word relapse comes with all sorts of negative connotations that culture and society and the media and film and television and folks probably on this call and some that are in the medical community have attached to it. And I think recurrence of use is probably a more widely accepted, attached term to a medical condition.

JENNIFER POTTER:

Thank you for that. It was an important point I wanted to draw out. Leslie, I saw you jump in there.

LESLIE MCBAIN:

Well, I would speak to that, but I wanted to talk about the previous question, which is what can families and friends do? One of the things that I stress often is inside that person with the addiction is the sweet little newborn. The cuddly kid, the mischievous kid is still in there. The person who is addicted is a person first. And that speaks to the language you talk about, for person-first, people-first language all the time. But, for family and friends, looking at who this kid was or who this person was before they were addicted, and realizing that that person isn't gone. This person just has a substance use disorder. The only disorder wherein we make people go onto the street and buy unsafe drugs in an unsafe way to stay balanced or to stave off withdrawal.

The other thing is, Ryan, our statistic that we use here, it's far greater than three to four times. And it could be - I've heard it up to 20 times in a person's lifetime. I mean, people want to recover. People want to but addiction is what it is in your brain. And it's the most difficult thing. And we have to have compassion with that. And we have to have the recovery facilities understand not to boot a person out because they have - I'm not used to your term - recurrence of use.

RYAN HAMPTON:

Don't quote me on that stat, by the way. I would refer everybody to Dr. Kelly's research because I read it. I don't - it's somewhere, it's several.

LESLIE MCBAIN:

It's a lot.

RYAN HAMPTON:

It's a lot. It's a lot. Yeah.

JENNIFER POTTER:

So, this has been such a great conversation and actually the time goes so fast. I've been told that we need to wrap up. I hope that everyone listening heard a pearl because there was more than one pearl that we heard today. Thank you so much for everyone on this panel for speaking so candidly, frankly and honestly, with this call to action about doing something different, related to substance use disorder. Thank you so much and thanks to the organizers for this time.

SESSION 2.2 - HOW TO INTERVENE OR CHANGE BEHAVIOR IN REAL-TIME

MATTHEW STEFANKO:

I am so excited to welcome you back to our second concurrent session This is session 2.2 How to Intervene or Change Behavior in Real-Time at Shatterproof, I think, we work around stigma. Probably the most common question I get asked is when you do see someone having a stigmatizing viewpoint or making a disparaging or discriminatory remark in your day-to-day life or in your workplace, what do you do to actually combat that? And I think sometimes the answer can feel a bit abstract. So we've assembled this panel to really dig into that question and obviously many others, and we're really excited for the dialogue. I'm going to quickly just introduce our wonderful moderator, Dr. Elizabeth Salisbury Afshar, associate professor and Department of Family, Medicine and Community Health, the University of Wisconsin School of Medicine and Public Health. So happy to have you all to you to make introductions to our other remarkable panelists. But thank you, everyone, for being here today.

And I specifically would like to thank the National Academy of Medicine shatterproof and the Dell School of Medicine for hosting this incredibly important summit. The title of this session is How to Change Behavior in Real-Time. And as I was reflecting on it this morning, I was sort of recognizing that there's always some self selection on who attends. Right. At times, the folks who probably most need to be here aren't the ones who choose to come. And the folks who choose to come are the ones already really working to improve behavior.

That being said, even just in our preparatory call with our amazing panelists, it caused me to reflect and I think we're hopeful that this session will make all of us reflect. And no matter what type of work we're doing, we can always do better. We can always push harder. We can always fight harder to deconstruct systems that are broken and that don't work and that are actively harming people who use drugs. And we can always push, whether within our own organization or just in our own self, reflection of the way that we approach things. So with that, I just want to say we really are happy that you're here. And we have three passionate, inspiring panelists that we'll be hearing from today. Will go ahead and hear from Guy Felicella first. Guy comes to meet us from Vancouver, BC. It's always amazing to hear from our Canadian colleagues where he is a peer clinical adviser and a passionate advocate in this space. So thanks so much, Guy.

GUY FELICELLA:

Hi, everybody, thanks for having me and thanks for the intro, Elizabeth. You know, stigma is something that's really impacted me in my life of using drugs and not only just using drugs, but also now recovered from those drugs, that our society just doesn't make it easy on people to move forward even if they stop using substances. I'm still looked upon as my past as a person who broke the law any time I applied for insurance purposes. They look at my record. I've been denied specifically on my criminal history and past drug use for insurance purposes.

That's not what I do today. Even my past still continues to haunt me. If you have to actually look at the reality of ending stigma, then you have to look at where it was created and where it started. And it's really rooted in racism, drug policies and laws. And this continues to impact us as a society. It's that structural stigma that has fueled the population's views towards people who use drugs, which is killing people. And the stigma that exists in our society is just as deadly as the drugs themselves. And any life lost to an overdose is a policy failure. And yet we just haven't done enough to change policies.

And now, even in today's times, you still feel this discrimination and stigma that exists in all our systems of care as a substance user, when I need help most and was struggling in my life and walked into a health clinic to ask for help, they looked at me as a drug seeking individual that was seeking substances. Of course I was seeking substances. I was in withdrawal. I was asking for help. And yet they turned me away because I am a drug seeker, a drug user, and who didn't turn me away 'you are the drug seller.' And so if you really, truly want to replicate a system of care that supports people who use drugs, then you're going to have to compete with how low barrier it is to access these substances on the street for people to line up at a clinic or to go to a pharmacy every single day or to see a doctor once a week for urine screens.

This is not normal. This is not normal practice in our society. But for people who use drugs, this is the reality. We don't give people any hope to move forward. People are homeless. People are struggling with poverty. And yet we expect them to show up at our facilities and follow our rigid rules and policies. And then we blame them. We blame them when it fails. And yet we are never held accountable. Our health systems are never held accountable for its failures, its failures in addressing people who use substances. And then on top of that, if you want to talk about mass incarceration of people who use drugs just for being a drug user, imagine just for being a drug user that you're incarcerated just for using those drugs.

Now, if you look at people who struggle with substance use disorder or an addiction, it's rooted in our trauma. And if that trauma is not ever addressed, we blame or we stare at the substance use. The symptom is why people use drugs. We do not do enough to address the trauma that people are struggling with. And then when we cause more layers of trauma on that individual with our systems of care, we wonder then why people don't reach out and ask for help. If you go through the system once and it's rigid challenges and loopholes and jumps and urine screens and stigmatizing and criminalizing questions and being incarcerated and looked upon and judged as being a substance user and then try to move forward with your life. And you get through that once. Tell me you're going to do that again and you wonder why people don't show up.

I mean, I look at the line up at a methadone clinic. It is very stigmatizing for people. People need freedom. And if we need solutions that give people the freedom, people deserve care, people deserve dignity. People deserve to have the health care that everybody else has health care. It's not a radical solution to support people who use drugs. There's nothing radical about it. It just should be health care. We discriminate in our health care of who is getting this full spectrum of care and who's not. If this was any other health condition, there would be a massive support system in place for people. And we just have failed miserably in addressing that.

And one of the things that needs to change is our policies and procedures. And if we truly are serious about removing stigma from our society, then we need to have vital harm reduction services such as syringe access, supervised consumption sites for people to use drugs in a place where they're welcomed. I kind of describe the supervised consumption site in Downtown East side of Vancouver, kind of like Cheers, you know Norm. I'm the Norm of the supervised consumption. Say, when I walk in there, everybody knows my name and they're very glad that I came. And it's that kind of environment it's no different from walking into a bar or walking into a supervised consumption site.

And if people often think, well, this enables people to use drugs or harm reduction, enables people to use drugs, people are already using drugs like it's not because of harm reduction that people use drugs. They're already using them. Harm reduction actually saves people's lives. This vital health services, the recovery that I have in my life today doesn't exist without harm reduction. I survived the first public health emergencies here in Vancouver, which was the HIV AIDS crisis, where one in four were infected with HIV AIDS. I survived the overdose crisis in the 90s. I've survived 20 years of being homeless. I've survived six overdoses from 2012 to 2013 where I had to be brought back to life six times. I survived all this and I'll tell you why nothing exists in my life.

This conversation wouldn't exist if harm reduction didn't exist. And if harm reduction didn't exist, my recovery wouldn't exist. My children wouldn't exist. None of my life exists without this vital tool of harm reduction, harm reduction, meet people where they're at and supports them where they're at. And if we can continue to change and do that and to show up in substance users lives, they're going to feel the support. This is a journey. Not everybody who uses drugs struggles with an addiction or a substance use disorder. But everybody who uses drugs is at risk of an overdose or a death.

And these deaths are preventable and these deaths are our policy failures. I hope this inspires you to look at yourself as a person and understand the root causes of our prohibition and our drug policies. And it changes your views to people who use drugs, because when somebody shows up to your facility, your clinic, it's not just you and him or you and her or you and them. It's you and them and every single bad experience that that person has gone through from the health authority. And if that's the one thing that you can remember, have awareness, listen to your patient and be patient, things will change. Thanks for listening.

ELIZABETH SALISBURY AFSHAR:

And I should have mentioned we will be having time for a Q&A at the end, so if our participants and folks are listening and please feel free to go ahead and put questions in as they come up. Next, we'll be hearing from Laura Guzman, who is the senior director of Capacity Building and Community Mobilization for the Harm Reduction Coalition in California. Thanks so much for being here Laura.

LAURA GUZMAN:

Thank you Elizabeth, and thank you to our panel, I'm very, very privileged to be here and I've been working for the National Harm Reduction Coalition since February of last year, but I've been associated since 1995. And the National Harm Reduction Coalition actually was formed in part for all the reasons that Guy mentioned in 1993. That was the gathering of actually activists, people living with HIV, and drug users who for 10 years were actually neglected and dying in the United States because there was no focus, no public health focus or government focus on people who use drugs and were dying of AIDS. And just for context, for those of you who don't know history in New York, 53% of all the infections in the 90s actually were and people dying of AIDS were people who inject the drugs at this point. Given all of the efforts by implementing harm reduction syringe service through service programs, less than 3% of people are impacted by HIV AIDS.

I like to say that, you know, the National Harm Reduction Coalition has been now for almost 25 years providing training, technical assistance, policy work. We're now grant makers. And at this point, we really are focusing on creating spaces and dialogue. And I would say stigma is one of the first things that we do, because I think that what Guy is saying is not only changing individual perceptions, but actually changing systemic impacts of what we call

racialized drug policies. So we are really focusing on not just changing stigma from an individual perspective, but really undoing all the violence systems that actually keep drug users, in particular poor drug users and drug users of color hostage and colonized.

I want to say that I came to this work in the 90s and I was blessed to have been invited to work in a hotel called the Ambassador Hotel, which for those of you who don't know, there is actually a YouTube video called Life and Death in the Muscle Hotel. It was one of the first places in the country that allowed people with AIDS that were dying to die with dignity. And so I was privileged to be taught by actually those pioneers. Many of them were social workers and nurses, actually, besides people with AIDS and drug users themselves. And so I had that first crash course Harm Reduction and learning from the community that was, again, suffering and dying of AIDS with absolutely no support to know what it meant to learn to understand all of the barriers the drug users faced to learn about drugs.

Right. I'm from South America. I knew a lot about cocaine. But I'll tell you, heroin was not in our repertory. So I had to learn how to work with injectors, how to work with meth users. And actually, I would say bring in the love. And that is very important for us in harm reduction. And we really uphold the dignity and the human rights of drug users. But also we're thinking of this work as a work of love and therefore stigma doesn't have a place. So I was very impacted by my first supporting, advocating, you know, I was an outreach worker. I was all over the city working with the folks that, again, nobody else wanted to take care of. And so that's how in some ways I bring my perspective through the Harm Reduction workers as the critical piece is to bring the love and to bring the very challenges that, again, are not just individual, but really are the systemic violence.

So when we say reducing the harm, we're not talking just about reducing the harm of drugs, because what I've learned in the experience of people who use drugs and are impacted by poverty and racism and incarceration, drugs are the least of their priorities. There are so many other things that make them feel so bad. And in that way, I think it's very important that we really take this big lens when we're talking about what it takes to do the anti-stigma work because it is undoing the very systems of violence like I mentioned. I also wanted to share. I think that is very important, that we also in this work seek the meaningful inclusion of people who use drugs not just in treatment, but in all of the systems that touch our communities. Our communities need to be involved.

And this concept of nothing about us, without us, is really critical. And it's still even within the harm reduction movement. And a lot of our systems is something that we haven't prioritized and we must. Because one thing I want to say about stigma I learn from the community I serve is that not only stigma makes you feel really bad, it gets in the way of change. So if we're not prioritizing, stigmatizing drug use and the very folks who need actually the very support that the systems like Guy said impact them and actually create in some ways chaotic drug use, drug use that doesn't get treated, pain that doesn't get treated. And we don't do that. It's going to be very difficult to change the tide. So the meaningful inclusion of people with drugs and systems, it's really critical.

I wanted to just finish in this first piece is to mention that there is no harm reduction without anti-stigma work so concretely is very important that we talk about drug users, we know that people are beyond their drug use, that we treat them as whole human beings. That's why language is so important. So we actually shifted. I remember in the 90s, we used to say drug users and now we say people who use drugs because we learned that by just mentioning drug

users as drug users, really confines them to a very specific thing that actually most of us share. Most of us are drug users, but we tend to really just confine it to those folks. Same with addicts. And addiction is one word that we take very lightly. And we consider a very complicated definition that actually we don't think that people should ever be labeled as addicts unless they want the person themselves chooses to do that definition.

We also think that in health care in particular, we're so obsessed with outcomes and don't see that process is the most important outcome in the process of trust-building, of actually making people feel comfortable and actually seeing that we're willing to help. In a second going to want to talk about drug-seeking guy because we were just having an interaction with all of our storage service providers about how do we define that horrible term of drug seeking behavior and rather focusing on actually realizing that treatment providers may be doing compassion, compassion, withdrawing or compassion, we hold them when they're actually not treating people with the medications they need when they're not addressing their pain. So language is so critical or emergency rooms that says we're not giving any pain meds here, which is just cruel in a medical environment where we're not prioritizing. The very thing that people need is to address pain with drugs and drugs that take care of that pain.

So we feel that there are a lot of intersection between harm reduction and stigma that we need to address and also to again, consider again the big picture of all the other things we got to beyond the needle and beyond overdoses is the systemic violence that we still are doing in health care. We're still doing in treatment. We have one of our initiatives in California. It's called the California Harm Reduction Initiative we actually advocated for and 140 million dollars by the state of California to support syringe service programs, which is one of the first in the country. And this was advocacy by drug users and SSPs. And we just did actually a participant survey, about five 500 folks who participated in syringe service programs. And we asked them, what are the barriers to linking to treatment, in particular opioids?

That's what we were asking for, although help of our folks also use meth, methadone, I'm sorry, methamphetamine. But what we heard out of the sample of responses, 50% says the big barriers are all your bureaucratic barriers and the poor treatment our communities face when they go to methadone. I think I mentioned that even in my treatment provision, even in buprenorphine, we're seeing that there is a significant divide between who has access and who doesn't. And we know also that black and brown folks are the least likely among Native Americans to actually get buprenorphine, get hooked, get supported and stabilized. So we're seeing that directly from folks themselves.

And I think the only other thing in closing I want to say is that I think that there's a history of liberation that we talk about in the tree of stigma. And so as we advance this conversation, I'm inviting everybody to think about what are those root thoughts that you have when you talk about drug users and how you consider them as trustworthy and honest and able to change and able to be as resilient as Guy describe? Or is it in the back of your mind, still your roots, what you're thinking? Are those what we call the real stigma? The folks are really not able to change? The folks are really not deserving of the treatment or pay medications that we have or that folks are just, you know, I really don't need to focus there because I don't think there is any hope. So I'm just going to leave it with that.

ELIZABETH SALISBURY AFSHAR:

Thanks so much. Next, we'll be hearing from Gilberto Perez, who is the co-executive director at the Texas Harm Reduction Alliance. Thanks so much for being here.

