

homeless, trains outreach workers for the National Health Care for the Homeless Council, and blogs at Stone Soup Station.

Unfortunately, many of you may know that Gloria Dickerson, recovery specialist with the Homelessness Resource Center was supposed to co-present with Laura and Steve today. Unfortunately, she can not join us, but she was integral in putting together today's presentation for all of you.

At this time, I will turn it over to Laura and Steven.

Laura:

Thanks Kristen. I would like to take a minute to talk about why this topic is important to us. The topic of consumer integration is important to me because I was once homeless after running away from a psychiatric facility a lot of years ago. I feel very fortunate to be here today while so many others just like me disappeared into an anonymous abyss of the streets. And as I shuffled from program to program, I began to give up on the world and despair. I was fortunate to meet people with similar experiences who understood because they had waged their own battle with the dark knight of homelessness, trauma, addiction, and emotional distress. They encouraged me to take risks and to wake up from the safety of the world I created far behind my eyes. Their presence was a powerful reminder that I wasn't alone and even if I couldn't muster the courage to hold onto hope, they promised me that they would hold onto it for me until I could do so.

Because someone believed in me when I was poor, afraid, lonely, and hearing voices, I learned to believe in myself and eventually learned to pass on that message onto others. Today, it is my mission to try and give back just some of what I was fortunate enough to receive. And as I travel through psychiatric hospitals and jails, prisons, domestic violence and homeless shelters in this country and over seas, I have learned that the need for a living, visible testimony of recovery is universal, no matter what language is spoken. Not only for the people receiving services, but those who are providing them as well. One of the ways to accomplish that goal, I believe strongly, is by working together to create an ongoing, sustainable presence of people who have received services at every level of service development and delivery. People need to know that it is possible and it is that living testimony that people give by being present in all kinds of services that lets them know that recovery is possible.

I would like to introduce Steve and he is going to talk for a minute about why this topic is important to him.

Steve:

Thank you Laura and good afternoon to everybody listening. I spend much of my life mired in the impacts of my own addiction. It began when I used my first drug on my 13th birthday and really for about the next 25 years, I found myself medicating away my undiagnosed bipolar disorder. I was wondering in and out of homelessness during that time, destroyed my job, the lives of people around me, people who love me, all along the way. Honestly, I was a semi-functioning addict for the most part. Every time I would get myself together throughout that period, something would happen that was usually precipitated by my own drug use and things would come crashing down around me all over again. This of course fueled even more drug use,

until finally in 1998 after a couple of serious overdoses and extreme poverty I had just had enough and felt that there had to be something better.

Since that point, I have furthered my education and I have worked diligently to get a little further in my education and career. I have worked in Nashville now as an Outreach Specialist for the last couple of years and recently took a position at Operation Standdown as the Veterans Services Coordinator. Today I work with the organization that assists homeless veterans in rebuilding their lives, getting employment and housing, and re-entering their community as productive and responsible members. The idea of giving back and paying it forward is absolutely essential to me. I believe that our voices, the voices of people recovering are essential in progressing treatment protocols and policy.

Laura:

That's great Steve, thank you. I am going to start by going over a brief outline of what we plan to cover today. I do this with the understanding that we will cover these topical areas, but we will not have time in this hour and a half to go into them in depth. We will be covering, as Kristen said, more detail of the concrete how to in the second webcast. But I want to let people know that these are the areas that we are going to be covering.

The first part, the integration and historical context and background, the value of recovery in creating accessible environments for integration, why do it? What is the benefit? What are the challenges? What is the range of opportunities? What are some of the things people are doing in the field? And what are some of the first steps? What comes next? Again, that will be the first part of the second half, and I hoping folks will tune in for that in order to hear more and discuss more about how they can take it from there, followed by a brief discussion today.

Integration, as many of you know, is not new. In this country, in particular, we have a fairly lengthy legislative history focused on the rights of protected classes of people such as women, people of color, people with developmental and physical disabilities to access goods and services enjoyed by all citizens. From the 1964 Civil Rights Act to the 1973 Rehabilitation Act, many of you know exception 504 and 766, public law 194-42. Actually that was reenacted again later, more recently in the 90s. The 1990s American's Disabilities Act and the 1999 Homestead Act decision, which provided people in institutions with the right to the least restrictive alternative in the community. And the most recent exciting thing that has happened, I think, in terms of legislation in creating standards for integration, has to do with the passage of the United Nation's Declaration of the Rights of People with Disabilities, which is the first time that the world has taken a look at the place of people with all kinds of disabilities across the range of disabilities, and their role as citizens in countries all over the world. It was a very exciting Declaration that people can look at that begins to set standards not just at a local and national issue, but really I want to give people the idea that this is an international conversation that is happening with folks all over the world and in all kinds of countries, how to best create places as citizens in different countries for people with a broad range of abilities and disabilities.

It is from that context, the historical context that I like to begin this conversation because it reminds me that we are really building on a history that has already happened. We are building on something that people have already begun; it has just been in a different context. So this gives

us the opportunity to jump off from the work that they've began and create a different kind of conversation by applying what we can learn from the best of what they've done, the feminist movement, the civil rights movement, and the disability movement, to create a different inclusion for people with experiences of homelessness and poverty. With that in mind, there is no longer any question that involving current and former consumers in the planning, delivery, and evaluation of all mental health and homeless services is essential. The question really is, where do we go from here?

We have had support from involving current and former consumers through federal agencies, such as the Substance Abuse and Mental Health Services Administration, the Health Resources and Services Administration, the National Association of State and Mental Health Program Directors, the Department of Housing and Urban Development, have all recognized that the benefit of involving actively consumers in all aspects of design, delivery, and evaluation, has been beneficial. This is the place where we get to start, which I think is a very exciting place because people have really begun to take notice that this benefits not only individuals who are receiving services, but it benefits those individuals working, designing, and delivering those services as well.

