**Rhode Island Community Academic Partnership for Behavioral Health**

**Second Symposium: Recovery Perspectives – Understanding Behavioral Health Wellness**

Time and Date: May 28th, 2019 8:00am – 12:00pm

Location: The Leadership Council, 200 Metro Center Blvd., Warwick, RI

Agenda:

8:00am- 8:30am **Registration and Welcome**

8:30am-8:45am **Introduction of RICAP**

* Susan Storti, Ph.D., R.N. Substance Use and Mental Health Leadership Council of Rhode Island (SUMHLC)
* Bart Laws, Ph.D., Brown University School of Public Health

8:45am - 9:30am **Overview of Recovery and Q&A**

* Ronald Seifer, Bradley Hospital/Brown University
* Stephen Gumbley, SUMHLC

9:30am - 10:30am **Panel discussion on lived experience of substance use disorder,**

**and general discussion**

* Facilitator: Susan Storti

10:30am - 10:45am Break

10:45am - 11:45am **Panel discussion on lived experience of mental illness,**

**and general discussion**

* Facilitator: Beth Lamarre, National Alliance on Mental Illness Rhode Island

11:45am - 12:00pm **Feedback and Closing Remarks**

* Stephen Gumbley
* Ronald Seifer

Purpose: The purpose of this symposium was to hear from the panelists as well as the keynote speakers about recovery and what that means. There are various definitions of recovery, but from an individual perspective, what does that mean? As RICAP moves forward to develop an agenda, we hope this symposium will identify topic areas that will help us frame research proposals. At that stage, we plan to match academic investigators with community-based organizations to conduct stakeholder engaged research.

**1. Overview of Recovery**

Ronald Seifer and Steve Gumbley, co-chairs of RICAP, each presented on the topic of recovery in behavioral health to provide a brief overview of recovery.

Summary of Ronald Seifer’s presentation:

Recovery is one of the core terms in behavioral health, especially in substance abuse. Part of the struggle in recovery is that we collectively don’t have a firm grasp on the definition of recovery. Individual pathways are important when addressing recovery. People talk about assisted and unassisted pathways of recovery but essentially, it’s around doing fewer “bad” things and doing more “good” things.

Wellness also has many meanings and individual pathways in characterizing it’s meaning. It is certainly about functional behaviors and many people talk about it as a state of mind. Again, it is generally about doing “good” things and preventing “bad” things.

Substance Abuse Mental Health Services Administration (SAMHSA) has its own definition of recovery:

“A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential”

SAMHSA talks about four domains in which recovery is important: Health, Home, Purpose, and Community. While SAMHSA’s definition of recovery does provide a starting point on discussing recovery, there are still several questions that need to be answered including:

* What behaviors lead to recovery?
* What are overlaps regarding substance use problems and mental health problems?
* Are there differences in the recovery process for different levels of severity?
* Is the full life course addressed (prevention, treatment, social determinants, etc.)?

There are a lot of conflicting language and concepts in mental illness and substance use disorder. In the psychiatry department, we use the DSM book that list all the disorders, but we often find the diagnostic categories are at odds with research and behavioral agendas pursued by the research team.

In developing the research agenda, it is important to understand where we are now, where do we want to be, and how we can get there. Currently in academia, we are (for the most part) driven by models of disease and pathology particularly because that’s where the money comes from. NIH and SAMHSA use resources towards issues driven by pathology and disease because they cost the society a lot of money. There are also observational studies, treatment studies (including randomized trials) which are developed largely within academia.

What we hope to achieve is to study things that matter to community members and identify what works for whom at what times. We also want to identify what doesn’t work because recovery is complex and different individuals require different pathways. Understanding what doesn’t work can also inform researchers on identifying things that do work. We definitely want to learn things quickly because there are people encountering problems in their daily lives as we speak.

One of the ways we can achieve the goals state above is to convene all interested parties including community members (including those affected by substance and mental health issues), providers, insurers, government, and researchers. And through this we want to develop an agenda that addresses things that matter in the daily lives of people. As an academic researcher, I get to see the big breadth of studies with nice research designs but doesn’t necessarily have meaning. Through collaboration between interested parties and stepping out of our boundaries, we can implement a meaningful agenda that has been collectively developed and find resources to support the efforts. And we also always retaining fundamental goal of maximizing individuals’ potential for meaningful lives.