GILBERTO PEREZ:

Yeah, good afternoon, everyone. My name is Gilberto Perez. And as I mentioned, I'm the co-executive director with the Texas Harm Reduction Alliance. And I want to thank everybody for the invitation and the opportunity for being on this wonderful panel, I want to echo what Guy and Laura have been mentioning. I think the last thing that Laura mentioned about unconscious biases is something that we all have to think about on a day-to-day basis, especially when we're working with folks. As a brief introduction and background about myself. I am originally from El Paso, Texas, and had been focusing on harm reduction and binational health for the last six or seven years or so by now. But the opportunity to join Texas Harm Reduction Alliance September of last year.

And so I would like to share that Texas harm reduction alliance really shaped and formed racial and drug policies and all of the health inequities that as people who use drugs suffer on the day to day basis. I think that my background particularly is unique in the sense that, as I mentioned, I have done a lot of binational health work, and so whenever we're looking at communities, border communities, we really need to take into account the policies and procedures and as well as the whole systemic structure of both countries. In my particular case, looking at Mexico and the US because El Paso as a border community, we have a lot of interchange between our systems. And so there's a lot of differences. There's some similarities. But ultimately we have to look at both of those in order to really deliver adequate health care services, because no big enough wall is going to stop from anything, from folks coming in, coming back and forth and sharing and very unique and very meaningful experiences between border communities.

And so let's...a little bit about who I am and what I bring to the table. I did want to share and I go where Laura was mentioning about meaningful involvement of people who use drugs at every level, not only at the frontline level, not only hiring recovery coaches to do the work that is that is very much needed, but also involvement in strategy, development program development and program execution and implementation. Through my work, I have done several community-based participatory research projects at both ends, one where researchers and principal investigators are heads of these programs only include people at the front lines or only tokenized people in order to say that they have involvement. And I've been in programs, I have been participating in programs that really, really include folks and in the whole context and really value that input and really hear out their voices and their experiences to help inform whatever it is that is being implemented and put into place.

However, there is a larger problem here, and I think it goes back to the stigma around policies and regulations based on funding decisions. A lot of funding decisions tend to go through federal channels where grassroots communities-based organizations do not have access to these funds. And so a lot of these funds to help deliver meaningful programs are funneled in a way that make it very hard to deliver harm reduction services through honest-based harm reduction services out in the community. They're often channeled through universities, research institutions. They're often funneled to do academic settings. And that only imposes a lot of barriers and a lot of red tape at the institutional level and decreases access of who this monies are intended for and communities.

And oftentimes I find it hard to fight on both ends of the spectrum as to where we're challenging our systems that are further stigmatizing or continue stigmatizing us in our communities. But at the same time. Fighting for funds and making sure that there's

meaningful involvement of community in our current system to move forward with program development and program implementation, and so a key strategy that I always bring to the table is having folks at the table from square zero, right from step one all the way up to the execution of whatever it is that we're developing. So they're systemic, stigmas that are at play here because they are not trusting of grassroots community-based organizations that oftentimes tend to be driven, which makes the work that much meaningful. And so that needs to change.

But there's also stigma. And then that alone also brings internalized stigmas that question, self-worth, self-value and ultimately impact our empowerment and autonomy as a first-generation Latino myself. And so from a lot of internalized stigmas of not being able to move the needle forward and create and provide systems that are actually meaningful because of all my negative experiences with the larger health care system, particularly with larger governmental entities. In my experience as a queer person, as a person of color, as a person who uses drugs. And so as my last point, is that we need to value and respect each person's identities and hear them for what they're worth and take them into consideration into account when really putting programs. When developing programs in order to also reduce that impact the negative stigma of folks. Thank you.

ELIZABETH SALISBURY AFSHAR:

Thanks so much to all of you for your comments, your stories, your willingness to share your own experiences, it's extremely powerful. One of the things I was struck by that each of you said, and I'm going to ask you to elaborate a little bit more, was when we talked to each of you spoke in different ways about things that need to change largely around systems of care. But even more broadly related to funding and research in particular. But when we think of systems of care, I'm really talking about everything from community outreach to service programs to care received in hospitals and clinics to license the sort of formal addiction treatment.

And so I would ask each of you sort of when you think so, we know we've heard some of the things that are wrong with it and some of the reasons why. But when you think about what it could look like, right when we try to re-envision, what we would want, can you say a little bit more about what that looks like? And you can extrapolate on that however you think is most relevant to your own experience and work. But for the audience who may be working in some of those settings, what are the things we should be striving for? And whoever wants to jump in, pick up the mic first, I'll open it up.

LAURA GUZMAN:

I just want to say I think that those and you know, it's interesting to hear Gilberto talk about community taking care of community, because I didn't say that. But it's very important to us not only to have the meaningful involvement of people who use drugs, but this idea that community takes care of community better. And so I want to say that a lot of us have worked in programs or develop programs myself I directed for 16 years a harm reduction center in the mission district of San Francisco, targeting immigrants and the neighborhood, not just people who use drugs, but people who are on unhoused and at risk. And in our model, which was a very beautiful weaving of not a lot of funding, but really the concept of community taking care of community. We had a drop-in service shopping center with survival services, that we had showers. We had actually laundry services. We served coffee in the morning. We had a clinic.

We were a health care for the homeless clinic funded clinic and actually took us about 16 years to get the wraparound services like a behavioral health expansion. And so what we did is had a very Latino centric harm reduction program that was taking care of and supporting people with their survival needs, actually fought for housing, organizing our community. We actually developed probably the only housing in the United States that targets undocumented folks and has four million undocumented workers, many of which were also impacted by trauma and drug use. Many of them were from Central America. They're now elders. We had a peer model, peer-led, professionally supported. We felt that the peers had a much important role than the professionals in actually shaping how community engaged, whether it was in organizing community programs. We had tons of community programs, so we had ladies night was actually a model program for women who use drugs, and it was both for a cisgender, the women and transgender women.

We had a program to help the community to pick up needles and make sure that we had a neighborhood policy so that the NIMBYism was not that intense. We had an LGBTQ day, so we actually did a lot within our Latin X and the mission community. We always offered different ways in which our community will engage that trickle at some point in interest in medical care, sometimes the interest in behavioral health support. And then we managed to have an addiction clinic. We were started to do induction. We were also trying to see what other ways we could treat through the clinic the other impacts of drug use. We actually did a pain clinic. We actually had pain contracts. We were actually given medicine for pain. And so to me, that was a very dreamy project where you're really integrating and then collaborating.

We collaborated with folks. We collaborated with Women Community Clinic. They were doing all of our women care. So I want to say we have it. The key is how do we make that sustainable? How do we believe community taking care of community? And I want to say in San Francisco, in our overdose, which San Francisco is actually does better than the rest of the country in terms of overdose death, but yet we've seen a double of overdose deaths since 2018. That also is double in 2020. We don't have yet all the data, but we have a community-led Naloxone distribution program, one of the oldest in the country.

And as we had and suffer 699 deaths by overdose, the community. And when I said the community, I mean individuals, civils, we have a whole system of care. They reverse 3600 overdoses. So that means that without community intervening we would have had 4500 deaths. And for us that is very telling about how we have to really get community to lead because community knows better. And so I just want to say that to me sort of some of the ideas, things that we've done and guidance moving forward.

GUY FELICELLA:

I think in harm reduction, there's really if you look back at its original rules, there's two kinds of harm reduction. There's drug user, grassroots activism, harm reduction and then there's this clinical medicalized model of harm reduction and they don't jive. And if we want to make a systems of care that actually endorses harm reduction, then you need to include people who use drugs in this system of care, because if you don't, or you'll never be able to compete with the grassroots harm reduction, that is the true meaning of meeting a substance user where they're at. And so you're going to need to collaborate with drug user groups, drug users, to create a system that benefits people who use drugs in a way that supports them, where they are.

What the medical version of harm reduction has done is supported the medical system of where it's at. So it doesn't support the person who uses drugs. It's supporting a system. It's completely different. And this is why it continues to fail people. And then we blame people for its failures. It's rooted in our institutions who we have to look at ourselves has to be held accountable, and then we can move forward and support people who use drugs. And until we actually get there, you're always going to be seeing people accept us in a way that causes harm. And we spend billions and billions of dollars a year of trying to keep drugs out in this country. And then we spend billions and billions of dollars reducing the harms of those drugs that weren't supposed to make it into the country, but yet they are in the country anyway. And so why don't we just end the war on drugs, take all that money and build a new system of care that supports people who use drugs and get people the support that they need? We can have this and really change the complexity of not only this is our societies, but the world. And we get there. And we will one day, I just would love to see it in my lifetime.

GILBERTO PEREZ:

I think you said it perfectly. I think that in comparing the true harm reduction efforts that were peer to peer led grassroots in comparison to what we're seeing a lot more now, as harm reduction has been talked about more and more clinical medical settings, we're talking about embedding this system into something that's already in place and something that is bad, that has failed us and has failed people who use drugs for long periods of time. And so, I mean, my advice to my short advice, Elizabeth, to your question is to get out of the way, and let folks who know what's best for their health lead.

ELIZABETH SALISBURY AFSHAR:

There's a question from an audience member that I think sort of dovetails perfectly into what we're discussing right now, and it says, can anyone speak to how they've included individuals who are currently using drugs? And I'm assuming they mean either in program development or in thinking about programmatic changes. And so they go on to say this may be important as they're the target of improvement efforts and are still left out. So I would love if anyone has a specific example to share on that note, of how we do this.

LAURA GUZMAN:

Yeah, I mean, in the on my lead, basically our pure and professional staff had a live experience of using drugs. And so it was very important to us is that we're hiring our team. And again, not just our peer team, but even our managers. We had a management team of people who use drugs and also know particularly black and brown, because we were so in the black and brown community. So we were all so rooted not only racial and cultural practices, but also in the community we serve, which was a very strong Latino community. I want to say that in our current work with California, we're also amplifying with the meaningful involvement of people who use drugs means because it's not just hiring folks, we have programs that actually do all of their program development based on the feedback of the participants.

So there is a way in which you just check your program and see that you know exactly what Guy says those people who use drugs define whether that program needs to be changed, shifted, etc.. In our program, we were actually not only doing community meetings, but constantly checking, doing surveys and getting our folks to really, again, redefine start a new program that will always check with community. What we found is a lot of programs actually do very little check with community whatsoever, I mean, and not even the informal survey. So I think that for a lot of people in the audience, it might be just starting that little step. But

meaningful involvement of people who live experience should be considered very broadly, including all the organizing and advocacy and policy making that oftentimes is just done by two or three people that have a law degree or policy experience.

So I will say in every possible way, defining meaningful involvement should be really broad and actually should be able to check with, you know, people with live experience to say, what does that mean? What does it mean for me to have? One more thing to say is a lot of folks form advisory boards and in Alameda County, we're doing that with youth, with live experience, and we decided to color youth action board. So what is the Decision-Making authority that any of your bodies have to really have that meaningful impact?

ELIZABETH SALISBURY AFSHAR:

Yes, anybody else there's a few more questions that if there's anything to add, please go ahead. No, nothing, nothing really to add, but yes, valuing life experience as part as the center of the program of the organization is also very important for us, not only in a friendly level, but also in leadership, in our leadership and within our board of directors. If reporters or other directors does not align with our organizational values or if a board of directors is just white, people and that's not representative of the communities that you're serving, especially if they don't have that experience.

Changing gears just a little bit, there's a question that came in and I'll just read it, it says, We're seeking ways for medical students to be able to respectfully respond to attendings that stigmatize people with substance use disorders. Speaking truth to power for medical students is particularly challenging especially in a dynamic where the attending grades the student. So a student could hear, for example, one of the head physicians say something that is stigmatizing may want to respond but doing so may impact their grade in particular. And so the question is, are there any resources or thoughts that you can offer that would be helpful? And I would just add, I think there's...

LAURA GUZMAN:

I want to - I just want to say Guy wants to chime in.

GUY FELICELLA:

What's the, what's the question?

ELIZABETH SALISBURY AFSHAR:

The question is about medical students and like let's say, for example, a lot of their work, their clinical work is in a hospital. And if they, for example, here, one of the doctors that's grading them, that's essentially their boss for the month, using stigmatizing language or speaking in a way that would be stigmatizing toward a person who uses drugs. Specifically, they're asking either resources or thoughts you have on how they could do that, sort of given the power dynamic

GUY FELICELLA:

Yeah no for sure. And it is very hard for I do a lot of talks with medical students that run up with the same types of questions like that. And what usually happens is, unfortunately, is that you can't say anything. There needs to be something outside of that where you can file something anonymously as well so that it doesn't target the person. But if we don't say anything, then what we are is complicit in allowing it to continue. It doesn't change anything. It's actually a lot of the times I remember meeting a social worker who told me that I don't

help people unless they help themselves. And I actually thought to myself, I said, well, that that is kind of the old guard of how it was in the in the 80s. And unfortunately, you know, this individual should be immediately removed and severance package and move on because you're not helping people.

If you're continuing to be judgmental or think that somebody doesn't want to have support, you know, people want to be supported. The unfortunate thing is that we don't make it easy for them. And so for any medical student, sometimes it's also to even if you have to lie and pull the attendant over the director or whoever your boss is and pull them aside and say you were impacted by that conversation as being very hurtful, that you may have the substance use your or someone who uses drugs that's in your family or somebody who has died of an overdose or something like that. It's very, very important to actually call out that behavior because who's at fault? Unfortunately, it's not the medical student. It's the person that has their biased and judgmental views. And that person needs to be removed and put out some other place where they're not training medical students.

And I would actually call on the medical system to actually put people in place that have gone through rigorous practices with people who use drugs and also people of color and indigenous peoples so that they understand also trans and LGBTQ people as well, so that they understand all the sensitive issues that are behind all of this, and so that there is no biases or judgments when training these students, because these students essentially are going to be the generation that replaces that generation. And so we have to do a better job at training the medical system, and that should be part of it. And I know that a lot of it, that training just doesn't exist and it's really sad and unfortunate.

LAURA GUZMAN:

We're partnering in California with the California Bridge project, and so we have a project where we have train above, I think it was 50 hospitals in the first round and now it's about 200 hospitals. And the training is actually there is amazing tool kit. So I will put my email for the medical student so I can see if I can connect you with those two kids. And the idea of actually investing funding, is through the Public Health Institute investing funding to train emergency rooms to work with folks that are landing in the emergency with a drug-related issue.

And also we are funding substance use navigators for every emergency room hospital in California. Actually, we're training, but there are models that are evolving that I think Guy so, you know, we've been building some pretty interesting curriculum and also really kind of mandatory training for emergency rooms in California that I think hopefully will slightly change some of the dynamics worth mentioning. But I also want to echo what Guy says. I think we should be unapologetic. I was one of those people that will call any hospital, any emergency room, any social worker that was working with my clients and make them feel bad, treating them badly or said any shit that I felt was inappropriate. I will call them on any discharge that I feel was inappropriate, like people who when you know, because of alcohol intoxication or were let go within two hours back into our drop-in center. So any discharge mis-practices. So I want to say be empowered. We need to be unapologetic at this point.

ELIZABETH SALISBURY AFSHAR:

We just have about five minutes left, and so I wanted to ask my guest just for each of you to give like any sort of last-minute thoughts, reflections. This has been just a tremendous panel, I think we've heard and hopefully everyone here like myself has been reflecting on sort of

what I can do, what I can do better, what I can do more. So any last sort of last words, if you will, before we take a break, before the final session. Then we'll start with you, if that's OK.

GILBERTO PEREZ:

I guess that's the last thing that I would want to close off with, was that we need to challenge ourselves and challenge the system around us at every level and at every turn. And by challenge, I mean looking at oneself, like looking at our internalized biases and how that impacts the people around us and people that we serve and then systematically is questioning why our funding channels are coming down this pipeline instead of this other right? Questioning why people who use drugs are not included in this session or why they're not included in this conversation and the strategic planning meeting or an advisory council if it ultimately is going to impact their or their health and questioning our policies and procedures. I think this issue that was raised by medical student goes very, very deep as to the lack of a system of accountability system by the medical institution where that medical system doesn't feel comfortable disclosing or just confronting that medical provider with or without fear of retaliation of some sort. And so this is deeply embedded of a lack of accountability. And so also looking at our system or our policies and our procedures at that very level. So, yeah, I thank you so much for having me here and appreciate it.

ELIZABETH SALISBURY AFSHAR:

Thank you, Guy do you want to go next?