Steve:

That is just absolutely true, Laura. I entered into recovery 12 years ago, which occurred during a time of specialization and a separation of mental health and addiction treatment that made overcoming my own homelessness and addiction really far more difficult. And I am sure that period of time made things difficult for a lot more folks than just myself. Clearly during that time, consumer's voices just weren't heard, especially in areas of treatment protocols, available services were just fragmented and disconnected.

Over the years now, I can look here in Nashville and see that here alone we have two mental health facilities that also provide integrated addiction services and homelessness assistance. There is a lot I think that still needs to be done, but surely, from the time that I entered 12 years ago into recovery, progresses and changes have been made and they are still occurring. Adding consumers to staff positions at all levels, I really see this is underway and to me it is the logical progression for the field. I think that consumers can and do act as a force to help people understand what works and to me that is also a very critical step forward in treatment and understanding. Not to mention the validation of self-worth it provides both to the consumer and for the agency in which that person may be working.

I remember when I first began seeking services, no one provided integrated mental health and drug and alcohol treatment and really the idea of homeless services was essentially unheard of. So, I can certainly speak for the frustration and really the hopelessness that I would ever be able to get someone to understand just what was going on inside of me. It really was an introduction to a counselor, who was also a recovering addict that turned my life around for me. It was really a small shift if you think about it. Just a person who had obtained his degree in psychology, but who was also a recovering addict, this coupled with a very small influx of recovering consumers into these fields, as I have advanced in my own recovery, has made such a huge difference in my own life. I think this historical perspective is such an important one for me and kind of a guiding beacon for where we are heading in the future.

Laura:

Thanks Steve. Principles of recovery, we introduce this because we know that homelessness is a traumatic event. And like other traumatic events and experiences, it can be devastating. The losses are numerous, that includes loss of health, sense of safety, sense of efficacy and control, power, and connection to ourselves and to others and to a higher power.

Because of the impact of traumatic events, because they lead to loss and disconnection, recovery and healing trauma must happen in environments that foster connection and empowerment. So, that provides an opportunity for us to look at the principles of recovery for creating a framework for thinking about creating accessible environments. If we can take the principles of recovery and these are just some that you see in front of you that were provided to us from the National Consensus Statement on Mental Health Recovery. They provide a really nice set of principles for guiding organizations to move from a traditionally service-based delivery system to one that uses recovery-based approaches and recovery principles. If we use these principles as guide-posts, they can really lead us to creating accessible environments that can encourage consumer integration.

In order for people to reclaim their lives, it is important to create these welcoming and accessible environments. These can be guide-posts for doing that. One of the things that I think is critical when thinking through these principles of recovery as organizations go about doing that, is to access our assumptions. Steve and I have talked a lot about this and when we speak to organizations about integrating consumers into their services, design, and delivery, they also speak about the need to revisit their assumptions about the possibility of recovery even, that everybody can recover. This is something that is important to take a step back and take time to assess core beliefs and assumptions that create strong underpinnings for an environment. Those underpinnings for the environment can foster hope or can create barriers to people feeling like they are welcome and can actively participate in the program itself.

Steve:

That too is just so true. Whenever I do outreach training, I think one of the strongest teaching points that I make is that, we can never give up on someone just because we might find them difficult or uncooperative. I think we have all had, anyone who has spent time in the service industry, have run into clients who for whatever reason, have given the appearance that they are uncooperative or they don't want to get with the program. In my own life, I knew for more than 7 years that I needed help. I cannot tell you how many times in that 7 years, that people actually offered me help and for one reason or another I didn't take it. Throughout that entire period, I cannot tell you what it was that made me finally grab hold and really hang on.

I go back to the counselor that had the recovering addict as well, but for me the point really is that you can't give up on anyone because never know when they might get it together and succeed. Those who have been out there for a long time, those folks have so much to offer agencies and other consumers because of the struggles they endured prior to coming in from the street. And there is always hope. Honestly those of us who are recovering and are in positions where our voices can be heard, we are the beacons of that hope. I think people who are in recovery are really living testimonies. We inspire others and provide access to support. Our

presence affirms the possibilities, it breaks down stereotypes, and stereotypes flourish often when people don't have these kinds of experiences to share and put together around folks who are delivering services. Laura, thanks for bringing that up.

Laura:

Great Steve. I actually want to build off of something that you just said, which was that I remember being in a facility and I had given up speaking to folks and I was on a lot of medication and I was sitting on the floor really feeling so vulnerable that I sort of just rocked back and forth. The more vulnerable I became, the more people assumed that I didn't hear them and they began to talk about me, they began to talk around me, they began to talk over me. I remember this one day that someone came in and they sat down on the floor next to me and they just sat with me and they rocked with me, and then they began to talk to me. They tried to make eye contact and I was really too vulnerable to do that, but I never ever forgot that they made the attempt, never forgot. They made a huge impact on my life.

So as we go thinking about the power of recovery and hope, we think of those things generally as conceptual principles somewhere out there, but it's a very concrete thing. Meeting people where they are at lends a promise that you see them. I know that the more vulnerable I became, I ended up on the street, the more addicted I was, the less I felt sane. Reaching out to people and letting them know that you see them is a huge part of what people can do in creating welcoming environments so that people feel like they want to be a part of the organizational structure. It's not a small thing; it's a really large and concrete thing people can do.

We're asking people to shift their vision and that is why this particular overhead is up. I love what Marilyn Frye does with the word "realm" and "reality". She relates reality and the vision of the king back to power. And she says, "the reality of what the king can see, is related to his eye, and anything he does not see is not in his realm." I think what we are asking is to shift the vision and make it broader, to see people who receive services in a complex manner. As resources, and as people with capabilities and strengths, as well as vulnerabilities, it's to broaden the vision of who people are as complex individuals, and to begin to see them in multi-dimensional ways.

I like to use this example of integration. We were talking earlier about creating accessible environments for those who have experiences of homelessness and to be comfortable in the work place. I like to use this analogy of people with physical disabilities because I think it's one that people can relate to.