Summary of Steve Gumbley’s presentation: “Recovery in the 21st century”

Bill White defines recovery as:

“The ongoing experience through which individuals, families and communities use internal and external resources to resolve these problems by **actively managing continued vulnerabilities** to such problems”

Recovery is dynamic. Recovery is managing continued vulnerabilities and counterbalancing them with resilience and recovery capital. When people enter recovery they have more risks and vulnerabilities than they have recovery capital and this dynamic changes over time.

Recovery and Remission are different. Remission is about no longer meeting the diagnostic

criteria for the disorder. Remission is focused on pathology while recovery is concerned with wellness. Recovery is more than just remission; it is about managing the disorder and wellness. The Betty Ford Institute Consensus Panel says:

* Recovery from substance dependence is a voluntarily maintained lifestyle characterized by sobriety, personal health, and citizenship.
* Although sobriety is considered to be necessary for recovery, it is not considered as sufficient. Recovery is recognized universally as being multidimensional, involving more than simply the elimination of substance use.
* The additional health and social aspects of recovery are potentially quite important to the prevention of relapse and may be the most attractive aspects of recovery to affected individuals, their families, and society as a whole.

Steve echoed Ron’s point that there are many pathways to recovery. This is one of the most important aspects of the new recovery movement. Recovery can be abstinence-based, moderation based, unassisted, peer assisted, treatment assisted, or other forms.

Treatment is not recovery, but rather a possible pathway to recovery for some people. Some treatment is necessary for some people for some of the time. Not everyone with a SUD needs specialized treatment in order to recover. People who enter treatment are a distinct subgroup of substance users whose problems are particularly severe and intractable. For most people, SUD treatment alone does not provide the breadth and depth of support to sustain change.

In the new DSM 5, there’s a single disorder called substance use disorder, but clinicians are required to modify that as “mild, moderate, or severe” depending 11 different criteria. Extrapolated data shows that about 60% of the people with diagnosable disorder had mild form of disorder, 20% and 20% for moderate or severe each. This shows there are a range of needs depending on where people are.

Patient-centered outcomes are important in recovery. The patients need to be able to carry out the processes of recovery. Portability is an important element of sustainable recovery and Bill White says this is based on the concept of choice. Also, how much recovery is enough? This question is not asked enough.

Bill White states:

“Long-term recovery is not possible without choice. If there is no rehabilitation of the power to choose and encouragement of choice, we are left with, not sustainable recovery, but superficial treatment compliance.”

Research conducted by the Recovery Research Institute shows a national prevalence estimate of 9.1% which translates into 22.35 million US adults in recovery from SUDs. 53.9% were in the “assisted” pathway (i.e., lifetime use of one or more AOD treatment or recovery support services). 46.1% were unassisted. The most commonly used services were mutual-help groups (e.g., AA, NA), followed by professional treatment received equally in outpatient and inpatient settings.

The Betty Ford Center also identified stages of recovery as:

* Early sobriety–lasting for at least 1 month but less than 1 year
* Sustained sobriety–lasting for at least 1 year but less than 5 years
* Stable sobriety–lasting for at least 5 years.

The important concept here is that people earlier in the process of getting well often look different than those who have sustained wellness for a longer period of time.

The term “behavioral health” is a contrived term to cover both mental health and substance use disorders. Behavioral health is not another term for mental health. mental health and SUD have differences. For SUD, recovery is often thought as overcoming the difficulties and leaving them behind. This is often not true for some mental health disorders. The best outcome is one learning to live as fully as possible with difficulties. Recognizing the difference is important in addressing what expectations we put forward to people about what wellness could look for them.

Co-occurring disorders data shows that an estimated 8.5 million adults aged 18 or older (3.4 percent of all adults) had both any mental illness (AMI) and at least one SUD in the past year. 3.1 million adults (1.3 percent of all adults) had co-occurring serious mental illness (SMI) and an SUD in the past year. This goes back to the idea that not everyone are the same.

Medications in SUD recovery is a huge issue. Various medications are used to reduce cravings, moderate withdrawal symptoms and produce use inhabitations. Historically identified as “medication-assisted” treatment/recovery. There are a number of people who think the terminology is stigmatizing and should not continue to use the term. Recovery is recovery, whether or not medications are used or not.

Discussion: Discussion after the presentations included the following points.