GUY FELICELLA:

For sure. So first, I think everybody should read Dr. Carl Hart's book, start their Drug Use for Grown-Ups and obviously in order for us to remove the stigma that exists in our society, it's really simple when somebody comes into your clinic or your facility, actually, a person who uses drugs and needs support go above and beyond to give them that support. And don't just tell them what they need, ask them what they need from you. And when they say that they need to get on methadone or buprenorphine or whatever it is, then you go above and beyond to make sure that that happens and you go above and beyond to make sure that that happens immediately for the person. Because I'll tell you if we can do that just starting there, you know, it's simple words like be kind it's really not that hard. And if you're not, you're actually pushing somebody to the illicit drug supply right now it's just that deadly.

And, yes, those drugs, they don't remove they're not drugs that are meant to remove people completely from the illicit drug supply. But what they do is they give people the freedom to actually focus on other things in their lives, like family, housing, friendships, employment. Those are the types of things that we need to remember that it frees up somebody's life. This shouldn't be a prison for somebody to live in for the rest of their lives. There should be freedom from the prison that we put them in. Thank you.

LAURA GUZMAN:

That's beautiful and so on and so close to liberation and, you know, I started to talk about the tree of stigma and the tree of liberation but liberation actually means that we are doing the work that it needs so people can feel free. And that means also that we create plans together based again on people's goals as Guy says and it's someone that has been doing trainings. And I know a lot of people in this audience have trained on stages of change. I want to say, quoting Gilberto's, start with yourself. Where are you and the tree of liberation versus the tree of stigma. How many times you're meeting with a patient and you just carry your own agenda? How many times you deny some, you know, filling SSI papers? I cannot tell you

how many times I have to fight with doctors who felt that this person was not sick enough and could work when all evidence showed this person was not going to be able to get a job.

Can you help someone get an SSI and get extra income and also ask clarifying questions? Be curious instead of being judgmental? That's the place we want to go first for all the ideas that I have in my head, the story I tell myself about my clients rather than really, truly listening to the story. And so to close again, I think, you know, let's move through a process of liberation for ourselves and from the folks that actually need that support. And I also feel, again, not forgetting love because actually stigmatizing people is not loving. So thank you. Thanks so much to this amazing panel, and I see Matthew came back on the screen, so I think he's going to close out the session. Thanks to all of you.

MATTHEW STEFANKO:

Thank you, Elizabeth. And thank you, Gilberto, Guy, and Laura. This was just truly an awesome panel. And I think we got our first set of sessions, obviously spoke a lot about where stigma was showing up, where discrimination was showing up. And I think this panel gave people a lot to think about on when it does show up. What do you need to do about it and how can you sort of empower yourself to do better? So we're so appreciative of you all taking the time. And I think this will be a great resource for many moving forward for those who are attending the summit. Thank you. We know that many of you are taking time out of your very busy day to attend. We want to build out a pretty lengthy break at one point so people can step away, eat, grab a coffee, do other work, take a nap, whatever it might be.

We're going to come back at 3:40. There's just going to be one session taking place. It will all be coming back together. You'll be able to find that in the 1.1, 2.1 opening panel room will have a really incredible set of an innovation session. We're actually showcasing six of our winners of our innovation process and doing some really cool workaround and anti-stigma and anti-bias work nationally. And then we'll leave with our keynote are a few incredible speakers.

SESSION 2.3 - RESEARCH, EVIDENCE, AND MECHANISMS FOR ACTION

AISHA SALMAN:

Good afternoon, everyone, and welcome back, you are now in session 2.3 titled Research Evidence and Mechanisms for Action. I'm so pleased to have an expert panel with us here today, who will discuss what we know, how we can learn more and how to promote future research and implementation. Today's session will be moderated by Dr. Brea Perry, Professor of Sociology and Associate Vice Provost for Research at Indiana University. Dr. Perry, I will turn it over to you to take us through the rest of today's session.

BREA PERRY:

Thank you so much. I am so pleased to be here and really excited to hear from this outstanding group of panelists that we have here with us today. And so I will go ahead and introduce them all and then they are going to provide about a five minute introduction to what they do, sort of who they are. And then we will start in with some directed questions. So our panelists today are Tom Hill, he is a senior policy adviser in the White House Office of National Drug Control Policy. We also have Dr. Beth McGinty, who is a professor of health policy and management at the Johns Hopkins Bloomberg School of Public Health.

And we have Jessie Gaeta, who practices internal medicine and addiction medicine at Boston Health Care for the Homeless program and is also an assistant professor of medicine at Boston University School of Medicine. So we will go ahead and kick it off with Tom, who is going to provide some introductory remarks.

TOM HILL:

Thank you so much. And yes, indeed, I'm really pleased to be a part of this panel, we met last week and I feel like I'm in really good company here. So good afternoon, my name is Tom Hill and I'm a person with lived experience. So first I'm a member of a family that has experienced generations of substance use, addiction and mental illness. Second, my direct lived experience with using substances and addiction is as equally important as my lived experience as a person practising almost 29 years later this month of abstinence based recovery, which was my choice.

I feel neither shame about my addiction nor particularly heroic about my recovery journey, it's all just become a part of my life, a part of who I am. As a queer man, my pronouns, he, him, his in recovery, I have learned that when I treat all people with dignity and respect, I can expect to be treated the same. I'm currently serving as a Biden-Harris political appointment as Senior Policy Adviser at the White House Office of National Drug Control Policy, we call that ONDCP. The administration's first-year drug policy priorities have a strong focus on reducing the rising overdose death rates in our country.

And we are committed to grounding all of our work in the latest science, research and evidence. Aside from addressing the supply of drugs into our country, ONDCP public health response addresses access to quality treatment, including medication and including medication with incarcerated populations, harm reduction services that includes service programs, sentinel test strips and naloxone, youth prevention. Workforce issues that also include recovery ready workplaces, recovery support services in general, and then an overall theme that we shared with the entire administration on racial equity.

So we're now in the process of developing our 2022 national drug control strategy, and that

will be released in February of next year. Operations are underway started and being initiated in terms of various drafts. So stay tuned, I think it's going to be really, really exciting. That's all for me, thank you.

BREA PERRY:

Thank you, that's super interesting and I can't wait to hear more. Next up is Beth.

BETH MCGINTY:

Hi, everyone. I am pleased and honored to be part of this panel this afternoon. I'm a researcher by training, one of the several hats I wear is director of the Center for Mental Health and Addiction Policy at the Johns Hopkins Bloomberg School of Public Health. And within the center, I am one of the leaders of a group called Stigma Lab. And Stigma Lab is a group of researchers focused on rigorously studying stigma reduction strategies. And specifically communication strategies, the types of messages to reduce stigma that we disseminate through large scale stigma reduction, campaign billboards, television ads.

You see them in health care settings where there are messaging campaigns disseminated on screen savers and electronic bulletin boards, etcetera. We try to rigorously study and evaluate those messages to make sure that they are in fact stigma reducing and that they don't have unintended consequences. So we use a variety of research methods to study stigma reduction, communication strategies, with a strong focus on strategies to reduce addictions, stigma specifically, and stigma toward drug use more broadly.

And those methods include news media content analysis, surveys to test the persuasiveness of different types of messages, as well as randomized experiments to formally test whether different types of communication strategies have their intended effect of reducing stigma. A key theme of my remarks today that I'll just tee up briefly here in the introduction is the absolutely critical importance of rigorously evaluating these types of stigma reduction strategies. Too often we design messages sort of based on our gut feeling about what might work, and while well intended, that there are some real cautionary tales about that approach.

Where we see messages that are not effective being disseminated broadly through really costly communication campaigns. One fairly well-known cautionary tale from the world of mental health stigma reduction is the, disease like any other campaign, which was a national large scale campaign in the 1990s with the tagline of Mental illness is a disease like any other. You know, I could imagine putting myself in the room of folks who came up with that message and saying, yeah, that seems like that might be stigma reducing, it might be normalizing.

After the fact, after a very large scale costly campaign, a research by (UNKNOWN) and colleagues showed that not only did that campaign not reduce stigma by some measures, it actually had the unintended consequence of increasing stigma. Perhaps due to the fact that the disease framing increased perceptions of the permanence of mental illness. And so that's the kind of cautionary tale that our group tries to help fend off in the future by developing and testing rigorously messages before they get disseminated in the field.

BREA PERRY:

Great, thank you so much, Beth, that's fascinating. OK, next, we'll hear from Jessie.

JESSIE GAETA:

Good afternoon, everyone, I'm really excited to participate in this conference, I've been learning a lot all afternoon. My name is Jesse Gaeta, I'm an internist and addiction medicine specialist at Boston Health Care for the Homeless Program. And we are a community health center with about 40 different clinics around the greater Boston area. And just to give you a sense of where we're coming from and where our practice exists, we have had the number one cause of death for the last 15 years in our practice, drug overdose death.

And in fact, in the fentanyl era here in Boston, which really started in earnest in 2014, since then, overdose death accounts for one in three deaths of the patients that I see at an average age of 43. In the building where I'm sitting right now, at our main site, this is really the epicenter of the overdose epidemic in Massachusetts. We respond to about five overdoses every single week in the building that I'm sitting in right now. But just by way of introduction, I wanted to share with you two quick stories about stigma from my practice that are just so memorable to me.

The first story is one that really seemed to play on repeat for a number of months, and that ultimately led to the creation of a harm reduction program within our community health center. I can see it really clearly in my mind because it's happened so many times. On the floor, in our public bathroom, in our main building here in clinic, I'm hunched over a young woman who we've just revived from overdosed using naloxone and rescue breaths. And as she begins to wake up just underneath me, feeling the immediate withdrawal from opioids, she's both disoriented and afraid.

She's half dressed, she's shaking like a leaf, she started to sweat and she's completely vulnerable in that moment. Our team felt worried because she's a stranger to us, she isn't seen in our clinic because even our services, which are far from mainstream, are fairly structured. It's hard to imagine this woman sitting in a waiting room before she's being seen. So there are elements of the way that we operate that simply make her reluctant to engage with us. But the single greatest reason for reluctance to engage in health care and social services is stigma within our system.

So as we had called 911, she and the paramedics have arrived, she just adamantly refuses to go with paramedics to the hospital. She's completely reasonable because of fears of being stigmatized there. We're afraid to see her walk out the front door, we don't know if we'll ever see her again. And all I can feel in that moment is like desperation to let her know somehow that we can be here for her no matter what is happening and I want to know her better. But just the reluctance to go into the hospital after an overdose, I think is one great example of stigma.

We hear heartbreaking stories of trauma and loss and stigma at the intersection of homelessness and addiction that cause so many people to avoid many health care settings and actually social service settings as well, reasonably and relentlessly. And so with some understanding of how much stigma is playing into this, we started to really shift our programming here in 2015 and we opened a harm reduction program called SPOT, the Supportive Place for Observation and Treatment. And this is a program we just opened up out of desperation to save lives and really to deepen our relationships with people who are actively using drugs.

This is a non-judgmental drop in space focused on reducing the harms of drug use, where

we've provided overdose monitoring and harm reduction services to thousands of people. From the beginning, we really tried to design this program by trying to listen as best we could to the needs and concerns of people actively using drugs. We want to make it clear in this program that no matter what you're doing, we want to care for you, you have worth and we love you. Where someone might be struggling, we really should be seeing resilience and great strength.

In this program, we sort of shifted the paradigm that we hear so often and said you really don't need to stop using in order for us to start offering help and this brings me to the second story. So often unwilling to go to any other provider in our health care system. One woman who we had never seen before we open this program, began coming in during periods of really dramatic sedation from substance use. And one morning after several hours of sort of waking up, she just was completely surprised to be in a healthcare setting and feel this loved, I remember her literally waking up and saying, like, what is this place? She was like in total shock.

Who are you? I haven't slept on a pillow in years. Why do you care about me? And this was just a hint of how she had internalized what I would later come to understand as just decades of deep and intersectional stigma with addiction at the center of that. Now, on a different day when we narrowly convinced her to go to a local emergency department for care of a serious wound infection, she later described the experience in the emergency room to us. And I couldn't believe that her wound was debrided without local anaesthesia and I've actually heard that story many times since.

But also she recounted the following that just sticks with me. A nurse actually jabbed a needle in her arm aggressively and without consent, surprising her. And when she flinched and screamed, the nurse said, it's a hepatitis B vaccine, what's the problem? You do this to yourself all the time. I just thought I would start with those two stories.

BREA PERRY:

Wow, thank you so much for sharing those really important stories. I think it really illustrates the stigma that people with addictions face in the health care system and I'm so glad that you're doing the work that you're doing to care for them and show them that they're valued. So as you can see, we have an outstanding group of panelists here with sort of a range of experiences and expertise. And since this panel is about research and evidence, I'd like to start by asking Beth and then others, what do we currently know about the stigma of addiction from the scientific literature?

BETH MCGINTY:

Happy to start us off here. This is a tough question to get the universe of research in a short, concise answer. So I will take a stab, but admittedly not be comprehensive and I look forward to my co-panelists jumping in with points that I have missed. So I'll make three points here about what we know in a foundational way about stigma from the scientific literature. So first, we know that stigmatizing attitudes surrounding drug use and addiction are pervasive and persistent among both the general public and among professional groups that serve people who use drugs and people who experience addiction, including but not limited to health care providers. As you heard in some of Jessie's really compelling stories just a moment ago.

You know, I won't bore you with a laundry list of statistics here. But one illustrative statistic

that I'll use to frame up this issue is that, a recent national survey that our team conducted with a representative sample of primary care physicians in the US. Who are at the front lines of treating people who use drugs, although they're not addiction specialists, we found that 75%, three-quarters of primary care physicians in the US reported very high levels of stigma as measured by social distancing attitudes, which is a standard way of measuring stigma.

So 75% of primary care physicians said that they were unwilling to have a person with opioid use disorder marry into their family. Two-thirds viewed people with opioid use disorder as dangerous and those statistics are as high or even a little bit higher than the same measures of stigma as determined by social distancing attitudes that we see in the general population. So I think many of us often have a prior that our health care professionals might have less stigmatizing attitudes than the general public. And evidence suggests that on a national scale, that is not the case and that we have a lot of work to do that.

The second point that I will note is that it's well-established in the literature that a really key driver of stigma toward people experiencing addiction is the belief that addiction is a personal choice, reflecting a lack of willpower and a moral failing. So when we think about overcoming stigma, that belief is a key one that we need to surmount. And then third, circling back a bit to my particular area of expertise around communication strategies to reduce stigma. The evidence has identified some guiding principles for communication strategies to reduce stigma.

I say guiding principles rather than sort of definitive, effective strategies, because this is a pretty limited area of research to date, there's a lot of work to be done. But the principles that we have identified are one that language is incredibly important, small language changes can have big effects on stigmatizing attitudes, in particular there is rigorous evidence from randomized experimental studies showing that using person first language, so person with a substance use disorder is significantly less stigmatizing than using terms like addict that conflate the person with the condition.

There's also evidence from experimental studies that the term abuse is problematic. I raised this one because it is so widespread and institutionalized, I get much of my research funding from the National Institute on Drug Abuse. And this is very problematic and not only because this is a term that has been shown to be stigmatizing in recent studies, but also because it no longer has any valid clinical meaning. Since the most recent release of the Diagnostic and Statistical Manual, which is the manual we use to diagnose mental health and substance use conditions, there is no such clinical condition as substance abuse or drug abuse.

There used to be, which is why this term has been so institutionalized. But now the clinically meaningful term is substance use disorder. So really working to scrub that term abuse from our vocabulary and from our institutions is a priority in terms of stigma reduction. The next guiding principles that I will emphasize briefly, three more guiding principles are around communication. One is that evidence suggests that messages emphasizing solutions can be destigmatizing. I think this is intuitive when I say it out loud, but often when we talk about public health problems in general, including but not limited to substance use, we're very focused on talking about the problem and less so on framing it as a solvable issue.

And so talking about solutions, and there's a broad range of evidence-based solutions, prevention, harm reduction, treatment (UNKNOWN) messaging can actually be stigma reducing. Next, there's evidence that use of sympathetic narratives that melds compelling

personal stories with cues about a societal and biologic factors that influence addiction, can reduce stigma. This is, I think, a very important point in that, the communication research shows that there are some downsides to personal stories, they are emotionally engaging. But if they don't pull in some of those cues about societal forces contributing to the problem, they can actually backfire and lead audiences to blame the individual telling the story for their own problem.