Environments that are non-accessible are those that lack integration. They are environments where consumers must adapt to the environment itself. There are a lot of meetings that I have been invited to in the past and other consumers have been invited to in the past by people who are very well intentioned and very excited that folks are going to come to the table and they don't show up. When we don't take the time to do an environmental assessment, and talk about access to the environment, we can assume that people just don't want to come. There have often been times where I literally was not able to get to the meeting itself, but I was invited. The assumption was that I didn't want to come after people had done all this work and gotten all excited about consumers participating. And they didn't understand why, they just thought that I didn't want to be there, when in fact what was going on was that I wasn't able to get there. So, we need to take

time and look at our environments and to adapt our environments so that it creates an opportunity for people to really participate. We can do that by creating a dialogue with folks and asking them what would help? What would make the meetings and environment accessible for them to participate in the best possible way?

Lastly, I am going to tell a story about being in a wheel chair. I was in a wheel chair a number of years ago when I was in college, and this exact thing happened to me. This was before the ADA of 1990. It was in the late 70s and the van picked me up to go to my class and drop me off to my class. It was the spring semester and it was right in front of the building, and of course it drove off. There I was sitting in my wheel chair, outside of my classroom with a big long set of stairs to get into the classroom, and there weren't cell phones then. I was sitting in my chair for an hour and half until the van came back and picked me up and people didn't understand why I didn't show up. I had to tell a lot of people that I really wanted to go, but there was no way into the building. This was a good reminder for me that even though we may be inviting people, if they don't come to the environments, we really need to step back and begin to think about why that might be and adapt the environments to make it possible for them.

Steve:

I am thinking about that in terms of inviting the homeless to participate in community forums and speaking events where their input has been requested. Often, nationally, regionally, folks don't realize at times how difficult it is for someone experiencing homelessness to actually get from point A to point B. The idea that because a homeless person didn't show up, or a group of folks didn't show up at a meeting, means somehow they don't care about their situation is just absurd. It typically is because it has been an issue of poor planning on the folks who were responsible for setting and establishing the parameters of the meeting. So, it's just one of those issues of accessibility.

Laura:

This is similar to what we have already talked about, so I am not going to go into it in too much detail here, but this is another way to think about creating an emotionally accessible environment or a recovery oriented environment in focusing on people's capabilities and assets rather than their deficits.

I know that the more involved in services I was, the more I saw myself as somebody who was service-identified. The more service-identified I was, as someone who was case managed or a disability recipient, I didn't play softball anymore, I was doing recreational therapy, I wasn't hanging out with friends, it was Milieu therapy. Everything in my life was related to therapeutic benefit, rather than being a citizen. The more that happened, the more I was standing outside of my life looking in. And the more that happened, the less connected I was to the community.

So what we are really talking about here is helping people move from the margins in their life, into the center of their life. And to support them in the many facets that people function as spiritual beings, as partners, as friends, as community members. What we are doing when we are talking about integration is supporting this recovery process for individuals and also for environments as well, making them more accessible for everybody and supporting a whole life process or whole life where people have multiple relationships in their life that need to be

attended to. In shifting environments as well, it means having a dialogue with folks and beginning to talk about things that are difficult to discuss, like assumptions, beliefs, and the underpinnings of the environment itself.

I like this slide because it breaks down the word, “dialogues” through words. There is many way to have a conversation and some of them don’t involve words at all. Some of them involve exercises, team building, retreats that people go on as agencies, they take afternoons if they don’t have that time and resource, or they may take an hour and get together to do some deep discussion with one another or to do some exercises that again don’t involve the use of words to begin to assess where people are in the process. When they do this and have this dialogue with consumers as well, who are involved in the process, it opens up new kinds of conversations and new understandings. We don’t have conversations with people we don’t feel are visible or competent to have them. So in doing the conversation itself and having the dialogue, we are giving really potent messages, we are giving the message that people are going to be seen, that they are going to be heard, that we take them seriously, that they are competent, that they are capable and worthy of what they say has meaning and value.

Some characteristics of accessible environments for integration, people have asked, what are some of the characteristics itself? Creating safety and I am hesitant about this word “safety” because I think it really needs to be defined by the people who receive services because there are a lot of different definitions of safety. There is emotional and physical safety that are two components of that in the environment and that again is a really potent discussion, addressing language as a potential barrier to access, discussing people first language, using people first language, instead of pathologizing a language or short-hand or militaristic language. People ask, what do I mean by militaristic language? Well, I often hear such phrases as on the front lines, in the trenches, target populations. All of that language pre-supposes that we are in the middle of a war and takes the question, well if we are in the middle of a war, then what is that all about? That tells me that there is a lot of stress. Those who are providing services are really under a lot of stress. We need to step back and begin to ask the question about self-care, so we don’t get into using the militaristic language of being in the trenches.

Avoiding tokenism, supporting a significant representation of those for whom services are intended, it never feels good to be the only one. That’s the big message there. When people are the only one, people begin to feel isolated and it undermines the agencies’ efforts in the long run.

Labeling and loss. Once folks are labeled, it is hard not to be seen through the lens of the label. Again, I know that for me, the more labels I received, the more I believed other people were seeing me through those labels as well. It began to be hard to tease out, when people were talking to me about the job I was doing, were they seeing me through the lens of the label or were they assessing the job that I was doing? It took some connection with other peers, other consumer survivors, and other people who were working in the field. I used them as supervisors, really to help me tease out and get some guidance about undoing some of the learned responses that I had to being labeled and to tease out what was the environmental effect of people knowing where I came from. What was my internalized stigma? And trying to find ways to undo that.

These are some other characteristics, which I am not going to go into any great detail of accessible environments for integration because I will follow these up on July 23rd with Steve. Again they have to do with increasing diversity and representation. A part of creating accessible environments of integration is also to pay attention to diversity and cultural diversity as well, which I haven't mentioned before this. Committing resources to sustaining opportunities that you are creating in your environment is really key, too. So before we move on to benefits, Steve, I would like to hand it over to you.