* SUD recovery and mental illness recovery really look different in the public mental health system.
* In mental health recovery, gaining captaincy of recovery is probably the single most important goal. Empowerment and peer support have helped with this a lot but there are still so many obstacles towards recovery in mental illness.
* It is important to have a discussion about what helps people recovery unassisted. When thinking about where the supports come from, like anything, it is still crucial to note there are individual pathways. But one unifying theme seems to be one or more healthy, fulfilling relationships that serve to support functional adaptation. The reality is that there are no silver bullets.
* It is important to focus on language because certain terminology can be stigmatizing.
* There is a wide spectrum across the continuum of care. Not only there are young individuals in recovery, there are also there are a whole host of older adults in recovery. We need to be cognizant of other generations and problems unique to them.

**2. Panel discussion on lived experience of substance use disorder, and general discussion**

Four panelists, George, Laurie, Angela, and Nick shared their stories and described what recovery and wellness mean for them. They also were asked to share what were potential obstacles in their pathway to recovery and what guidance they can give community providers and researchers as they move forward to make a difference and support others.

George shared his story of being a person of long-term recovery and how his 23 years of incarceration directly due to SUD affected his pathway to recovery. George picked up his first drink when he was 8 years old and became an alcoholic when he was 16. When he was 18, he had several charges and was sentenced for 30 years. He mentioned how he continued to do what he used to do outside of prison for the first eight years, pretty much being able to do whatever he wanted. As the prison implemented more changes and it became difficult to use or sell substances, George was in complete abstinence for about five years.

George told that his pathway to recovery started when he attended 12-step meetings in prison. For 11 months, he worked the steps diligently but faced obstacles. For Step 5 of the program, he was not sure who he was supposed to talk to in prison, so he turned to a clergy to share his story. One other thing George mentioned was that when he was in prison, medication assisted treatment was not available. While he’s not sure if he would have taken it, he remembers it was a horrible way to detox in a prison cell. Through his support system, George volunteered and subsequently found employment in the program he was once in. He went back to school and received his bachelor’s degree and took a position as the Executive Director of a program he actually graduated from.

Laurie shared her perspective of being a parent of a son who overdosed. She described her son as someone who grew up in an affluent neighborhood, a hockey player who graduated honors from boarding school, and went to college. After her son’s overdose, Laurie hit really bad depression and was diagnosed with PTSD. She, however, told us that she spent 6 months without seeking professional help and during that time got a really good understanding of chronic depression and what that meant. When she started to seek professional help, she also started doing things that the treatment facility for her son was asking him to do and really started to get educated on SUD; for example, 90 meetings in 90 days. She was happy to share that her son is working on his recovery for about 3.5 years and has improved his health and wellness. While she absolutely hates this disease, she is also extremely grateful for the journey that she has been on because she met many unbelievably great people who supported her son. Laurie dedicated herself to creating and organizing resources and support groups for patients and families to teach new coping skills, communication skills, and behavioral skills.

Laurie emphasized that SUD is not just a personal disorder but rather a family disorder and even a community disorder. She considers herself in recovery from SUD and constantly working on the recovery. Her following quote highlights what families are feeling when their loved ones are going through recovery:

*“Families are not typically a part of any individual SUD and their improvement, recovery, or health and wellness. We are often left out and in fact pushed away. We are told we are toxic; we are told that we need to stop enabling. We are given all sorts of unsolicited advice. And we are already in devastation mode.”*

She strongly believe in the peer model and absolutely loves what she sees when it comes to the certified peer recovery specialist with lived experience trying to meet people where they are at. She thinks the same thing has to be done with families. We need to meet families where they are at and empower them. She said families should be able to support and guide their loved one’s choice in recovery rather than tell them what their loved ones should or shouldn’t be doing.

This symposium was the first time she heard about families being a part of recovery in order to help patients with social functioning. Steve’s presentation mentioned long-term recovery is not possible without choice and we need have families understand this as well. Families can be a safe place to land and we can support in overcoming and managing one’s disease. We need to help families learn new coping skills and how to become a part of the support structure for our loved ones with SUD.

Angela shared her journey of 12 years of long-term recovery with medication-assisted treatment (MAT) and the stigma attached to MAT. Angela was young when a doctor prescribed Demerol for her pain issues. She expressed the pills became a coping mechanism when her father passed away in addition to the pain. She overdosed and went into a detox unit where she was told she had reasons she was taking pills and she could go home. They released her with more pain pills. She went home and continued her routine of going to one doctor after another.