And then finally, and this is where I will stop with my whirlwind overview of the evidence, there is good research showing that it's important to really emphasize those societal rather than individual causes of substance use and addiction. So I'll stop there, thanks.

BREA PERRY:

Excellent, thank you, that was very thorough. So I was hoping that Tom could follow up because one of the things that Beth mentioned but didn't talk a lot about is this issue of what causes people to become addicted to drugs and this issue of a moral failing. So I'm hoping that you could tell us a little bit more, given your experiences in the work that you do. What is it that drives stigma? What are sort of the beliefs or attitudes that underlie the public's inclination to exclude or avoid people with addiction?

TOM HILL:

Absolutely and thank you so much Beth for that layup that was really, really nice. And I just want to add that, you know, I've been doing recovery community organizing for over 20 years, and we started talking about language and the word abuse over 20 years ago, so it's great to see it use less and yet it's like people still cling to that word and (UNKNOWN) institutionalized, so I get it. But there's also concepts like calling somebody clean or dirty, calling people non-compliant as if they have no part in their own health care or well-being, and not only the word abuse, but the word abuser. And for folks who have suffered abuse like myself, (UNKNOWN) it has a particular sting. So it's like I'm glad reading more research on that but it's like you can't change your attitudes unless the language follows it or the language leads it. So I just want to say that the solution stuff, we've been talking about, strength-based that that people have the wherewithal to make their own decisions. People with addiction have the wherewithal to make their own decisions and that's really a strength-based, not a deficit-based approach and it is a solution based. We're going to talk about the stories later, I hope.

But I do want to talk about the causation stuff, because I think, you know, there's been so much research done on trauma and how that affects addiction. And for me, it was really informative to start to piece parts of my childhood and life together through a trauma lens that started to answer questions as to why I experienced what I experienced. So I think, you know, the science is catching up, we still have a lot of work to do. But I also just want to flag that we are living in a society right now where there is yet another wave of anti-science backlash that's happening in communities across the country, we've seen with COVID and we're seeing it with addiction again.

And so, you know, we really established a good base of a concept of addiction as a chronic brain disease. And that's a science-based is being refuted back to that idea of moral failing and character weakness. So it's disheartening to see that, but I think we really need to double down in terms of presenting the science, no matter what. The belief that, you know, I can't tell you how many times I've presented as a person with lived experience and recovery and certain people have said, I didn't put a needle in your arm, you chose to do that yourself.

And that's a showstopper until you come up with the idea that, well, you know what? There's a lot of science behind why my brain became the way it did and the way that drugs and alcohol countered that brain and then often affected that brain as well. So I think we have a big pull in our society to pull it back to science and I think that there are forces out there that just do not believe what the experts say and we just say it louder and say it clearer. So I hope I answered your question Brea.

BREA PERRY:

Yes, that was perfect. Yeah and I totally agree, it's so hard to counteract the sort of anti-science attitudes, particularly when people just sort of fall back on stereotypes. Particularly, in like cases where there's a lot of uncertainty around the condition, we just tend to fall back on our base instincts, unfortunately. And so I would like to talk a little bit about translation of basic scientific research. And someone in the chat actually asked about what sort of interventions work to reduce stigma. And Beth knows very well, as do I, that it's very challenging to translate this research into policies or interventions, that can actually move the needle on stigma or help individuals with addiction to cope with stigma.

So I would like to have Jessie talk a little bit, given her experience working with and on behalf of people with addiction. Are there sort of conditions within health care settings or strategies that you found that help to reduce stigma, even anecdotally? So what kinds of interventions have been successful in the work that you do, if any?

JESSIE GAETA:

This is a really good question, and I just want to emphasize that I'm talking anecdotally and I don't have a great science packed answer to this. I'll say I'm really thinking about health care and also social service settings, which is kind of where I sit. I found that, first of all, what we're really talking about is establishing a new culture often, and that's a really tall order among health care workers, social service workers and it takes time. Some of the things I thought to mention that I think have been successful, shifting culture in some of the places where I work have been.

For example, hiring people with lived experience to do the work and embedding them in teams, you know, where there can be sort of direct confrontation about some of the unintended, but still consequences of the ways that stigma plays out in these settings. I think in terms of establishing culture, it's really helpful to have people who are in leadership positions set a clear path and a clear vision for what the work entails, how we are approaching addiction in any setting. It's really helpful to have a clear vision set and then to work to build (UNKNOWN) among more and more people in a program or industry.

And how do you do that? How do you work to build (UNKNOWN) that, addiction is a chronic brain disease, for example and that it's not a moral failing? I think there are lots of ways to do that. I think different things speak to different people and I don't know if Beth and Brea if this kind of bears out in the research. But you talked something about the power of personal narrative. And I think for some people, especially in health care, perhaps science, there is some weight given to science. And if we can go back to the primary, you know, basic science of substance use disorders and present that.

Or we can show outcomes from various, what we would think of now as evidence-based treatments, etcetera. I think science does help in these kinds of settings for some people, that

really does help drive the needle a little. I think also setting up the chance for people to process and talk about what this means to them in small group settings, that can be hard to do and it can backfire also. But I think people need a chance to talk about the shift in culture or what it means for them to talk about their feelings about addiction. And to do that in a way that's going to be sort of safe, so small group facilitated discussion processing, I think helps. And then finally, I think at some point we have to not settle for pathologic culture, we have to set a hard line and we have to stick to it. And that's easier said than done but those are some kind of anecdotes that I thought of.

BREA PERRY:

Those are so valuable and some of the things you said made me think a little bit about some of our research, which looks at the effect of social contact on stigma. And we find that one of the best ways to reduce stigma is to foster sort of meaningful, positive social contact between the person and a stigmatized group and someone in the general population. And so having these contacts, as you mentioned, is so important. And this also leads me really naturally into the next question, which is about bringing people with lived experience into stigma reduction research. So how can we do this? Why should we do this? What unique strengths do these individuals bring to the table? And I would love to, given your experiences, hear from all of you on this question. Beth, do you want to go ahead... Tom you want to start, go ahead.

TOM HILL:

First. I just want to make a comment to what Jesse said. We do have research and we have corporate research and customer satisfaction. And there's been a lot of lessons learned in terms of return policies, customers coming back, treating people well that it's a very different culture than it was 20 or 30 years ago. Think about going to a return line at the department store after Christmas and having to deal with all that. So the bottom line there is if you treat people right, you treat people well, they'll feel comfortable and they'll come back, if they feel respected and honored.

So I just want to say that, the thing about lived experience and I think we have to be careful about this because, you know, one size does not fit all. And I think it's really important that we do sort of expect to have people with lived experience at the table now, we fought hard for that, I think our stories are really important. I go back to what Beth said earlier about the principles, about the stories and the lessons learned there. And I think another lesson learned is how do we build a framework for those stories that we don't create a them and us and that we don't separate the innocent victims from the bad people doing bad things.

And I think we have a history of that, of sort of cherry-picking the stories that we think will win people over rather than having authentic lived experience stories and narratives that are often crafted by the people themselves in a way that is to their own ends. So I just want to just say that because I think we're always in danger of doing that. And it seems like an easy, early win, but I think it backfires in the long run. I'll turn it over to somebody else.

BETH MCGINTY:

Yeah, I can go next. I agree with Tom's points, I think that my view here is that it's really critical to include people with lived experience in this line of research and all of the research I do around mental health and addiction policy. I think part of being a good scientist is assuming that you don't really understand an issue if you haven't lived it. And so you need to, sort of as a starting point, engage with people who have lived experience. I think in terms of

stigma reduction, it's just really illuminating to understand all the ways that stigma manifests, which I think Jessie perhaps sees as a health care provider but someone like me who's an academic researcher doesn't see it on a day to day basis.

And so having people embedded in my teams who have lived it, sort of keeps the whole motivation for this work very front and central and also helps sort of craft, as Tom was alluding to authentic messages that don't inadvertently exclude or other the people that we're trying to help by reducing stigma. You know, just totally, practically I think a lot about how to do this well in a research environment, I don't think I've struck on the perfect way to do it yet, so I'd love to hear other ideas. But I think there's a variety of ways to do it.

You know, as a mental health and addiction researcher, I try to hire folks on my team who have lived experience and who (UNKNOWN) full time members of the research team contributing equally in the same way that I am. In cases where that's not feasible, we often use mechanisms like advisory boards. I think doing that well is challenging in that those types of boards often include a lot of people including but not limited to those with lived experience. And you need to really make sure that everybody has an equal voice and equal power, I won't go into tons of details about how one does that, but there are some strategies out there and I think it requires a lot of intention to do. I'll stop there.

BREA PERRY:

Thank you, Jessie did you want to add anything?

JESSIE GAETA:

No, I don't have anything to add to that.

BREA PERRY:

OK, great. So that was a really interesting discussion. One of the things that I want to make sure that we have time to talk about is the issue of intersectionality. And for those in the audience who may not be familiar with this term, it refers to sort of the interconnected nature of social categories like race and social class and gender. And how these forms of social inequality might influence or interact with the stigma of addiction. And of course, it didn't escape any of us when we were planning this panel that we are all white and that some people who have addictions are not white.

So I think discussing this issue of intersectionality and how things like race and social class might play into the stigma of addiction is really important. So I wanted to make sure we got to that. So, Tom, did you want to start us off with this? I know you had a lot of really interesting thoughts about this during our initial discussion.

TOM HILL:

You know, I will thank you. And I think, you know, I'm always on a delay, I just want to say one more thing about lived experience, I'm sorry. The other thing about inviting people with lived experience to the table is that you need to take the time to process and prepare people. Because they may not speak, it's a culture shift again, they may not speak the same language, they don't know the vocabulary, It's a lot of patience. But it's sort of coaching and mentoring to sort of make them feel comfortable in any given situation they're in. And I would be remiss if I didn't talk about participatory research also as a community-based way to bring in people with community and lived experience.

The thing about intersectionality, so I told you I've been doing recovery community organizing for a long time. In the late 1990s, I had a group called Speak Out LGBT Voices for Recovery, it was out of the community center in New York City. And we had a group that was very, very diverse and the kinds of discussions we had about stigma, about language, about all these things, we talked about harm reduction versus (UNKNOWN), we talked about all these things. But we really talked about what we brought to the table in terms of various cultures of queer people, Puerto Rican experience, black experience, lots of trans-experience, like all these different sort of identities that people had brought in.

And lots of layers of trauma and lots of layers of hurt and lots of layers of stigma. And we sort of tried to figure out a way to unpack that as a group, to talk about advocacy and peer services in a way. And it was important for me because I didn't want to design recovery services that were built around a white experience that looked good to me but didn't include people the way I thought it might include them, because they didn't see themselves reflected in the programming. So we built all the programming from scratch and had everybody build it in a way that made sense to them and that made sense to the whole.

So I learned a lot of really important lessons there about people who I never really saw as being left out of the picture that had always felt left out of the picture, even the recovery picture. They see it as a white thing. So it's like when you unpack all of that and you see tons of intersectionality, tons of people that were excluded, no matter what community they were a part of and they were part of many communities, there was always a piece of them that they couldn't bring in. And so it affected their sense of wholeness, they were very fractured.

So, I don't know what point I'm trying to make with this, only that there's an intentionality that we need to bring in terms of when we talk about stigma that is going to affect people in various different ways. And they're bringing stigma from a lot of different parts of their lives, not just their substance use or their addiction or their homelessness or any of those things.

BREA PERRY:

Yeah, that is so important, I mean not to mention that people in the general public view people of different races or sexual orientations or genders with addiction differently, so we know that those things can magnify that experience (UNKNOWN). So, yeah, that was great, thank you. Jessie or Beth, did you want to weigh in on this?

JESSIE GAETA:

In thinking about intersectionality and stigma. First, I was just remembering that the person that came up with this term intersectionality in the late 1980s, I believe, was a black woman, a law professor named Kimberly Crenshaw. And she was really creating this term, I think, to describe the way that black women felt in a largely white women's feminist movement that has been now, I think, used in lots of other ways, but just to recognize that. But as I think about, though, intersectionality as it relates to the stigma of addiction, I think that the place where my head goes right to, is really thinking about the intersection of stigma around race, identity and addiction. And sort of recognizing the profound ways that the racist war on drugs, which has been our society's primary approach to addiction in the last four decades, has shaped our mindsets about addiction and how much it has really informed our opinions about people with addiction. And I'm thinking even about the fact that we've moved so far and we're still trying to move the needle toward public health approaches. Of course, that's happening at a point in time where we're in an opiate epidemic, you know, has affected or at least has been talked about as more of a (UNKNOWN) condition.

You know, even the fact that, like, we're sort of thinking about addiction from the point of view of stigma in recent years, so much has some, you know, overtones that are so racialized. And so that's really where my head goes most when I'm thinking about stigma and intersectionality.

TOM HILL:

That's where stigma bleeds into discrimination because they're very closely linked, but then we have policies that are discriminatory and really damaging to entire communities of people over many, many decades and targeted that at that experience. So I totally agree with you.

BREA PERRY:

Beth, did you want to weigh in on this one?

BETH MCGINTY:

I think the other panelists covered it.

BREA PERRY:

Alright, sounds good. So I wanted to, I mean, this went so fast because it's been so interesting. You all are so knowledgeable that we're sort of getting close to the end of our time together. So I want to leave the audience, I guess, with something that's going to help them remember sort of why we're all doing this work and why this is so important. So I'm hoping that you can weigh in on the costs of ignoring the problem of addiction stigma. How is stigma affecting the lives of the people that you work with, the people that were studying? You know, and what happens if we just pretend that this doesn't exist? So I'll let you guys go ahead. Jessie, do you want to start with this one?

JESSIE GAETA:

Sure, I'm thinking about like even the stories that I told the beginning of this session, you know, I think if we ignore stigma, if we don't really take this on, take ownership of this in our society and work to change it, then the two cases of the women that I talked about, they're not going to come in health care settings, they're going to die prematurely of things that are treatable. And, you know, more broadly, I guess I would say that we'll continue to see this profound effect on people's self-worth, how much people will continue to internalize the stigma that they're feeling from society around them, I think it just has so many detrimental effects. And we've heard from so many speakers actually throughout this whole program about the effects of kind of internalized stigma and oppression on people with addiction, it's absolutely deadly. I'm not sure what else to say about it, it's deadly.

BREA PERRY:

Yeah, I think that's really well put. Anyone else want to weigh in on that?

TOM HILL:

We have evidence right now that it's deadly because we have an overdose death rate that is just alarming and going up. And the systems that we have that are, I think, largely influenced by decades of stigma are not working very well. So people show up for help, we often don't treat them very well, we don't trust them to make their own decisions and choices. And the bottom line is we don't expect them to win and we're expecting them to fit into systems that we know don't work and then we blame them when they fail, which just exacerbates stigma. And so, you know, we have research on social determinants of health.

We have research on recovery capital, you know, I came in with relatively large recovery capital, but a lot of people don't. A lot of people don't have the resources to put together to even access healthcare, much less addiction treatment. We haven't even talked about the stigma of medication. We haven't talked about the stigma of methadone for 50 years, and that's embedded in our system. So we have answers that are stigmatized and that we have to fight against that. But the system we designed is really built for acute care, it's not built for a chronic care model.

It's not addressed for long term care and people cycled through it many times and we said just relapse again and again and again and we stigmatize them for that. Even the word relapse is stigmatizing because of the sort of shame we put on it, we don't do that for other chronic conditions. We don't do that if somebody who has diabetes, that's a piece of cake, we don't shame them and say, well, you failed, we get them back on course again. What Jessie's talking about with the women in the stories is, you know, folks that have been really abused by the system and are gun-shy to come through the door because of the way they've been treated.

And so how do we build systems that engage them? We know that harm reduction has engagement tools to keep people coming back because they don't feel judged, they don't feel stigmatized, they're offered a cup of coffee when they come in or a warm blanket, whatever, and people are treated really well and they come back and in that level of engagement we don't have anywhere else. You know, we penalize people for not showing up for their appointment without asking them what kept them from making the appointment.