Steve:

Thank you and I just think you are spot on with what you just described. The idea of diversity is just so important. I think part of it was in the conversations we had leading up to this webcast. The most critical thing that stuck in my mind, was the idea that when we have individuals who we are viewing one-dimensional through some particular lens, regardless of how advance we may believe ourselves that we don't have any biases or any prejudices, it is seeing somebody who you have some predisposed idea that is unable to do something actually doing it, that completely changes dynamic and destroys that stereotype forever. It is using this diversity, I think, having a number of different folks, backgrounds, different viewpoints, is just so important in advancing both the agency and the caregiver, the whole basis for treatment and recovery. I just think it is a critical area.

Laura:

Some of the benefits of integration really fall along a couple of axis. There are individual benefits for consumer involvement, and then there are system and service benefits for consumer involvement. We are going to just take a few minutes and talk about the individual benefits of consumer involvement. Many of these, I am sure you folks have already seen.

The fostering a sense of hope, I don't think can be overstated. By providing positive role models in the environment, the agency itself provides an opportunity for people to see folks not just as folks with vulnerability, but with their strength. I think that this is really key.

I had my first opportunity to work in the Department of Mental Health after I ran away from a psychiatric facility. 6 months later I was hired as co-coordinator for human rights for the Department of Mental Health. One of the things that happened in all of that was that there was a gentleman who had come onto the unit where I had been for a long time and assessed me for case management services. He found me eligible for case management services, but he said that there weren't any services to provide. I was very frustrated with this gentleman. I ran away after having been in restraint and was homeless.

When I got hired by the Department of Mental Health, 6 months later, I walked onto the job, after getting my suit at the Salvation Army. I call it my swiveling suit because they had one suit that I loved but it was a couple of sizes too big and I thought it was the most beautiful suit that I had ever seen, so they let me have the suit and I wore it, but the skirt swiveled as I walked. So I call it the swiveling suit and I saved it for years because it reminded me of how excited I was to be on this job and to do a good job. It is a good reminder of where I had been.

I had my swiveling skirt and my new suit, I walked on the job, and there was the guy who had assessed me for case management services. We were in our brand new orientation meeting for the Department, and he knew my most personal details of where I had been six months earlier. I wasn't ready to share all of that with the entire Department and I felt very vulnerable. At the same time, the benefit of that and having that happen was that it created a dialogue, it created an opportunity for me to see this gentleman eventually in a multi-dimensional fashion. I am also told that he also began to see people who receive services in a different way as well. We began to learn about each other, and I don't think that could have happened without having both of us at the table at the same time. Without having the conversation at which I went to him and said, "we need to talk about how we are going to handle this." He was very gracious and to this day is a very gracious individual. We worked out something that was amenable to both of us.

It is a process, but the benefits are huge. My first call as a Human Rights Coordinator ironically was to go back to the unit where I was a patient where I ran away. There I was, 6 months later, going back to the unit, this time with the Department of Mental Health. As I walked onto the unit, people kept coming up to me and touching me. It was the most striking thing. They kept touching me and they kept saying, "How did you do it? Where are you? What are you doing?" And so did the nurses and the people who had worked so hard to support me in a life and kept encouraging me to move forward in my own recovery. They kept saying, "What are you doing? How did you do this?" It dawned on me that we don't go back. It dawned on me at that moment that the power of going back into the environment was a testimony of the possibility.

Folks in the units and in shelters only saw me when I was vulnerable and they only saw me when I was in need. They hadn't seen people come back to those services when they were in a different place in their recovery process. So the people working in those environments didn't know it was possible because they didn't see people who were coming back in a different spot. And the people who were receiving the services, like I had, who were going from program to program, didn't trust that it was possible because there weren't people coming back in positions of authority and positions of power to let them know that there is another life, another way that they can be living. This is the power of consumer involvement. It is that kind of living testimony of possibility.

Steve:

Absolutely, Laura. I think it takes us back into the historical aspects. I think it really highlights the lack of visible presence of the people in leadership positions who actually have some germane real life experiences and who can drive policy and practice so the systems and the services aren't fragmented. I think that often, they are better able to focus on the needs of consumers, rather than the social science theory. Please don't misunderstand me, I don't mean to throw individuals who have these experiences under the bus here because one doesn't have to be a heroin addict in order to help addicts recover, and you don't have to be homeless in order to understand the very important need for shelter. I do believe having people who have had these experiences, as consults, co-workers, peers, can really help hone and focus treatment protocol.

Here is an example. I feel like I have been pretty successful in my recovery. I have been clean, sober, and housed for about 11 years now. I am very proud of that fact. For 8 of those years, I have also been a methadone maintenance client. With how I overcome my heroine addiction, I

have been a model methadone maintenance patient for 8 years. I have done every step of the program. I have given a monthly drug test for 8 years and never relapsed. I was absolutely a model methadone maintenance patient. In transferring to another clinic, I had come into the clinic as an individual who was able to split his dose half in the morning, half in the afternoon. The reason I split my dose was because it minimized the narcotic impact of that drug full force and at full dose in the morning. I am a morning person. That is when I do my writing, my best thinking, and I need my wits about me in the morning. I came to this new clinic. I was not allowed to split my dose, and I challenged that. I went to the psychiatrist in charge. The gentleman I don't think looked at me the entire conversation we had. It didn't matter to him at all that I was aware of what was happening in my own body, nor did it matter to him what I was doing in my career. All that mattered to him was that there was no scientific evidence that splitting the dose was beneficial. So, I was refused. I cannot tell you how that made me feel and how that still makes me feel to this day. Every month I have to go to that particular clinic and I have to take the full dose in front of them. It affects me for three days after I do it that way. I really felt stigmatized, I felt like an addict all over again. I was humiliated and still am humiliated. And, I lost a lot of respect for someone that I have entrusted my well-being to. To me the challenge is to getting individuals like this to listen to people that are being treated. I think occasionally, this is going to be a real challenge for long term service professionals, especially if suggestions by consumers go against the grain of the established treatment protocols.