Angela believes in the medication-assisted treatment route because it helped her tremendously but shared that more people need to be accepting of this pathway. She shared an anecdote of how people stigmatized medication-assisted treatment as not really being recovery. She often speaks to women in prison who are under MAT and are afraid how they are going to tell their families that they are on these medications when they get out. She said this brings back to Laurie’s point that families need to be educated so they can support individuals in their recovery. We need to get more families involved in recovery.

Nick’s SUD experience started long after when he first thought about committing suicide at 9 or 10 years old. Drugs did not fill that void or make it better but made him not think about it for a short period of time. He mentioned he was so fortunate to attend a high school with so many resources. If this wasn’t the case, he thinks his story would have gone down a much darker path than it already did. After graduating from high school, he went to college and got a job but struggled with SUD. The metaphor Nick used to describe his experience was:

*“Something circling the toilet bowl. Just slowly spinning around, spinning around, eventually going to the same place.”*

He later interviewed for a long-term, intense, working program around biblical concepts called Teen Challenge in Boston where his pathway to recovery began. Nick noted he was honored to be on a panel like this because the panelists have four very different experiences in addiction and recovery. This is sort of the picture of what it really is like in reality.

It was extremely difficult for Nick to come off drugs but within 6 months or so he started to build himself back up. In the program he found certain things that he did not find elsewhere; for one the philosophy, bible, and proverbs at the center of relearning who he was and who he could be. He also built incredibly strong bonds with fellows who went through the same program. Learning to build resilience and be a peer for others helped him a lot. One common thread he heard a lot from the symposium is “stakeholder-engaged” recovery. From his experience, people around him were absolutely critical in recovery. His family, his community at teen challenge and at his current work. Involving multiple stakeholders at the table is important not only in the policy formation process level but also in the individual process of recovery.

*“(Ron mentioned) the model of treatment as ‘do as your told’… and I was like wow that is exactly what it is. Sit in the chair, I’m going to tell you what the treatment plan is, you’re going to listen, you’re going to follow it. If you don’t, you’re not compliant. If you miss two meetings, you’re out. You have to start over and have your initial thing over. Superficial rewards for compliance rather than recovery. The cold and shallowness of it. For me as a person with suicidal depression… for me being treated as sort of like a subject to be treated rather than a human being with agency to be brought into the process of my own recovery was just as dehumanizing as I valued myself inside.”*

He sees a lot of people going through the same thing. However, coming through the other side, he is still on no psychiatric medication, has an incredibly fulfilling and rewarding life, and got married in January who is also a Teen Challenge program. He also goes to church at which he has great friends and emotional supports who are from similar backgrounds or not.

He agrees with William White’s definition of recovery that it is about actively managing his vulnerabilities in the presence of risky situations. He shared personal anecdotes from the Teen Challenge program and his current work in how he had to manage his vulnerabilities and practice skills he learned and internalized before. He emphasized the importance of internalizing and incorporating the skills he learned in recovery rather than just drawing diagrams in a notebook. He described his experience in IOP programs and partial hospitalization programs (PHP) to be lacking because things learned in those programs are not internalized by the patients. He explains:

*“It’s just stuff on a white board… It’s notes in a notebook. It’s not written into my pattern… Without the full immersion of my recovery experience at Teen Challenge, I would have never gotten it. I believed by the end of my time before I went there, that I was so useless, so worthless, so broken, so incapable of anything else, that another five or eight or thirty days in a program would not have taught me anything. I need that full immersion…One of the things I see that’s becoming harder and harder to get is more than 30, 60, 90 days or whatever insurance will pay for…”*

He explained it’s just like learning a new language. Being immersed in France for a few weeks would have taught him more French than 8 years of classwork did two or three times a week.