You know, like there's just little tiny things about customer service, about treating people with dignity and respect that I think that is a culture change. And I think that, you know, like the stigma reduction starts here, it starts right here and then it fans out. And so I need to take responsibility for ways that I promote stigma and don't do it anymore. And everybody else, both in our health care system and in our society, needs to sort of figure that out. So I just realized that I stepped right up on my soapbox, so I'm going to just sort of gently step down. But I think, you know, like some of these answers are in front of us and they're very, very simple and they have to do with human compassion. And you can't have human compassion if you're blaming somebody for their medical condition. And we don't do that with too many other medical conditions. Alright, I said enough.

BREA PERRY:

I just got chills, so I think that was really, really well put. And also reminds me that this panel could be like four hours and I would enjoy, like sitting here talking to all of you and learning from all of you. We have just like one or two minutes, if you guys have a last thing that you want to say, something you really wanted to express, that you didn't have a chance to get out yet. So, you know, please, if there's any last minute stuff you got to say, get off your chest.

BETH MCGINTY:

Now, I have one thought that I have been sort of increasingly focused on, which is that, you know, I think that as we think about stigma reduction and particularly stigma reduction among professionals who are working with people who use drugs. I think that where the field needs to go is to figure out ways to sort of integrate stigma reduction alongside other evidence based practices. I work with a lot of health care systems on stigma reduction, even a

very highly evidence-based communication campaign seems to me that it will be unlikely to reduce stigma if front line providers in that system don't have resources to effectively treat or refer to harm reduction the people who they serve.

They have incredibly frustrating experiences on a day to day basis and are sort of unable to help the people who they want to serve and that reinforces the stigma over and over and over again. And I think that the field so far has really not thought about stigma reduction in that way. It's done in this stand alone, let's do our campaign or a smaller scale, deeper sort of social contact-based intervention like Brea was talking about, which is quite effective, but hard to scale in a broad way. And I just think that the sort of paradigm that we need to shift towards is that stigma reduction is going to make implementation of evidence-based practices around addiction more effective. And those evidence based practices are also going to make stigma reduction more effective.

BREA PERRY:

Yeah, for sure. Unfortunately, I have to turn it over to Aisha now to end the session. Thank you all so much, I have learned a lot. It's really been a pleasure meeting and talking with all of you.

AISHA SALMAN:

Absolutely. Thank you to you as well, Dr. Perry, for moderating and to all of our panelists for your remarks. I have to agree with Dr. Perry, I think this session alone probably could have spanned the entire summit. It was incredibly fascinating discussion; I think each of you brought a really important perspective to the topic. We will be taking a 30-minute break now. So the next part of our program will be the innovation session, and that will begin at 3:40 pm, Eastern Time. So thank you so much and we will reconvene soon. Thanks, everyone.

INNOVATION SESSION VIDEO PRESENTATION

AISHA SALMAN:

Hello, everyone. Welcome back from the break. As a part of today's program, we are so pleased to be able to bring you an invitation session. Of course, we are in the virtual environment, and in lieu of a traditional poster session, what we did was issue a call for abstracts and will now be presenting a handful of videos of the submitted abstracts that were selected as top submissions. Several months ago, we invited individuals, teams and organizations to submit abstracts showcasing innovative programs, initiatives, strategies, research or products that could be at any stage within the development lifecycle but had the aim of reducing stigma on people who use drugs. We received nearly 100 submissions from across the country. All the submissions that met the requirement criteria are included in a compendium which includes the full abstract along with contact information for the authors. We hope this compendium can be used as a resource that fosters connection and collaboration on a range of promising sigma initiatives and can ultimately help build a stronger and broader network among those who are working to reduce the stigma of addiction.

You can access the compendium on the right-hand side of our event page, and we encourage you to make use of this compendium. Today, we will be featuring the top six submissions in video form, and those featured videos are listed here on the screen. Congratulations to everyone who was involved in these submissions. The initiatives that are featured here span regions across the US. We have initiatives specifically focused on reducing stigma within marginalized populations and strategies that include everything from a media campaign to developing a primary care clinic curriculum and everything in between. We're so pleased to be able to share these innovative initiatives with you. So, let's go ahead and roll the tape and you can learn more about these programs.

VIDEO 1

Project ECHO is a performance optimizer. Think of it as a high-speed Internet connection for the health care system. It spreads new medical knowledge throughout the health care system from university medical centers and other specialty care sites to the front lines of community care. Rather than information flowing in one direction, community providers learn from specialists, they learn from each other and specialists learn from community providers as new best practices emerge.

ADRIENNE MADHAVPEDDI:

There has been tremendous effort across the state of Arizona to increase the number of buprenorphine waiver providers. And if this was the goal to simply get providers waived, these programs would have been deemed quite successful. However, despite these efforts, the reality was that very few, about 3% were actually integrating MAT into their practices, and in looking at why this was self-perceived lack of knowledge and confidence in MAT best practices persisted, coupled with an ongoing stigma around OED and OED patients. In response, our team here at Arizona State University gathered an interdisciplinary team of specialists in MAT. These experts represent prescribing physicians, a pharmacist, a policy expert, and a harm reduction specialist. Together, this team built and launched our Medication-Assisted Treatment ECHO.

ADRIENNE LINDSEY:

We've been very pleased with the outcomes of the MAT program so far. We've had robust participation and engagement from the community. Nearly 300 learners have joined since we launched and an average of just under 50 learners join each session. As you can see from these heat maps, our learners are spread across the state with some learners joining from out of state. They come from rural and metro areas and practice in opioid treatment programs, office-based opioid treatment programs, hospitals, and tribal clinics. Our audience has been very interdisciplinary, including health care providers, behavioral health providers, peer support, administrators, and other professionals. This is made for really rich discussion of the patient cases.

We assess learner outcomes through post-session and biannual surveys. So, far, these surveys have indicated high rates of satisfaction with the program. Our average satisfaction rating is 4.6 out of five, with most participants reporting they're extremely satisfied. Participants have also reported improvements in their knowledge of opioid treatment after participating in ECHO, including general knowledge of the treatment of opioid use disorder, knowledge about medications to treat opioid use disorder, and knowledge about related treatment modalities. Similarly, participants have reported improvements in their confidence across a number of domains, from starting a conversation about opioid use disorder with the patient to assessing for buprenorphine contraindications.

This side-by-side graph shows the percentage of learners who reported they were very or extremely comfortable with these domains, both before and after ECHO. And as you can see, participants reported improvements in all confidence domains. As a whole, we found high learner satisfaction and improvements in learner knowledge and self-efficacy in providing opioid treatment using this ECHO model.

CHRIS ABERT:

One of the key elements to expanding access to buprenorphine and methadone is understanding that people who are living with substance use disorder are survivors. All too often they're blamed and treated as criminals. Stigma, as we know, is alive and well, both for the patient and for the provider. So, one of the things we really want to do at the ASU MAT ECHO is to give the back story, to understand that folks have survived trauma, that they have high adverse childhood experience scores. And then it took a lot of courage just to even show up to the prescriber or provider's office to seek help. When we were curious about people's stories and when we understand that substance use disorder is a complex bio-psychosocial phenomenon, then we can meet people where they're at. We can then walk alongside them and witness as they struggle and try to make positive change in their life. And we can kick up the love a notch.

AUDIENCE:

MAT ECHO. Yay, yay, good job.

VIDEO 2

MONA ABDALLAH-HIJAZI:

My name is Mona Abdallah-Hijazi, and I'm representing our study, Public Health Stigma Towards Substance Use. If you're wondering what I said in the beginning of the video, it was hello in Arabic, commonly used in Lebanon and surrounding countries. The reason I greeted you in Arabic is because our project is in the Arab-American community. Before I describe the project, I will explain that the project is a collaboration between a large multi-service

agency in metropolitan Detroit called ACCESS, or the Arab Community Center for Economic and Social Services, and Wayne State University. I am a Community Engagement Manager at ACCESS for a federally-funded community coalition promoting prevention on substance use and a PI for this project. The other PI is Dr Cynthia Arfken, a professor at Wayne State University who has conducted extensive research on substance use in the Arab-American community.

We also have team members who we want to acknowledge. We cannot do this research without everyone on our wonderful team. Substance use is a problem in the Arab-American communities, like all communities. The community traces their heritage to countries in the Middle East and North Africa. The countries share Arabic as a language and culture that emphasizes the group as opposed to individual. People from Iran, Afghanistan, and Pakistan are not Arabs as they have different languages and different cultures. Similar to this culture, substance use and misuse are stigmatized. The use and misuse can bring shame to an Arab-American family. The community reinforces shame through public stigma towards those who use and misuse substances. The community is diverse with people migrating at different times and different reasons. Major areas of settlement include Michigan, New York, and California.

In Dr Afken's work, she documented the differences and willingness to discuss substance use in the community by people born here compared to immigrants, by gender, and by religion. By religion, we mean the two major religions in the Arab world, which is Christianity and Islam. In my prevention work, I have personally seen how people do not want to talk about substance use or if they do, it is to stigmatize those who do so. The stigma is a barrier to our coalition's prevention work. Locally, alcohol and drug overdose deaths are increasing among Arab Americans while declining among whites, emphasizing we need to expand our research. Our substance use advocate works with our local police department to provide treatment options to care for individuals who have run-ins with the law.

The goal of this program is to provide medical care for individuals with mental health and substance use. Miss Marla has an expert in health education who helps with prevention activities in schools. So, what is our project? We want to develop a reliable and valid scale measuring public stigma towards substance use in the Arab-American community. We then will use the scale to measure stigma components of it in the next phase of our project hopefully measure its reduction from our prevention measures. We have established a diverse and national expert panel of Arab Americans at universities who are knowledgeable about research and substance use.

The panel includes women and men, immigrants and US-born and Christians and Muslims. Our local team reviewed the published literature of public stigma and modified its items to use for the Arab-American community. We added a few items to reflect religious perspectives that were missing from the lecture. An example of modified item is, in my community, most people would be willing to marry someone who has been treated for substance use. We then sent the 50 items to our panel for the review. We asked them if the domains were missing and how useful the items were for the community. The next step, reduce the numbers of items with positive scores to 19. Currently, we are conducting interviews in our community. We want to know if the items were understandable and if so, their responses.

We are using quota sampling to make sure that we have data by gender, religion and nationality. With this data, we will refine the scale. With the new scale, we will survey the community to obtain internal consistency and independent sample and binary data, and test-retest reliability. It was a work in progress, and we thank our organizations for allowing us to present what we believe is important work to reduce stigma, promote prevention and outreach, and lower the burden of substance problems in the Arab-American community. If you have any questions, please contact me, Mona Hijazi at mhijazi@accesscommunity.org or Dr. Cynthia Arfken at cynthia.afken@wayne.edu. Thank you.

VIDEO 3

MAIA SZALAVITZ:

I'm author and journalist, Maia Szalavitz, and I co-founded Changing The Narrative because I got tired of the media being a conduit for misinformation. Most people get their information about addiction from the media, but many journalists don't know about the racist history of our drug laws or their unscientific nature. They think that the overdose crisis is driven by pain patients getting addicted when in fact most people who became addicted got their drugs from friends or family members. They think that exposure alone causes addiction and then it can happen in an instant. They think that addiction can turn ordinary folks into criminal zombies. If we actually want to destigmatize addiction, the public needs to know what it really is and how it happens. And in order to teach the public, we've got to first educate journalists to do better. And that's what we hope to do with changing the narrative. Thank you.

TRACIE GARDNER:

I got involved with Changing The Narrative because I'm a black woman in recovery from substance use disorder, and I know all too well that stigma is a form of oppression. So, language can either perpetuate it or it can educate to eliminate that kind of oppression.

ZACHARY SIEGEL:

I got involved with Changing The Narrative because as a writer and journalist, I believe in the power of language to shape our world. For decades, the media has labeled people who use drugs as addicts and drug abusers. But research shows that this language elicits negative attitudes, harsh judgments and it even impacts people's health care. Humanizing people who have long been dehumanized is one of the founding principles of changing the narrative. In practice, this is actually quite simple and everyone should be doing it. Instead of relying on outdated, stigmatizing language, we simply refer to people as people first. No one should be defined by their behaviors that stem from a mental illness. And working together, we've been able to tell more empathetic stories that truly change the way people think.

SARAH WAKEMAN:

I'm here to talk about why we need to change the narrative when it comes to talking about drug use and addiction. We are in the midst of a massive public health crisis, the drug overdose crisis, which is predicted to have claimed more than 90,000 lives in the past 12 months. This has been driven by failed policy and inadequate access to effective treatment and effective care, largely driven by stigma and misunderstanding about drug use and addiction. During the time of COVID, we've seen overdose death rates surge. We've seen worsening racial disparities with rising rates of overdose deaths amongst black and LatinX Americans. And we've been reminded of the health harms of living in a racist society. When it comes to drug policy and addiction treatment, policies in our country related to drug use have always been fueled by discrimination and by racism. It's time to change that narrative and educate people about what works and what's effective.

As evidence of how the narrative is malformed access to effective care, we've long known that medications like methadone and buprenorphine for opioid use disorder reduce the risk of death by more than 50%, and yet our policies limit access to care. And nearly 50% of US counties don't have a single provider who can offer these medications. We continue to let myth and misunderstanding about drug use and addiction fuel our clinical care in the way we approach people who use drugs. Common myths and misunderstandings include the notion that all people who use certain types of drugs will develop addiction. For example, people who use opioids or cocaine as opposed to more socially sanctioned drugs like alcohol or that tough love treating people poorly, being hard on them will actually help people get better, or that being kind or compassionate to a loved one or someone with addiction or a substance use disorder is actually enabling them or causing harm. We need to undo this harmfulness and let science and compassion guide our approaches.

Through Changing The Narrative, we hope to challenge some of the most common myths and tropes about drug use and addiction to better inform the public, policymakers, clinicians, people working in the health care space, people working in law, policy, public health and to generally change the way we think about and care for people who use drugs.

LEC BELETISKY:

Just about everyone agrees that stigma is one of the biggest causes of continued growth in overdose rates and rates of addiction in America. But one of the blind spots is that the very point of criminal law is to stigmatize. So, the continued criminalization of people who use drugs is a huge barrier to better policies and programming to prevent overdoses and improve treatment. That's why we fight to decriminalize drugs and decriminalize people who use drugs.

VIDEO 4

JULIE BURNS:

RIZE in 2019 together in recovery is designed to foster an accessible, integrated treatment and recovery network in Massachusetts that champions evidence-based approaches, supports multiple pathways to recovery, and puts people in charge of their treatment choices. After conducting convenings all across the state, it was very clear that finding accessible, accurate information about treatment and recovery support was a challenge. And an even bigger challenge was finding information about the rights and protections for people with opioid use disorder. And that's why we decided to produce the Know Your Rights Toolkit. Together in Recovery is led by an advisory committee of diverse influencers, and they helped us design the toolkit and provided subject matter expertise on the content.

PRESENTER:

So, when we click here and we go into the toolkit, you'll see the landing page. So, this landing page right here really just provides that grounding that I just provided for you. But one thing I really do want to elevate here is this equity statement that RIZE really recognizes the trauma, inequities, and violence that structural racism has caused for BiPAP communities and people in long-term recovery or any type of recovery. There are lots of barriers that exist to getting the help that folks want and this toolkit recognizes those, tries to highlight that, and also work to create the foundation so that folks are able to get that treatment without those barriers and create that world where discrimination associated with drug use is over. So, to go through each of the sections broadly, there's this navigation bar on the left-hand side, and these are all the sections that you can find more information on rights and advocacy, and

resources. So, for example, if I go to treatment and recovery pathways, you'll see here that broad statement that there's no right way to recover.

Again, your recovery is your choice and you are the driver in that journey and this toolkit really does aim to help build that and empower folks to choose what works for them by not only giving them the knowledge but also the rights that they hold so they can actively exercise their rights in all areas. So, here under clinical pathways, for example, what I can do, I can open this and it takes me to all different types of services or clinical pathways for opioid use disorder.

DARYL MCGRAW:

This is a big deal. This is huge for all families and impacted people. You know, I don't know about you guys, but I wish there was a toolbox when I was going through my process 'cause I know my parents and my mom couldn't figure it out. And they wanted to know and really wanted to know why, how can we help? How can we be involved? So, I'm super excited about this toolbox.