One other thing I would like to add here is a benefit that I see is this huge impact on crushing stereotypes, and this happens when people see consumers in leadership roles or in positions of authority. We are so often viewed through this stereotypical lens. I have said this before and I will say it again, I had my own biases just shattered when I discovered someone who I may have had some preconceived idea about doing something I never thought possible for them. I see that often in the homeless community when people who I am looking at wondering, how they are ever going to overcome these tremendous obstacles they have just bull through them, persevere, and do it. There is just tremendous growth potential for others who may unconsciously be carrying stereotypes. Thank you.

Laura:

It's really important, the things you are saying, Steve. The system and service benefits are similar. We have gone over some of those and I think they are also worth repeating, just briefly. The benefits are, in short, the biggest benefit is that it makes organizations more effective in what they do and responses in what they are doing if you have people in those services who can provide feedback about how the service is being delivered and the effectiveness of its delivery.

As an example of that, I had received 14 years of therapy in and out of hospitals and various shelters. I had been in addiction programs and so on. All that time and detox and in that time I didn't meet folks in those services who had the same experiences as I had who was working in those environments, with the exception of some substance abuse programs early on and that was really encouraging. But, folks didn't seem to ask me if I was safe in the present. Because that question never came up, the assumption was that if I had trauma history, it was in the past. I was being stalked, while I was receiving services.

Because there weren't really folks who are formerly homeless who were working in those programs, folks didn't think to ask me that question. Because they didn't ask me that question, I was receiving all kinds of services that I kept saying weren't really relevant for me. What I needed was some help with legal protection, what I needed was to feel safe, physically and emotionally. Safe, prior to the 1990s stalking law, which was a very powerful thing, and I did end up getting legal remedy, which changed all the kind of treatment that I was getting. Why? Because I felt less vulnerable. What that circumstance taught me was the more people we have participating and working in environments of service delivery, the more responsive we are going to be to people receiving services because they have been there and they know they can provide feedback to the environment about the kinds of questions that need to be asked, tailoring the kinds of services people need, and about evaluating the effectiveness of those services.

Steve:

Well, you know, I am thinking about the gentleman that I met here in Nashville, actually the very first person I met as an Outreach Specialist here, and he had watched me for about 2 months. He hung at a particular park here that was frequented by a number of people experiencing homelessness and the gentleman had watched me for several months. He approached me one day and said, "You know, I have been watching what you are doing, and you're still here. You haven't come in and left and never returned. I will tell you what, I need some housing, I need some help and I am going to give you three chances to do it. But, three strikes are you are out. I will take whatever you have to offer, but anything else you can just kick rocks on."

So, I started working with the gentleman and it was a challenge, he certainly had some barriers, had some obstacles. But, he also had many things going for him. It took us sometime, about a year, but ultimately, the gentleman was able to receive social security disability, he is now housed, and the things that happened for him as he moved through that, were the acceptance by agency personnel that had been working with him, that he actually had valuable things to put forth. His own self worth had increased and he started really paying attention to his health.

He now sits on an advisory board for one of the agencies here in town and helps to set policy. He is the go-to guy really for questions, especially local issues. That kind of brings up the whole regional, cultural aspect. He is one of those individuals who had for 25 years, spent his life on the street here. This man knows the homeless community inside and out and he has become an extremely valuable asset. He has brought a number of other folks into the system in very constructive and productive ways. Anytime you see that happen, it is almost cyclical. It fuels a desire to participate for others because he is basically leading by example. As other people follow his lead, he gains respect and support, he gains his own self-worth, he puts that back out to the community, and everybody benefits. It's just an amazing transformation for someone who, up until a year and a half ago didn't even get a passing glance by people, now he has the ability to affect policy. It is just an amazing thing to see.

Laura:

And a really powerful example of what we are talking about, too. I am just going to briefly talk about barriers because we are actually running over time so I think that because a lot of people tend to be very aware of the barriers and challenges of consumer integration, I am not going to

go into that in the detail that I had planned to. We will come back to it rest assured, and I am sure lots of you will have questions, and that's just fine, but we are not going to linger here.

I can tell you that these are the main issues that come up when we speak to providers of homeless services in this country particularly. These are the grouping of issues that they tend to identify. They are interrelated with one another and are not always as discrete as they appear here. So, for instance, the issue of boundaries and multiple relationships is also connected to stigma and discrimination, which is also connected to the issue of confidentiality and disclosure. So these things are linked to one another and they may come up at different times in the agency as barriers. All of these issues, I believe can be addressed through strategic planning, and through focusing on shifting the environment, from one that is top down traditionally to a recovery-oriented environment, where people focus on developing ways to share as much power as possible, breaking down hierarchies and beginning to enter into dialogue with one another as potential colleagues and collaborators in a process that leads to a common goal and common mission.

So I am going to keep going here. I put this slide up because perhaps the number one issue that comes up is the issue of disclosure. People ask, "Why is disclosure so important? Do I have to disclose my history?" Many people that we know in service delivery systems, particularly in the helping professions, have their own histories of trauma. They have their own histories that lead them into this area because they want to help and they want to give back. So, disclosure becomes this incredibly potent issue.

Let me just start by saying, there are lots of reasons, really important reasons for having people who are willing to disclose. I believe strongly that people have a right to privacy, so those who do not wish to disclose, should never be put into a position where they feel in any way, coerced to do so. However, that being said, if we take a look at environments where there isn't anyone in that environment that represents the folks that are receiving services, how are we going to know that there is a visible presence of those who are there? It becomes important to set aside positions earmarked for folks, either the current positions as they turnover can be slated for people with lived experiences of homelessness or new positions can be created for people with experiences of homelessness, who are willing to publically disclose or share their experiences. I believe that the advertisement that was put out for the job that I applied for said, "People with experiences of psychiatric disability are particularly sought after." This was something advertised that made clear that was an asset, and when you put that out into the world that this is an asset, you open up a whole world of possibilities of people who will want to be in the environment because it provides an opportunity to give back. Steve, do you have something that you would like to add to this quickly before I move on?

Steve:

The only thing for me is that disclosure to me is a cathartic and powerful way for me to feel like I am giving of myself in ways that for so often, issues of addiction are just not brought out in very blunt and straight-forward ways. I have no problem disclosing. I am not proud of my past, but I am proud of where my past took me and by disclosing things, I am able to connect with people. It is the single most said thing to me when I am dealing with people on the streets, "I come to you because I know that you have experienced these things and I can look to you, not

maybe for answers so much, but for some hope.” That to me, more than anything is the reason to disclose.

Laura:

Absolutely, and this issue also has parallel in other movements. I just want to put that out for folks who want to research that more in the gay and lesbian movement particularly, people were encouraged to create positions where there was a visible presence of gay and lesbian folks in the environment because otherwise people wouldn't know that they were there. When people began to do that, there began to be evidence that people from all strata were gay and lesbian folks and people weren't aware of that before. They were everywhere.

Oops, I lost my little graphic here, I see at the edge, my range of roles got very small.

We are talking about the range of roles and what can consumer survivors do. People with lived experiences of homelessness are everywhere, engaging in opportunities only limited by the imagination and I am sorry Gloria couldn't be here today because she really wanted to make this point, that people become homeless with all kinds of experiences. The issue is a poverty issue, so some people have a lot of educational background, some don't. But the point is that there is a whole range of experiences that people come into services with. A part of what is exciting to me about this is that it gives us an opportunity to think through creative ways to look at people's abilities and to think about using the consumer integration issue as an issue of diversity and cultural diversity, we can think of it that was as well, creating the most diverse universe in our program as possible. That is a part of what makes it interesting and a part of what makes it fun. It opens up the possibility of new dialogue, it opens up learning possibilities for growth and advancement, it challenges old protocols, which can be hard and create a crisis in organizations as well.

However, crisis can be a time for opportunity, too, and provides an opportunity to look at revisiting our policies and practices that have typically been barriers to people who have been actively participating in successful ways. So what are they doing? They are doing all kinds of things. They are board members; they are policy makers, writers, filmmakers, artists. Steve has talked about founding a newspaper. They work in radio. I have a friend who develops real estate and makes it available for people with psychiatric disabilities and that can also be accessed on the website, the Homelessness Resource Center website as well. He runs main street housing out of On Our Own in Baltimore, MD. There are people who are housing and entitlement specialists and people develop speaker bureaus. There are psychologists, psychiatrists, nurses, lawyers. I have formerly homeless friends who are presenting at the UN who took a part in helping to develop and review the Declaration for the Right of People with Disabilities. It was a very exciting opportunity. So they are doing all kinds of things.

Part of what I find to be some of the most interesting things that people are doing come out of discussions at a local level of what folks would like to be doing, what excites them, and often something very creative comes out of those kinds of discussions.

Steve:

There are a couple of things that I really want to share here and it has to do with the creativity of the contributor, which is the street newspaper that we started about eighteen months ago now. And that arose as a result of barriers that we were seeing as a result of people experiencing homelessness, who simply could not go to work. For whatever the reason, whether they had felony convictions that were really stopping them, issues with substance abuse, the run of the gambit of barriers.

When we started “the contributor” our goal was ultimately to turn it over completely to homeless and formerly homeless people, so that they could run with it. But it originated as a way to do two things: One provide an income to people who are still experiencing homelessness, and two it was a way to make the broader community aware of issues that the homeless here in Nashville and I guess, really even nationally or maybe even globally, were experiencing. So what we wanted to do was present some diverse perspectives and we have taken anybody who wants to be a part of this organization and we have seen the homeless population in Nashville go from three or four vendors who submitted a couple of stories to people who have put puzzles together, put photos written stories, sold the paper, researched for us, tried to drum up advertising business, game solicitation, you name it folks are doing it.

At this point, we actually have enough circulation that we have taken people off the street, who have been existing, because of barriers, because of massive medical bills, we have been able to get people into residences through selling a newspaper for a dollar. At a time when newspapers are really just collapsing all over the country, ours is growing. It brought about, through a creative spark, and because there were so many barriers in place, it is just an example of a way to bring people together, get them focused on something with the idea that we are going to overcome whatever is put in front of us.

I am so proud to say that right now the majority of folks on “the Contributor” staff and writers are all either homeless or formerly homeless. And it wasn’t that way when we first started. It was all volunteers and it is just a joy to be part of.

Laura:

All right Steve, thank you for that. This is one way to think about this chart here. It’s a picture of a continuation of consumer involvement and integration. And it takes a little bit of explaining and I am not going to go into it. Again for folks who are interested in it we can send you a copy of the overhead. Basically what this shows is that if we take a snapshot of agencies, what we found was that there is a continuum of involvement that agencies can look at within their own programs to assess where they are along this very loose scale if you will.

I noticed that when we talked to people when they weren’t involved or were invited—they talk about inviting consumers—that tended to be the less formal or more informal end of the scale. The tendency was to invite one or two to meetings. That was the language that was used often and that’s what they meant. They would bring one or two folks in. And the less formal the arrangement was the less integrated people were in a sustainable way.

So what I am beginning to notice was that there tended to be different language that was used as people began to become more formally integrated as part of a system structure. And they went

from being invited and having one or two people involved to being included, actively participating, which involved more people over a period of time, to collaborating and being viewed as collaborators, not just being invited here or there or participating here or there to being partially integrated, which tended to involve more than two people. Those agencies tended to involve, they began to get that there needed to be an on going relationship with consumers in the community. They brought people in in a leadership position to coordinate that effort. And that person, in turn, brought more of the folks they new on. That began to indicate, that's one indicator of a more formal relationship, usually a contractual relationship of some kind with the agency itself to be fully integrated. What I mean by that these are individuals, who provide, are in position to find positions in the agencies, to find roles within the agencies and that there is some way of measuring performance of that role. How the integration effort is going, the feedback for that is provided to other decision makers of which the consumer/survivor is one as to how things are going. There is this feedback loop that's happening. This is just one picture of what we learn when talking to people about the integration efforts.

What's next and what are the steps? So you may be asking at this juncture and were going to whip through this is lightning speed: What can people do and what can they do now? I say, I really believe very strongly in agencies starting with where they are at, and starting from the strengths based-approach. Not just for individuals and there own healing and recovery and agencies too. I think that what that does is encourage people to take incremental steps and measure your success incrementally and longitudinally.