MAURA HEALEY:

The Know Your Rights and Recovery toolkit is going to help build the foundation that we need as we go forward. It's going to help people seeking services and seeking support networks. It's also going to be a resource to educate those who may be on the front lines providing some of those services. And so we want to celebrate this important concrete step forward in promoting health equity for all, especially for this vulnerable population. And I really appreciate it because it is putting the person who is struggling with addiction back at the center of the conversation about their care.

VIDEO 5

SHANNON GWEN:

Hello and welcome to our presentation entitled Ending Self Stigma for Justice-Involved Populations Being Treated with Medications for Opioid Use Disorder. I'm Shannon Gwen Mitchell, a senior research scientist at Friends Research Institute in Baltimore, Maryland.

ALICIA LUCKSTED:

And I'm Alicia Lucksted, a research investigator at the University of Maryland School of Medicine. Generally, in trying to reduce the harms caused by the stigmatization of any number of health conditions and other social identities, it's useful to break stigma down into the several facets. In this case, societal stigmatization refers to the broad messages, disrespect, and discrimination that is unfortunately commonly aimed at certain subgroups by society. And in this intervention that we're developing, we're going to specifically address the anticipated stigma, which is the anticipation of societal stigma, and the internalized stigma, which is people taking in the societal messages that has really corrosive effects on their well-being, their motivations, and their self-concept.

SHANNON GWEN:

One of the most overtly stigmatized groups in US society are people involved in the justice system who face discrimination in everything from employment and housing to the attainment of student loans. While it's estimated that approximately half or more of the people involved in the justice system are experiencing substance use disorders, there are few interventions directly targeting this group. Substance use disorder is a chronic health illness

but is not treated the same way as other chronic health issues with people with substance use disorders often being blamed for having the illness itself. One of the most effective treatments for opioid use disorder are medications such as methadone, buprenorphine, and naltrexone. Unfortunately, even the use of these medications is often stigmatized and people who take them are being treated and labeled as unclean as if they're not in recovery.

ALICIA LUCKSTED:

Because there are not tested interventions that address the stigmatization of this population, in our work, we're starting with ending self-stigma, a program that my team created to help people with serious mental illnesses navigate the effects that stigmatization can have on that condition particularly focusing on anticipated and internalized stigma. On the left, you see some of the inputs for ending self-stigma, academic research, clinical experience, lived experience, and several conceptual models which we then consolidated to seven practical strategies that people can learn in a weekly cycle education and skill-building class that is both manualized and interactive and personalized.

SHANNON GWEN:

So, the grand proposal that Alicia and I currently have under consideration) is to modify the Ending Self-Stigma program, specifically tailoring it to justice-involved people with opioid use disorder who are considering treatment or using medications as part of their treatment. The first part of the ESS modification process involves a systematic literature review and some stakeholder and focused groups to refine the ESS intervention to specifically target the stigma for this population. We'll then conduct two iterative rapid pilot tests of this modified ending self-stigma intervention and further modify each of the ESS-MJP sessions based on the flow of the intervention and the feedback we receive from the participants as well as the facilitator. Ultimately, we hope to finalize this refined ESS-MJP intervention and the materials to be used for it for future efficacy trial.

ALICIA LUCKSTED:

In the end, we anticipate we'll be able to both retain the core principles and lessons of the original ESS which has made it quite effective, as well as tailor the details of content and delivery to the particular situation and stigma dynamics of this particular population. So, we anticipate that we will end up with a intervention that is both practical to deliver and useful for the participants in reducing the harms of internalized and anticipated stigma so as to help them engage with and stay with treatment, as well as enhancing their overall resilience and recovery.

SHANNON GWEN:

Thank you so much for your time. Please contact us directly if you have questions or recommendations.

ALICIA LUCKSTED:

Thanks.

VIDEO 6

SAUNDRA NGUYEN:

Hi and welcome to our presentation, collaborating with community partners to develop a harm reduction and stigma curriculum. My name is Sandra, a primary care provider in the San Francisco Health Network and curricular lead for this project.

JAR-LEE LIU:

I'm Jar-Lee, and I'm a first-year medical student at UCSF.

JOHN HALIFAX:

Hi. I'm John.

SETH KATZ:

And I'm Seth.

JOHN HALIFAX:

And we're health educators with Syringe Access Services Department here at the San Francisco AIDS Foundation.

SAUNDRA NGUYEN:

We'll be your presenters today and also wanted to highlight some other key members of our team shown here. By now, many people are familiar with the opioid epidemic. Over the last few years, there have been sharp increases in mortality from drug overdoses across the nation, driven by the introduction of fentanyl into the drug supply and made worse by the COVID-19 pandemic. In 2019, 441 people died of drug overdose in San Francisco. This number rose to 700 deaths in 2020 and continues to rise rapidly. In response, a pilot was launched where community primary care clinics were identified as sites to distribute intranasal naloxone and safer consumption supplies to at-risk patients with the goal of preventing overdose deaths, increasing safety around substance use and access to harm reduction services.

Our project aimed to develop a training curriculum that would educate providers and serve as a foundation for these pivotal patient interactions. When we were initially developing the training, we were focused on thinking about how frontline staff could be trained on how to use intranasal Narcan and the safer consumption kits. However, our community partners at the SF AIDS Foundation, with their experience in serving the community and their own lived experiences said, 'You know, that's the easy part to teach that stuff. What's hard is addressing the main barrier for people who use substances.' And that stigma and stigma starts way before the clinic encounter and starts in the waiting room at the front desk with the environment and there's stigma from others, clinic staff, providers. And then there's self-stigma or internalized stigma. And all of this serves to keep people away.

And there's no point in having all these supplies and services if your patients can't access them. We need to address stigma. So, we developed a training with three components with the harm reduction in addressing stigma session as the foundation, followed by an overdose prevention and intranasal naloxone module and videos created by the SF AIDS Foundation reviewing the safer consumption kits. One thing that was important to us was including the voices of people with lived experiences as experts in their own care, both in the development of the curriculum and through the power of sharing their stories.

The harm reduction and addressing stigma session is a guided, discussion-based session that is conducted at each pilot clinic site. We talk about basic harm reduction principles, the effects of stigma, and how we can address it. We also learn and hear from our community members who share their experiences with stigma and harm reduction. The training provides a safe and protected space to start a conversation that we hope will continue long after the

training. Before the training, we meet with each clinical site champion beforehand to discuss the specific educational needs for their clinic and then tailor the training accordingly.

JAR-LEE LIU:

About our overdose prevention or Narcan module. It was built using Google Forms with material provided by our collaborators at the DOPE project, supplemented by video narratives and interviews shared by our community partners at the SF AIDS Foundation who have lived experiences of responding to an overdose. The model is super interactive with questions scattered throughout it. And it's pretty simple in terms of exploring objectives. It goes over how naloxone works, when to use it, or other words, how to identify an opioid overdose and how that's different from being high, and how to respond to that overdose in a way that's really informed. So, using the Narcan, calling the emergency services, et cetera.

SETH KATZ:

We recorded these videos on Safe consumption kits that will test drips to explain supplies and how to use them.

JOHN HALIFAX:

We asked other health educators with the Syringe Access Services Department here at the San Francisco AIDS Foundation to record these videos. These videos are designed to educate providers and other clinical staff on substance use and harm reduction to break the barriers of stigma so that substance use can be talked about openly and honestly between patients and clinicians in critical settings and improve health outcomes for all involved.

JAR-LEE LIU:

In terms of evaluating the effectiveness of our harm reduction and stigma training, before the training, we have participants complete a survey that tells us to what extent the interaction of people who use drugs as well as their levels of drug-related stigma. Post-training, we assess changes in that drug-related stigma, as well as changes in people's perceptions and practices around harm production. That's all we've got for now. Thanks so much.

AISHA SALMAN:

I hope you found those videos to be informative. Again, congratulations to those who are selected to be featured today and thank you again to everyone who submitted an abstract. For more information, please refer to our compendium, which can be found online on our website.

CLOSING KEYNOTE SESSION

MARGOT SAVOY:

Welcome back from the break. My name is Margot Savoy. I'm an Associate Professor of Family and Community Medicine and Urban Bioethics at the Lewis Katz School of Medicine at Temple University in Philadelphia, Pennsylvania. It is my distinct honor and pleasure to moderate this closing session of our Stigma Summit today. Those of you that stuck around are really in for a treat. I think it's about to be an outstanding session to close out our day. I am joined by two remarkable panelists who are going to kick off the session with opening remarks. First, you're going to hear from AD Regina LaBelle. AD LaBelle is the Deputy Director for the Office of the National Drug Control Policy and currently is serving as the Acting Director of National Drug Control Policy. As acting director, Miss LaBelle leads a component of the executive office of the President, whose mission is to reduce substance abuse and its consequences by leading and coordinating the nation's national drug control strategy. Following her presentation, you will hear from Dr. Keith Wailoo.

Dr. Wailoo is the Henry Putman University Professor of History and Public Affairs at Princeton University, where he teaches in the Department of History and the School of Public and International Affairs. Dr. Wailoo is the current president of the American Association for the History of Medicine, an award-winning author on drugs and drug policy, race, science and health, and genetics and society. Thank you both for joining us today. AD LaBelle, let's begin with your opening remarks.

AD REGINA LABELLE:

Thank you so much, Dr. Savoy, and thank you also Dr. Wailoo, for being here today and part of this discussion. I'm so grateful to the National Academy of Medicine, Dell Medical School at UT Austin, and Shatterproof for hosting this important discussion today. And I'm so glad to be here to discuss this topic. I did take some time today to listen to some of my colleagues from ONDCP, as well as all the great panelists who talked about this important issue. So, I want to begin by really talking about my own journey on this issue, and then we'll talk about the steps that we're taking at the federal level in the White House Office of National Drug Control Policy to build drug policy based on science and evidence and to improve outcomes for people with or at risk of developing substance use disorders. So, to begin, I want to again tell you about my own journey. I was raised in a rural area on a farm in New England, a town with a manufacturing past. I'm the youngest of nine.

My dad had an 8th-grade education, so we were fairly low income but so were most people in my town. So, we were all kind of in the same boat. But I was taught at the time to look down on people who were at the time what we called alcoholics or people who use drugs. And we stigmatized not only their actions but the people who did these things. You know the names that they were called, and I'm not going to repeat them here. We protected ourselves, I think, because while we may not have had much, at least we weren't like them. That stigma was a blanket that we used to wrap ourselves in a layer of protection. We stigmatized them and we stigmatized their actions, and by doing so it made us feel better about ourselves. But for many people who were like me or raised like me, this protective layer was pierced when people close to us started dying from overdoses. And you'll hear this - in the last decade you've heard this said - it can happen to anyone. Or they weren't people who usually use drugs.

Again, we embraced that stigma to protect ourselves because the people who were dying looked like us. They were our neighbors, our brothers, and sisters. They weren't like them.

And let's be honest, many of them were white like many of us. So, we wrapped ourselves in this protective layer of stigma, and that layer of stigma also led to silence. And as our friends in the HIV-AIDS movement recognized silence equals death, so now years later, how can we entirely reform a system and policies that are built on stigma and shame and that ultimately result in discrimination? So, in the Biden-Harris administration, we're starting to work on that. To start, the administration is making record investments in building the type of addiction infrastructure our nation needs, and we're building on steps that were taken during the Obama administration as well, in with the Affordable Care Act and Parity. So, this year, the American Rescue Plan Act, which President Biden signed into law in March, included nearly \$4 billion to expand access to substance use disorder and mental health services.

In an unprecedented move, the Rescue Plan Act also included \$30 million for harm reduction services to help communities grappling with record rates of overdose deaths. President Biden's new budget proposal for fiscal year 22, which was released just last month, includes \$10.7 billion, a request to Congress to expand access to prevention, harm reduction treatment, and recovery support services. In another historic step, the president's budget request includes a 10% set aside for recovery. This funding is included in the HHS's Services Block grant that states can use to fund recovery programs. These funds are sorely needed as part of an urgent effort to build out the type of addiction infrastructure that's really lacking in our country. And while significant investments are needed, we also have unmet workforce needs to address and policies to reform. So, many of our drug policies, as you heard about today, stand in the way of helping people with substance use disorder by putting up barriers to treatment and other services, including recovery support or services that would reduce harms associated with substance use.

On the policy side, earlier this year, the Biden-Harris administration's drug policy priorities for the first year were released. These priorities outlined how the president and the 18 agencies that make up the nation's drug budget will approach and fund drug policies. These priorities are based on further piercing that veil of stigma that rather than protecting us damages our country's communities and individuals. So, I want to briefly touch on each of them. One of our first priorities is expanding access to evidence-based treatment and recovery support services. Medication for opiate use disorder, or MOUD is, as the National Academies report says, the standard of care for opioid use disorder. Yet for far too many people, it's still out of reach. This is especially true for many of our at-risk populations. One study showed that in 2017, although about 24% of counties had a high risk of overdose mortality, about 72% of rural counties had no providers who offered medications for opioid use disorder treatment. People leaving incarceration are at much greater risk for overdose.

Yet the vast majority of jails and prisons in this country don't provide medications either behind the walls or upon release. This leaves people at greater risk for overdose when they leave. Now, these are among the most stigmatized members of our society. So, leaving them vulnerable to overdose just has not been a priority. This is also the case for pregnant or parenting women with substance use disorders. We must put policies in place that support women and their families, not vilify their addiction or create systems that scare them away from seeking medical help. Because we know that if stigma and shame worked, we'd have far fewer people with untreated substance use disorders and fewer overdose deaths. An additional one of our priorities is confronting racial equity issues related to drug policy, and a few studies recently have shown that unequal access to treatment for blacks and whites, we know that black individuals generally enter treatment, addiction treatment, four to five years later than white people. Even when controlling for socioeconomic status. And for Latinos,

they're far less likely to access care than non-Latino individuals.

And a third study showed that black individuals are much less likely to be offered buprenorphine, one of the three forms of medication-assisted treatment than whites, despite similar rates of opioid use disorder. So, the Biden-Harris priority is confronting these racial equity issues. This includes targeting unmet needs in diverse communities, developing priorities for criminal justice reform, including addressing the crack cocaine sentencing disparity, and identifying culturally appropriate practices for black, indigenous, people of color individuals across the continuum of care. For the first time, one of ONDCP's drug policy priorities is harm reduction. Syringe services programs, access to naloxone, and fentanyl test strips are all part of our harm reduction efforts. The other day, I visited a Baltimore syringe exchange and I was moved by how each person who visited was treated with respect and dignity by the staff. And we know that if you're treated with dignity, you're more likely to return. And by returning, building engagements, you're more likely to accept the help that you might and the services you might need, which can include housing, health care, or treatment.

We also know that so many factors can lead to youth substance use. The Health and Human Services Substance Use Block Grant has received increased funding in the president's request and in this fiscal year budget, and also it was increased under President Biden's American rescue plan. So, part of our job is to make sure that these funds that are included for prevention programs are spent on programs that are evidence-based and effective because we can't afford to spend money on things that don't work. It's far too urgent. We also do have to address reducing the supply of illicit substances. So, of course, we have to disrupt drug trafficking and transnational organized crime. And to do this, we're working with countries such as Mexico, China, India, and Colombia to keep substances from coming into our country and denying profits to criminal enterprises. We're also working at the same time to support countries to build vibrant communities and healthy economies to prevent cartels from exploiting people in poverty.

Our next priority is working to expand the addiction workforce. As I said before, the addiction workforce, including treatment, harm reduction, prevention, and recovery professionals is facing shortages in many areas of our country. So, we're working to increase the number of addiction treatment professionals, and one way to do this is through fellowship programs. And so, here are a few in the federal government and in the private sector. The Health Resources and Services Administration at HHS has 44 grants available in both addiction specialty and addiction psychiatry. That's through 2025 in its Addiction Medicine Fellowship program. Also, the American College of Academic Addiction Medicine is working with medical schools to establish new addiction medicine fellowships to serve communities, and they have approximately 80 or so fellowships. In addition, HHS's behavioral health training programs prioritize bolstering the behavioral health workforce to expand integrated behavioral health care and treatment services in underserved communities. Now, these training programs are intended to expand the number of behavioral health professionals and paraprofessionals in the workforce, and this includes expanding providers who can offer culturally competent care.