So what do I mean by that? I mean look around and talk to people that you already know about what people are all ready doing to identify consumers in their agency who can be resources, who is doing, who is engaging in interesting efforts, either locally or regionally or in the country. What are people and building off what works? Asking people who you know what are they doing and what is helpful and what is working. Creating a plan, being as proactive as you possibly can and getting folks who have received services in on the ground floor early on. Early, early, early. Because it will help you in the long run, because you won't have to gain buy-in later on. Nobody likes to walk-in at the back end of a process. It makes them feel like they are critical of what you worked so hard to created. So rather than back stepping and having to question is this the right way to go, create the dialog early as proactively as you can and begin to think about having the dialog among your staff and other folks that are volunteer and on board about some of the following:

- Defining consumers: Who are you serving? This is a very, you wouldn't think it's a contentious issues, but it can also often be a contentious issues. Who is it that you want to bring on? And define that really, really clearly. In the mental health movement, for instance, when family members began to define themselves as secondary consumers and we talked about involving consumers in the design and delivery of the evaluation of services it became very confusing.
- Who are we talking about? So usually consumers, as a general definition, are people who reflect the kinds of services that are being provided. That is the general definition that I give for who consumers are that I give. So if you are somebody who provides services to folks who have HIV then your consumers are people who have been diagnosed with HIV. So that is a general description

- Defining integration: What do you mean by integration? What kind of integration? What does it mean in terms of involvement? What does significance mean? Is that a number reflected by, what kind of standard would you like to set? What's your goal standard? What is your immediate standard and can you start with one person or two people optimally and move along to your gold standard? Creating a time line, these are really important things just to begin talking about. What are people wanting to do? What excites them? Getting a role or job description is also very key. I don't know that I have actually ever walked into a job with a job description and it is a very interesting thing to be hired to coordinated consumer integration for an agency and have people have no idea what you are doing. So it becomes very hard to judge my own performance and to know how well I am doing in the absence of a job description. It becomes very hard for the agency to judge how people are doing in the absence of a job description. In order to create that it is optimal to get a few people on board who can help you design that who have the lived experience. And walk through it with them from there.
- How many people does your program want to integrate and again how long? That is all part of the strategic planning, but it is also a part of early conversation to have. That includes a dialog on recovery and the assumption of recovery within the environment.
- What is meaning full involvement? It tends to include characteristics along two axes:
 - The first is qualitative. They are people with expertise. They are people who are willing to disclose. and they are people who have impact on the environment. In other words, you can have people in the room who have expertise who are willing to disclose, but if they are silent the entire time, than they are not having an impact in you process. So the question is how do you get people on board or how do you mentor people to bring them on board so that they feel like they have impact in the process. And the agency feels like they are changed because people are in the room.
 - And there is quantitative. To avoid tokenism we have to create numerical standards and optimally at least two is a place to start.

This is one conceptual model for creating ongoing quality improvement to consumer integration. It is just one way to think about it. It's the way I began to conceptualize it after talking to a number of programs who are attempting to do this because they wanted to measure how well they were doing. So, this is one way to think about how agencies can look at their own process and what it shows is a self adjusting process. It has the organizational environment, engaging consumers and stakeholders in the agency. They impact role innovation because that will be ongoing and changing as you get more people on board, as you find out what is working and what is not. You'll develop measurements and documentation to see what is working and what isn't. Whether it is working or not, the feedback will be given back to the organizational environment, which will then adjust how it does business.

This model should be ongoing and flexible and mutable and organic. It's the same as recovery, which is why I like the recovery model and principle for thinking through an organizational framework, which is going to support people in their roles. For additional reading on these subjects there are a number of quotations I can lead you to. Again you can ask for a copy of the website afterwards and we can get you some of these. And I want to give Steve a couple minutes here because I have rattled on. Steve is there something you want to add?

Steve:

Laura you just, it's such a pleasure to work with you, because you are so able to articulate what is desperately needed. And to me, honestly, agencies to actually begin moving forward together with consumers is through acceptance, integration, and, most importantly, strength in numbers. And the more consumers are involved the more forward progress, I think ultimately will be made. To me it culminates with the ability to assure proper treatment and care. And policy that is sensible that reflects our priorities rather than the priorities of those who often know very little of our actual situation. Experience is critical and it is often lacking within a large number of the agencies and this is not saying that agencies are not doing great work, because they absolutely are. But by adding consumer diversity, we can make them so much better, you know, inclusive hopeful, powerful and helpful. It will be a place where people are no longer sighing and shrugging and putting off going through. Instead we'll be encouraged to go and we'll actually feel like by going they'll be able to accomplish something that improves their lot in life, their situation. So, I think it takes recruiting staff or consumer involvement, establish consumer and provider designed recovery dialogs, collaborating with the staff and consumers. Really having the agency celebrate and visibly acknowledge the achievements of consumer employees. It takes a clear dissemination of a given agencies process. This just can't be said enough. These progresses and success are just so important and it can be used by others who might be considering consumer involvement.

So it has been an absolute pleasure and I hope that folks will tune in to the next one. And I thank everybody for listening. And I think that I am just about done Laura. Back to you.

Laura:

That's great Steve. Thank you . And you see in front of you the next webcast and the date and time so I think at this juncture we will open it up for thoughts questions and comments.

Kristen:

Thank you so much Laura and Steve. That was a wonderful, wonderful presentation and a great part one to get everyone ready for the next webcast on July 23rd where we'll be able to get quite a bit more into the nuts and bolts of how do we do consumer integration in our agency. How do we measure it?

We've gotten quite a few great questions and comments from the audience so we'll spend the next five minutes or so addressing some of those. One that has come up a couple of times goes back to the question of disclosure and whether an outreach worker should be a total open book, so to speak, as they are working with people on the street. To disclose their own mental health and substance use or homelessness issues.

Laura:

We'll I'll start then I'll turn it over to Steve to pick up. I think that the issue of disclosure is, it's really important and complex. Let me just start there. I don't know that it is ever great to be an open book. I think that there are circumstances where it is really important to share the information. Certainly it provides a model for hope for folks. I think it's really a key thing to do, disclose your experience, when the time is right. I also think that people are not often provided

enough guidance in the field about when and how to disclose and one of the issue that I think is key here is supervision around the issue of disclosure. Getting good training and getting orientation to the policies and practices of the organization, which can come into conflict with the issue of disclosure. Right? Folks who are in helping professions are told not to disclose that you are violating boundaries if you do that. Well, so what do we mean when we are encouraging people to disclose. I think judicious use of your story is really key and I think setting aside positions where that can happen is really important. But figuring out what that balance is is also really key. And I think that that can happen again over time and with good supervision and training. Steve do you want to add to that?

Steve:

I think you've pretty much nailed it. There are a couple of things I would add. One is, I am really open about disclosing. Absolutely. But I am also very careful to build credibility with whomever it is that I am dialoging with. Because disclosure in and of itself is kind of like a double edged sword. There are people, when you disclose, can immediately begin to prejudge or formulate their own opinions. Especially if they don't know who you are and whether or not you are actually trust worthy yet. Especially with outreach. There are judicious uses of that and I think the opportunities present themselves as you build a relationship. One of the things that Ken Kraybill has done, Ken is really a nationally recognized outreach specialist and has taught lots of stuff about outreach. He has often talked about being very person-centered. And it is this discussion, this building of a relationship with your clients or with your consumer that creates the conditions that allow the disclosure to take place in a very safe and, I don't want to say protected, but a safe environment. And you've also built the credibility ahead of time. It is an issue that takes time and practice and good supervision will really pay off especially having someone who will, again this is a really important role for a consumer, who can stand as a supervisor and help the individual just how much they should disclose.

Laura:

Thanks Steve. I think I want to add to is if folks are wondering if is it appropriate to disclose, I know I always ask myself two questions. Why and who is it for? And if I can answer those questions that I'm disclosing that I believe that that disclosure is going to create connection with another human being, then that's what I do. If I do a self-assessment and realize that I have another agenda then I don't disclose that. But those are to quick questions that you can ask yourself if you are wondering.

Kristen:

Thanks Laura and Steve. I think we will get one more question in before we wrap up. One of our participants wrote in that she has been a case manager and loves the work, but has always found the term to be very dehumanizing and so as an individual provider how can you promote more person-first language, not only about the people you are working with, but about the positions within you agencies.

Laura:

Person-first language. That is such a great question. Oh my god that is so great. I think it is incredibly insightful, first off, that you would ask. I know that what some agencies have done, which I thought was really innovative, was that they made it an agency-wide effort. It was sort of

like a contest to see if people could identify, within the agency, the terms, amongst each other, that were not person first language. They sort of work on calling each other on it, in a fun way, not in a dehumanizing way, but in a fun way. That can obviously come out of smaller agencies where you already have some trust built in. However I think it is really key to ask the people you are serving how they like to be referred to. I have rarely found that when people have asked me what's most important in my own recovery process or how do I like to refer to myself. I rarely have called myself the most important identification is to be case managed or to be referred to as my label. Rather I often tell somebody that I like to be referred to as somebody who experiences extreme emotional distress, rather than somebody who has mental illness. I like to be referred to as, it always starts as I'm a person with or I'm a person diagnosed with, because things change so quickly, meaning that diagnoses are flexible. That is depends on who does the seeing or who is doing the diagnosis as to what they see. So I think it is empowering to ask people them selves to ask people to come up with their own definitions. And if they don't have one, how they like to be referred to, that becomes a great tool for dialog. Why don't they have a way they like to be referred to, meaning do they want to be referred to by their first name? Some people want to be referred to as mister so and so who has dah dah dah dah dah, or certain vulnerabilities. I think it is an awesome conversation. There is no one answer to it, but there is a great conversation there that can lead to great potential and I'm going to give Steve a word or space for some comment here too.

Steve:

And I have to, it's very brief. When people have asked me that the first response out of my mouth is I'm a human being and that's kind of how I want to be referred to. I'm a human. When I talk to folks the first question I ask them is: What name do you want me to use? How do you want to be called? What do you want me to say? I want them to tell me. I'm not going to make that assumption or decision for them. It just shifts that whole issue of power and control. It gives them some and for so long so many folks have just been powerless, both in maybe their addiction and the situation they find themselves on the street and in the agency. So giving them some power and that person centered vocabulary, I'm trying to make that something I do without fail.

Kristen:

Thank you so much Steve. I think that is all the time we have for questions. And thanks to all of those who stuck on a couple of minutes past 1:30.

Before we end today's webcast, I would like to remind everyone to visit our website at <http://www.homeless.samhsagov>. For those of you who may have missed our earlier introduction of the website, you can register and create a personal profile, connect with other users, access thousands of articles and resources, and get up to date information about events and training opportunities. Materials from today's webcast including an audio recording and a written transcript will be available on our "HRC Webcast Resources" topic page on the HRC website within a couple of weeks.

To receive slides from today's presentation please email generalinquiry@center4si.com.

You may have noticed on your screen that we have opened a poll with a few brief evaluation questions about today's webcast. Please take a moment to complete these three questions. Your feedback is extremely important to us, and helps us to serve you better.

The next webcast in our series will be on July 23, 2009 at 12pm ET. As we mentioned earlier, today's webcast was part one of a two-part series on consumer integration. Part two will pick up where we left off today, focusing on next steps to creating recovery-oriented environments conducive for integration. Even though everyone talks about integration and recovery, how do we actually get that done? Participants in part two will engage in discussions about how to set the stage for integration, creating an agency plan and taking concrete steps toward implementation. Registration will be available shortly for that webcast on our website.

On behalf of the Homelessness Resource Center, I would like to thank our presenters, Laura Prescott and Steven Samra, and all of you for taking time out of your day to be with us. Thank you and have a great day!