Finally, we're working to expand access to recovery support services. We've moved far past the point where we think of substance use disorder as an acute condition, and we recognize the importance of ongoing recovery supports. So, to promote recovery, one way we're doing this is by working with federal partners and recovery housing stakeholders to develop

protocols for recovery housing. This includes certification, payment models, evidence-based practices, and technical assistance. And we're also hiring policy professionals across the federal government and including in our office at ONDCP, and this includes someone who you heard from earlier today, Tom Hill. People with lived experience. Hiring people in recovery is critically important as we develop these policies that directly affect people with substance use disorder. So, these are some of our policy priorities. We've already begun in earnest to tick through them. To date, we've worked with Health and Human Services to make sure states know they can use federal dollars for fentanyl test strips. We've revised requirements with DEA and HHS to allow health care providers to prescribe buprenorphine to 30 or fewer patients without additional training.

And we're working on other actions that will divert people with substance use disorder away from the criminal justice system while making sure that people who are currently incarcerated get the care they need for their health condition. So, thank you, all of you, for all the work you do to not only talk about stigma but to recognize how stigma helps form and continues to inform our policies, and to commit to changing these policies. We know this work isn't easy, but we're taking important steps on the road to removing that cloak of shame, stigma, and silence that has for far too long marked our approach to addiction because closing our eyes doesn't make it go away. I want to close with a really brief story I heard this weekend from a close friend. His nephew has an opioid use disorder that he's had for some time. And my friend called me a few months ago to ask me for recommendations for treatment. So, I provided him with some professional treatment providers in his state.

Just the other day when I saw my friend, he told me his nephew had decided that he couldn't do it anymore, that the shame he felt from taking methadone was too much. He was embarrassed and he felt that he needed to wean himself off of this life-saving medication. So, my friend now knows the risks that his nephew faces. So, stigma, as we all know, isn't just a concept, it's a very real fact of life for people with substance use disorder. So, let's continue this work and thank you very much for this important summit and for all the great work you do.

MARGOT SAVOY:

Thank you so much, AD LaBelle. Dr. Wailoo, the floor is now yours.

KEITH.WAILOO:

Thank you so much, first to Acting Director LaBelle, for those remarks on the challenge of change, stigma, and silence. I'd also like to thank the National Academy of Medicine, the Dell School of Medicine at UT Austin, as well as Shatterproof for hosting this event, organizing it, and also Dr. Savoy for moderating this panel. I should make it really clear that my perspective is that of a historian and sociologist of science and medicine with a focus on drugs. And in some ways I'll be reflecting on the nature of the challenge of reducing and eliminating stigma, as well as the path ahead, using what might seem at first to be kind of deeply disturbing if not depressing historical examples of how challenging the... How challenging the problem of reducing and limiting stigma actually is. You know, the novelist William Faulkner once said, "The past is never dead. It isn't even past." And in some ways, this talk will illuminate that, but hopefully point towards a path ahead that we might pursue.

What I'll do is I'll offer maybe 10 really quick points about what we know about stigma and historically with regard to drug use. And my starting point for understanding stigma is a book by a sociologist named Erving Goffman. It's a dated book in so many ways, and yet it still

offers some really trenchant insights into how stigma works. One of the things that Goffman said in this 1963 book is that stigma concerns relationships, not attributes. And you heard a little bit of that echoed in Ad LaBelle's comment a moment ago. "The term stigma," he writes, "then, will be used to refer to an attribute that is deeply discrediting, but it should be seen through the language of relationships, not attributes." Stigma, he pointed out, involves profound social judgments about aspects of identity that Erving Goffman labeled as spoiled and in need of some form of management. And drug use creates and raises particular kinds of challenges with regard to stigma.

Historically, the stigma associated with substance use has involved a wide range of judgments along the lines once again, that Ad Labelle referred to, questions about the moral failings of the individual, to what extent substance use is entangled with questions of laziness or unscrupulousness, or shiftlessness, somehow kind of unworthy discrediting qualities of personhood. There is also a kind of set of judgments surrounding the psychological deficiencies that may lead to addiction. Addiction often gets entangled with concerns about criminality and a wide range of socially transgressive behaviors that warrant shame, ostracization, or in many instances, imprisonment. So, what I'll offer you is sort of just 10 observations about how history can illuminate our understanding of the present challenge and the path ahead. The first comment I'll make is that substances are stigmatized, but not equally so. So, we can all understand that. And much of this relates to the effect that substances have on people, the effects on the body, and the effects on behavior. But we can just whether we're experts or not, understand that marijuana has gone through periods of intense stigmatization.

And also we're in the course of profound destigmatization of marijuana use and the kind of stigma associated with cocaine and marijuana differ dramatically from that associated with, let's say, opium dens in the 19th century or opium use today or nicotine. Not to mention alcohol and crack and a wide range of other substances that feed dependence, right, so substances are not equally stigmatized and stigmatizing. Users are discreetly stigmatized, quite separate sometimes from the substances. And I would argue that the history of stigmatization often revolves around the stigma associated with users rather than just merely the substance. But even here, that stigma is often pervade. It's often created by experts themselves in terms of their thinking about what an addict actually is. And I'll hearken back to writings, let's say, 100 hundred years ago by this Memphis-based physician in a book entitled, *The Narcotic Drugs Diseases and Allied Ailments Pathology, Pathogenesis and Treatment*. And what George Pettey writes is kind of the sorts of judgments you would hear about addicts really through much of the 20th century. Addicts, he wrote, are weak, self-centered, and unwilling to suffer.

He writes, "So little moral purpose, so little kindness and so little care they have for anything but themselves that they are unwilling to suffer for even one moment. And elsewhere, he writes that, good people of good character will never become addicts. "The man with positive traits of character, fixed habits, and strong convictions as to what is right and wrong and who has a keen sense of obligations to humanity will be by the mere possession of these opinions and convictions," Pettey writes, "be protected from many of the snares and pitfalls that inevitably await those who are less fixed in their habits and convictions." So, these are the kinds of social judgments about personhood that lead to decades and decades of stigmatizing of substance use. It's not just experts who stigmatize users, but a wide range of social actors, experts, policymakers, citizens, families, communities that also stigmatize users, but doing so differently depending on the existing stigmas associated with different aspects of identity and social difference.

So, you cannot disentangle attitudes about the opium den in mid to late 19th century America without understanding these fiercely virulent anti-Chinese attitudes that were particularly prevalent on the West Coast but migrated into the Midwest and the Northeast as well. So, we stigmatize drugs, but we also stigmatize people, different social groups. And those public stigmas can be powerful and enduring, often amplified by the public media. So, these are just about four examples from the newspapers, from Chicago to Los Angeles to New York City to San Francisco, it gives you image, give you images of the kinds of behaviors and psychological qualities that were seen as inherent to the drug user or the addict. Maniacal cravings, fiendish criminality, minds unhinged and enslaved by substances. My sixth point is to juxtapose what is a kind of a prominent recurring public anxiety about the drug user from what is also less known, which is the private face of substance use, dependence, and addiction.

Because even at the time of the early 19th century or early 20th century, sorry, when George Pettey was writing, it was not widely known, but increasingly became the source of awareness, broader public awareness that the true face of addiction was not the maniacal craving criminal, but white women who had been treated aggressively with morphine or opioids during childbirth. And this form of addiction was often hidden from public and also physicians who were hidden.

A good example of this is the really exceptional work of really fiction, but also autobiographical play written by Eugene O'Neill, *The Long Day's Journey into Night*, which focuses its very autobiographical in the sense that it's focused on his mother, his child, her addiction to morphine, his family's alcohol struggles with alcohol. It's set in 1912. But O'Neill would not allow this book to be published until after his death because he did not want the full story of his family to be disclosed. This is how long these kinds of stories lay hidden. It was ultimately published. It is regarded as an American masterpiece published in 1956. And you get glimmers of this story in the historical archive from the nineteen-teens, the well-known Keeley Institute in Atlanta, Georgia, which was there for the in the name of rehabilitation.

In its pamphlet would note that more than half a million sufferers, including 17,000 physicians, have been successfully treated by Keeley in this rehab facility. And this is one of the images of the mother and the child. This is the private face of addiction, by the way that's Katharine Hepburn in *Broadway on the Left*, who played Eugene O'Neill's mother on Broadway. My 7th point is that calls for drug reform, however, often make strong appeals to the public image of the addict and often highly racialized images of the drug addict, public fears which feed moral panics, whether it's the opium den of the 1880s or in this instance, the physician, Edward Huntington Williams, who writes this well-known and rather infamous piece in *The New York Times* about the Negro cocaine fiend emerging as a new Southern menace, leading to murder particularly and insanity, particularly among low-class blacks, he calls them. And these Negro cocaine fiends, he writes, "There is little hope once the Negro has formed the habit, he is irreclaimable." So, public image, private realities.

My 8th point is that drug use can itself be therefore racialized in ways that reinforce already existing noxious stereotypes about violence or criminality. So, those images that Edward Huntington Williams trafficked in *The New York Times* could also be found in the Atlanta Constitution article about how human victims are wrecked by the terrible cocaine habit. And what is the image associated with this cocaine habit? Well, it's the black man as criminal

breaking windows in order to obtain his drugs or the pathetic begging cocaine fiend appealing for help or for understanding from criminal justice authorities. This story of private and public images, public stigma, private reality is indeed a recurring theme. I teach an entire course on the history of race, drugs, and drug policy, which is it is not exactly the same story over and over again. But as Mark Twain once said, you know, history doesn't so much repeat itself, but it rhymes. And in that recurring narrative, Ad LaBelle referred to a more recent example of this private and public divide, the story of cocaine portrayed here in 1981 as a jet-set drug.

The martini glass illustrating the kind of a drug of status and menace pictured here on the cover of Time magazine. And 10 years later, a different image of cocaine in crack form. Which pictures the crack child as the victim, their mothers use drugs and now it's the children who suffer. Of course, the irony here is same drug, different social imagery, disparities in stigma producing different social policies, congressional legislation, harsher policing, and strong sentencing disparities which emerge out of the 1980s and carry a legacy even into our own time. So, the crack cocaine, powdered cocaine sentencing disparity is one of the many ways in which these stigmas projected and acted upon produce disparities that are literally structured. We live in a year when we've been talking about structured disparities, structural inequality. There's no better example than the fact that sentencing disparities mandated by federal law determine that having 500 grams of cocaine results in a five-year sentence. But five grams of crack produces the same prison sentence. We've been struggling to revise, undo and eliminate that 100 to 1 disparity ever since it was passed.

My final point before I conclude is that just as Edward Huntington Williams and his views about the cocaine Negro underpinned ideas about the policing of cocaine use, this is also true in the rise of the crack cocaine sentencing disparity. Scientific and medical expertise is often implicated in these stories of stigma. So, it's not the case that media stigmatizes and medical professionals try to push back against stigma. In the middle of the 1980s, it was researchers who were speculating about the long-term effects of being in utero, born to a mother who used crack cocaine and the crack baby became a particularly gripping kind of stigma, a particularly gripping kind of fear of innocent victims who were caught in the vortex of this new drug epidemic and this anxiety about what should be done to and about women who used crack while pregnant produced a wide range of policy responses, the use of Norplant, long term incarceration and enduring stigma.

And it took 23 years before The New York Times, which had produced an article on crack babies filling hospital nurseries, revisited this question in a new article entitled The Epidemic That Wasn't, which revisited the crack baby story and determined that it was nothing more than a myth that children born to mothers who had used crack are no different developmentally, there's no long-term narrative that supported the kind of moral panic associated with crack cocaine, which is not to make light of crack cocaine abuse. It's to highlight the social dynamics of stigma that produced these lasting disparities. So, here are some concluding thoughts on how this leads us, might lead us to think about the challenge of reducing stigma. And the cha-, one of the things I would argue is reducing stigma often involves challenging norms, challenging both public and private images of drug use, and also teaching new perspectives on normality and difference. A few years ago, the student newspaper at UNC-Chapel Hill, where I once taught, published an expose story about students using ADHD medication.

And one of the students quoted who was anonymous wrote, said to the newspaper, "When

you think of people buying drugs, you think of people in alleys and the stoners in class. But it's becoming the kids that want to do well on a test that are trying to get into grad school or just trying to write a paper," who are using these particular medications Adderall, Ritalin, Concerta.

But she did not want her name used to protect her privacy. So, the idea of the privacy of drug use continues. Reflecting back on Erving Goffman's 1963 book, he wrote towards the end that, the challenge is that the normal and the stigmatized, and we put normal in quotes these days, although he didn't, which is one of the reasons why his book is dated. He says the normal in the stigmatized are not persons, but rather perspectives. They are generated in social situations during mixed contacts by virtue of the pressure of the unrealized norms, that are likely to play upon the encounter.

So, it's really a set of norms that we carry around about what normal life is, what private and public life is that need to be challenged. And my last comment is that, history is replete with examples of how the stigma that often leads to different forms of discredited identity, can be successfully challenged. One of the interesting things about rereading Goffman's book is that, there's a wide range of examples of stigma that he writes about, that we would argue have been successfully challenged over the intervening half century. He writes about the discredited identity of being disabled.

He writes about the social difference of the discredited aspects of sexual difference. He writes about racial identity as highly stigmatized. And so, I would suggest that one of the ways we should think about how you revise stigmas, or challenge them, or eliminate them, or reduce them is to understand that we have a recipe book for how we do this in other walks of life, disability, sexuality and race. And one of the things that those who are trying to quote, normalize, I don't want to use that phrase, but to use Erving Goffman phrase. One of the things we should do is to reach back to these broader stories about how not only stigma is created, but how it can be unraveled and undone. And I'll end with that and stop sharing my slide.

MARGOT SAVOY:

Thank you so much, actually, thank both of you for really insightful and very thoughtful remarks. You didn't disappoint at all for closing, kicking off a closing keynote in a great way. The audience, I just want to remind you that you're invited to share questions, while you guys are sort of coming up with the questions that you want to ask, I'm going to kick us off with one theme that I heard, sort of throughout the day today and then also, a little bit in both of your comments was this idea about stigma not necessarily being sort of limited into just, for example, addiction space, but really standing a lot at intersections.

So, I think about it like, for example, the intersection between race and also being addicted, or perhaps being pregnant and being addicted, or income and being addicted, or having income, race, gender and you know, being pregnant. Do you have thoughts about, sort of, how maybe we could think about stigma in a broader sense, instead of wanting to sort of pigeonhole, then let's just talk about the stigma of opiate use as opposed to, for example, the stigma of marijuana use, or figure some other substance or one of these intersections?

KEITH WAILOO:

So, what I would say is that, in the history in health care today and also historically, is that stigmas associated with drug use have this kind of pervasive impact, even outside of

addiction. And I'll give you an example from my previous work on the treatment of sickle cell disease, in which we often have the scenario where people who are experiencing painful crises in urban settings will be denied access to pain medicine because of the stigma associated with drug use. As in, they're regarded as drug seekers who are looking for ill gotten gains, something for nothing, rather than legitimately seeking relief.

And, we know that a lot of the disparities that exist in pain relief medicine, are informed by these stigmas of personal and group difference. So, even in areas where we're not actually dealing with addiction, we're often dealing with, you might say, the backlash or the echoes of addiction that limit care for other people along these lines of difference.

AD REGINA LABELLE:

And I think that there obviously are, it's kind of the stigma of addiction when you layered on pregnant, parenting women, race, people who have criminal records or in castrated. It kind of puts it in Technicolor, you know, it like takes the issue they may be facing and then amplifies it by 20, because the risks associated of not getting access to care, perhaps a criminal involvement, all those get amplified. So, as we look to address stigma, when we put on our policy priorities, I showed the policy priorities to a colleague of mine and he said, you know, everything that you've identified here, the root of all this is stigma.

And so, it takes a lot to unpack because you have all these other things layered on top of it. But it's a good question.

MARGOT SAVOY:

Thank you both. One question that came from the audience, was around thinking about how we might be able to prevent substance use disorder in teens or young adults if we were able to talk about it differently, or if maybe our language might look different, sort of, in how we're talking about drug use and addiction, and even just the idea of using substances in general. Do you have any thoughts about, sort of some of either the policies that have happened in the past and how they were great or not great? Or we're just maybe, what if you had all the money in the world and you could do anything you wanted to do.

What might it look like if you were going to design an effective policy that would let us talk about it, not necessarily policy, just the program. But like just something that we could do that would help us talk about it, that maybe can help our teens or our young people?

AD REGINA LABELLE:

Sure. So, let me just start. I think that, you know, we know that use of substances, put someone at greater risk for developing a substance use disorders, so prevention is obviously important. I think that we need to look not only at the genetic factors that might lead to substance use disorder, but also the environmental factors. So, much of what we have done over the years has focused on, perhaps an ad or some kind of social media thing that targets someone to say, you know, it's bad for you.

And, you know, I have a son I tell when something's bad for me, he'll listen. But, he doesn't necessarily think that it's going to affect him. So, what we have seen is, first of all, if I had, you know, billions and billions of dollars, we'd look at the social determinants of health as indicators, as part of our prevention framework. It has to be. So that's one case, you know, housing, poverty. All those risk factors go into substance use and substance misuse among young people. And then secondly, however, there are really effective prevention programs

that are out there. You talk, they listen, is a program that HHS puts out about talking to your kids about alcohol use, and the risks associated with alcohol use.

And so, there are effective programs. I think that, you know, they're not necessarily always out there. It's not necessarily something as parents that we do all the time. But it's a combination of those types of programs. Communities that care is another one as well, in combination with addressing the social determinants of health that will prevent youth substance use, that later lead to substance use disorder and other unhealthy outcomes.

KEITH WAILOO:

Yeah, I guess I would also add that, you know, my view about youth is, and this is I'm speaking as a father of about 20-year-olds, is that they're usually way ahead of whatever adults are trying to grapple with. In other words, by the time vaping became a major issue, it had already been like that for quite a while. And so, in some ways is we're often in the position of catching up with where teens are at, by which point the kind of sociology of drug use has become established. So, and therefore, what works to intervene is always going to be shaped by our knowledge of why it is that these kinds of practices flourish where they do.

Is it out of boredom? Is it about the quest for kicks? Is it about shrewd marketing? Is it, you know, what's really driving this set of practices? And the reason why I say that, is that, if you look historically, you know, youth have been at the forefront of a lot of both problematic drug use trends. So, marijuana in the 1960s, LSD and the hippie movement. And so, one has to kind of figure out how you get both ahead of some of these trends, how you learn what's going on before they're deeply rooted. And I'd say that, there's always this generational tension that AD LaBelle, which is as parents, our views are regarded as, in many ways suspect on, not just drugs, but pretty much everything.

So, how you intervene often involves finding respected members of their community to intervene. And we live in an era when social media is a powerful force for young people. And if I would design a system, I would really be thinking about influencers and social media, and how you really inform behaviors at the level of youth and adolescents, so that, we can intervene rather than, you know, from the top down. Because I know, as a parent I could say something, but I'm not sure it'll have a lasting effect.

MARGOT SAVOY:

And that raises a really interesting point. So, one of the themes that I've heard throughout the day to day, even starting with our opening panel, was the idea of inclusiveness and including people, for example, with music, with living experience or lived experience, people who may be actively using drugs, people who have used drugs in the past, people who have family members who have people just had experiences, to be able to have them included at all stages, and at all levels of whatever intervention you're working on. Be it a policy, or project or program. They're really having them involved.

And what I'm hearing you say, you know, I think I heard really from both of you, is that, maybe you need to talk to the teens, and have the teens talking to the teens and having them share their own experience. And maybe their lived experience may look different than to the adults lived experience, even though it's still around the same substance. I'm thinking about that in communities in general, because one community's needs may look very different than in other communities needs, even if we're talking about the same problems and the same substances.

AD REGINA LABELLE:

You want to say that, I mean, so it's important to have messages that will resonate with young people, but we do know that parents play an important part. An important role in their, you know, variety of ways to do that. But we also know that, scare tactics don't work. But I do want to leave just a brief mention that, actually alcohol use has gone down. And so, we need to learn from what's happening there. More research needs to be done about why alcohol use is down over the last 10 years.

MARGOT SAVOY:

A really good point. So, looking back historically, what actually did work and moving that forward. That actually brings a great question. One of the things that someone asked from the audience, was about whether or not there are historical things that we know for a fact, have worked and other destigmatizing campaigns that maybe could be used as a recipe, specifically addressing stigma and addiction use. And so, I'm wondering if maybe that's not a great segue to that question. So, just sort of, what things do we know work well for destigmatizing that we may be able to sort of leverage and make more valuable on this in effort that we're trying to do now?

KEITH WAILOO:

That's, it's a very good question, but it's a hard question to address. Partly because, the kinds of things that have led to the destigmatizing, let's say, of marijuana use are also highly controversial. AD LaBelle, referred to, for instance, syringe exchanges. Well, you know, syringe exchanges when they were first proposed were highly controversial and seen as essentially encouraging addiction by those who opposed syringe exchanges. And so, you know, one of the problems with how you destigmatize is often the tools of destigmatization, like methadone and syringe exchange has become stigmatized.

And so, you're dealing with not just addiction being stigmatized, but the actual means by which people can manage their addiction without stigma, become the source of new forms of stigma. So, you know, I feel as if, you know, I don't know that we ever really get rid of the stigma associated with substances, but we shift it into new places. Maybe reducing the pressure on the individual. So, that's a sort of a general way of saying, you know, that's a form of progress to be able to say, you know, but ultimately, the forces of stigmatization are very powerful.

And the kinds of social judgments that people make about substance use, they're very powerful. And, I want to say one last thing about fear doesn't work. So, I was in high school when fear was the strategy that was being used. Right? The whole scared trick phenomenon. And it took actually a decade or so to figure out whether that strategy, that it didn't work. So, there's a way in which we're constantly trying new strategies to figure out what will stick and what won't.

AD REGINA LABELLE:

I think, on what has worked in the past, I think there has been some literature and actually Dr. Wailoo mentioned this about, you know, learning from our colleagues and other movements. And my previous boss, who was the director of ONDCP in the Obama administration, Michael Botticelli, was a person in long term recovery, who had a criminal background. And, he always, you know, emulated Harvey Milk and would say, you can't hate up close. And so, one thing that we need to make sure we do is, and that's why having Marty Walsh, Secretary

Walsh, the secretary of interior, talk about their own experiences.

That is one step, anyway, that we can take towards breaking down the stigma. And the other piece. I think it's a harm reduction adage that is so true about, you don't, you meet people where they are, but you don't leave them there. And I found that with people who had previously opposed syringe services programs or were skeptical about them. We have, the State of Kentucky had a lot of at-risk counties by working with their director of drug policy in that state, it was a former law enforcement professional. They now have over 58 syringe services programs, because he went out to his former colleagues in law enforcement and talked to them about the difference that it can make and how it can improve people's health and lives. And so, you can't hate up close and having peers talk to others about issues helps as well.

MARGOT SAVOY:

So, another idea that I'm seeing floating around in some of the audience questions is, this is a tension between wanting to really promote the prevention and help people not become addicted, but still manage the pain and making sure that people are getting the care that they need, and how do you de-stigmatize one group without stigmatizing the other group or vice versa? And what does that look like in our language and our actions? How might that look, if you were going to try to be able to successfully balance managing pain basically, but at the same time, not sort of stigmatizing either group?

AD REGINA LABELLE:

Yeah. I mean, there's no doubt that there are people in this country who are not treated appropriately or adequately for their pain. And at the same time, we recognize that there are 20 million people in this country who have a substance use disorder and a very small percentage of them actually access evidence-based care. We can do two things at once. We can make sure that people pain patients get the treatment that they need to help them while also addressing addiction in this country. And those are issues... The Office of National Drug Control Policy, we are not clinicians. Those are issues that are dealt with primarily by FDA and CDC. But certainly, I think it's important that we address both of these medical issues and conditions for people.

KEITH WAILOO:

I just want to echo that last point, which is, I do think that the history of our drug policies has often been a kind of pendulum swinging, where you move towards harsher and fear-based and carceral solutions to trying to move towards treatment and the idea that we should de-stigmatize drug use, but at the same time embrace prevention. And it has been hard to actually do the two things at once as a priority, because we often have this with regard to oxycodone, for instance, are we over-medicating or under-medicating? And the idea that we're doing both and they produce two different kinds of problem when we do both.

And yet, we have to figure out a way to treat people both fairly and with compassion, while at the same time, making sure that we're not sowing the seeds of another set of problems of drug dependence. This really is a microcosm, a good example of how complicated this challenge is.

And in terms of policy, what happens is we tend to have the people who are interested and concerned about overuse and those who are concerned about under medication, but very little discussion amongst the two as to how we, actually, sort of thread a path that is good for

everyone concerned. But it's a hard challenge. It really is.

MARGOT SAVOY:

Another tension that I'm seeing sort of back and forth in some of the questions is this idea that you could have people who want to do the right thing, but they're sort of been culturally conditioned in a different way. And how do you help them sort of rethink or re-acculturate into this new space that sort of questioning some of the stigma? And is it even possible to do that, for example, among policymakers or healthcare professionals? Or are we sort of just banging our heads against the wall that's never going to work?

KEITH WAILOO:

Well, this is where I do think that listening to not just kind of recovering or recovered users, but talking to people who are grappling with the challenge of substance use comes in, is very important because what you find is that there's a range. A historical example I often give from about 100 years ago when we were building the system for, in some ways, the Harrison Narcotics Act in 1914 was the moment when we created a drug underground. That is to say, we created laws that said you couldn't get access to a wide range of substances legally anymore. So, in fact, if you wanted it, you had to go underground.

And some physicians who had become addicts came out and talked about their own personal struggle with substance use, which is ongoing. And there was this one lawyer who gave this wonderful anecdote that I read in my class, where he was the prosecutor was going at somebody on the stand and accusing them of being untrustworthy because they were an addict. And the defense attorney got up and said, "You know what? The prosecutor would like you to think that this person cannot be trusted at all, because they're an addict. I am standing here. I am addicted morphine. I use morphine regularly. It doesn't prevent me from doing my job." And that changed the whole conversation about what addiction is.

We often think of addicts as people who are so fundamentally tainted that they can't possibly be actual like functioning members of society, and which is... But those who are functioning are keeping it private because they don't want to disclose their struggle with substance use.

I'll give you one other example, which is I was watching the George Floyd, the murder trial. And I watched as the defense try to make his addiction into a disqualifying feature. Right. And what was interesting is to see how much sympathy his addiction and struggle with addiction elicited. To me, there are signs that it is, we are moving towards a slightly less stigmatized image of what addiction is, but sometimes it involves like peeling away these stereotypes, and actually having people be willing to talk publicly about what has been historically a private issue.

MARGOT SAVOY:

And I think that's been one of the really great benefits of this meeting this afternoon, that you got to hear from a wide range of people. And some of them had lived experience and could share their stories. And some of them have had experiences working with those who have lived experiences and have to share their stories. And I think having the conversation is really important. And so, just even having a space to be able to do it is a really great thing. I think it's really helpful.

One of the questions that came out though is, "Well, what happens when you sort of people are moving at different speeds? So, for example, the federal government is going at one speed

and your state government is going in a different speed. You have an idea about what makes sense, but your health system wants to do something different. How do you navigate these spaces where sort of there's lots of things happening, but maybe they're not all happening, where all the fish are moving in the same direction at the same time at the same speed?" Do you have thoughts or ideas about that?

AD REGINA LABELLE:

I mean, the state's experiment their laboratories of democracy that's really important. I lived in Seattle for a long time. And Washington State has experimented with lots of different approaches to substance use, to approaches to addiction as King County. So, I think that we often at the federal level can learn from what the states are doing. Again, we are seeking to have all of the work that we do be informed by research and evidence. And sometimes that research is done in states. And so, that information, it's a swirl, right, and it's a constant feedback machine that we get. And there are certain things that we can do that states can't do and vice versa. So, I think everyone is going to move at different speeds because everyone is in a different place. One thing I would say that is really important, and I know it is hard, is that we try to be patient with one another and bring one another together on these issues and to make sure that they in this very fraught political environment, that as much as possible we recognize this has to be a non partisan issue. There are areas we can agree on and in the end we are trying to do well by people who have a substance use disorder.

MARGOT SAVOY:

If there is one thing you would wanted people to walk away with, one point that you want to make sure everyone heard. Is there anything specific you want us to take home from this conversation?

KEITH WAILOO:

I guess I would say one of the interesting things about studying drugs, is constantly needing to challenge my own views about what substance use is, who substance users are, and what kinds of judgements I or others make about them. There are some really excellent historical studies that look at addicts and drug users in their own words, and it's incredibly revealing. They cut past a lot of stereotypes which sadly inform a lot of social policy. We often make social policy based on these images, these perceptions, that are amplified by medical expertise, scientific expertise, and the media. And sometimes the way to cut past that is to listen. Listen, not just listening to people who are challenged by substance use, but listening to yourself and as AD LaBelle said, what are the assumptions you grew up with? And what does that say about you? And what needs to change in terms of your outlook?

AD REGINA LABELLE:

Sure. I think, you know, first that we can't give up on one another. I think we're in a better place than we were ten years ago. And we're going to be in a better place in ten years. That's slow for a lot of people. And I totally get that. And I've worked in government for a long time but we have to bring people along. So, as much as possible, be open to having these difficult conversations about where people are at, because everybody's at a different place. And to try to understand one another and treat each other with compassion and care so we can get to what we need to get to, which is that we have a world in which we prevent, treat and reduce the harms associated with substance use for everyone.

MARGOT SAVOY:

Thank you both for a wonderful session. We really appreciate your time and your expertise.

You are amazing as I thought you were going to be. So, thank you both so much. Richard, I'm going to hand it over to you.

RICHARD BOTTNER:

Thank you so much, Dr. Savoy, for moderating this outstanding panel and to our panelists, AD LaBelle, the discussion of our policies and how they have sort of been built to a certain extent on stigma and shame. But yet, the sort of light ahead of us with all of the work that you and President Biden are doing around improving access to care. And I think your comments around health equity and sort of bolstering our ability to deliver patient centered and holistic care really resonated with all of our attendees. So, thank you so much for being here.

And Dr. Wailoo, thank you for taking us on this really impactful journey of stigma over time and its many roots and origins in our society and how that history has informed a lot of the structural stigma that we see today. I think your approach in terms of your ten learning points, but also just incredibly impactful imagery that you brought to the conversation today will be very memorable for all of our attendees out.

So, thank you, all. And thank you to all of our presenters today. And all of you who have been participating throughout the day. We are so grateful that you were here. And I'll turn it over to Aisha now.

AISHA SALMAN:

Great. Thanks so much, Rich. I would just like to reiterate that. Thank you. And I really don't think it can be underscored enough, just how powerful each of the sessions have been today. Just as a reminder, in case you were unable to attend one of the sessions, or perhaps you would like to re-watch a session that you participated in, we will be posting a recording online in the coming days. The recording as well as all of the summit materials will be available at nam.edu/stigmasummit. And then really quickly for continuing education, we will be sending out a survey link to claim CE credits for all of the attendees. So, just keep an eye out for that in our summit follow up email.

And if you do have any questions about CE, please direct those to the email address that you see on your screen, stigmasummit@austin.utexas.edu. And again, thank you all for your participation in today's summit. I will hand it over to Matthew to close us out.

MATTHEW STEFANKO:

We're really honored at Shatterproof to be able to participate, and I echo Rich and Aisha's sentiments. I want to thank the incredible presenters, planning committee members, and, of course, the National Academy of Medicine and Dell Medical School for their incredible partnership. Unfortunately, for many in the field today is a worrisome day. Overdose deaths are rapidly rising because of the isolation faced during COVID-19 and much of the progress made over the past few years seems to be receding. Well, this feels daunting. I hope you leave today with much room for optimism as well.

While stigma and discrimination are clear and pervasive drivers of the addiction crisis, we are beginning to understand how to eliminate it. And it represents a clear, if not one of our best opportunities to rapidly improve our response to this crisis. As Gary mentioned, during his opening powerful remarks, "There may be no truer expression of humanity than opening our hearts to those experiencing stigma and discrimination from their substance use disorder."

We hope you'll leave today with both strategies as well as significant resolve to make this change. So, we can begin to save lives and improve the wellbeing of the millions of our neighbors, colleagues, friends, and loved ones who face far too many barriers to receiving the care, love, and hope that they truly deserve. Thank you and have a wonderful night.