Discussion: Discussion after the panelists shared their stories included the following points:

* What coping skills helped in recovery that helped not taking drugs?
	+ Talking to the sponsor or a trustworthy friend helps.
	+ Gym is a great way to cope. Other hobbies like cooking also helps.
	+ Work is great but it can be an outlet for the obsessive tendencies that may come from the previous addictive mind. One of the things people can struggle with is due to replacing the addictive lifestyle with a work-centered one with obsessiveness. So how do we build an immersive experience that addresses obsessive tendencies that may drive individuals away from social functioning or wellness?
* The point on immersive experience is really valuable but there’s a cost problem in that we can’t afford to put everybody in.
* We also need to keep in mind that we need to meet the person where they are at. Immersion needs to happen with the individual’s choice to “buy-in” to recovery. It is a question of personal choice; you cannot force someone into treatment. It just does not work because peoples’ pathways to recovery look different for everybody.
* One thing to be careful about self-direction in recovery, though, is that in the beginning people often don’t understand what recovery looks like for them. So there needs to be guidance and immersion.
* Rhode Island has several residential substance use disorder programs but there are a lot of pushback from payers to not pay for 60, 90, or how many days but only for two weeks. And this is something that we are fighting. There are not a lot of research that showed longer term stays are more productive, so this would be a potential research topic.

**3. Second Panel and Discussion**

Five panelists, Charlie, Jean, Penny, Josh, Walter shared their stories and described what recovery and wellness mean for them. They also were asked to share what exceptionally worked well and what were potential obstacles in their pathway to recovery.

Charlie started off his story by sharing that he was first taught there was no such thing as a mental illness or therapy. Having this mindset to begin with was a struggle for him in his pathway to recovery. In the beginning, he explained he did not know how to advocate for himself and hospitals and medications were not that helpful at first. He then later went to the Providence Center. After trying different medications, one medication worked and accepted that medication was taking away the symptoms. He felt he was finally given a choice and the ability to make decisions toward recovery.

He worked at NAMI for about fourteen years and is now working at Oasis Wellness and Recovery Center. He also became a certified peer recovery specialist and that helped him a lot with his mental illness because the immersion in the peer movement allowed him to relate with others. What he found is that in both organizations, there are people who have hobbies like knitting, jewelry work, and gardening and how these things help people recover. So, I think this will be a great topic for research. At Oasis there’s also what’s called a Hearing Voice support group that help people with symptoms of seeing things or hearing things even when they are taking medications. Another great research topic could be ‘what are the coping techniques that help people live constructively when they are having these things happening; the voices, the visions, the beliefs.’

Jean started her story from where she is now. She is in recovery because of a different group called Compassionate Friends. Compassionate Friends is a support group for those who lost their children and Jean lost her son. Her son graduated from La Salle and was accepted to SUNY to study optometry. Summer before attending college, Jean realized that her son might be pretty sick and went through multiple hospitalizations. She found that having a purpose or something to do every day like work was important in recovery.

Jean truly believes in the concept of resilience and that resilience happens when you have a core, something to withhold that balance. She was constantly there for her son. It was difficult at first because her son thought Jean was involved because she was a nurse. After a while he soon understood that Jean was there as his advocate. Jean thinks this is the biggest piece: everyone needs an advocate.

Jean met multiple psychiatrists while her son was hospitalized and realized they do exactly what Nick was talking about earlier. They have the whiteboard saying this is the way things are supposed to look and let’s fit things into the box. But we can’t fit the brain into little boxes or files. During her son’s last hospitalization, the doctor decided to abruptly cut his medication in half despite Jean and her son’s objection towards that decision. After her son died Jean told the doctor to listen to the parent whatever the age of the patient. Jean wanted share that not every provider is fit to be a good provider and to question every time. She ended her story by sharing the acronym LEAP by Dr. Xavier Amador. LEAP stands for Listen, Empathize, Accept and Partner.

Penny was first diagnosed right out of college when two deaths occurred within a month of graduating. She went to see some providers about her depression and a year later was diagnosed with bipolar disorder. She explained she had an aversion towards taking lithium. Thinking back, she wishes she didn’t play the game with the doctors and this went on for 20 years. Penny shared that she had very wonderful therapists in the past, but nothing was really happening. She was just venting and expecting things to get better by itself.

Penny wanted to share that mental illness does not occur in a vacuum and her family was very affected. Penny mentioned her husband tried to ‘fix’ her like how her mother used to by suggesting things like taking a trip to New York which did not work. Penny thinks she had good tools, but she chose not to use them and sort of reject the idea of having mental illness. Penny shared that one of the things that really helped her was working at NAMI. It was a significant part of her getting well. You get to feel like you’re contributing and that for her was huge. She also shared that she finally met a therapist who helped her understand that nothing will change unless she decided to apply and use the tools she learned. Now she feels the missing piece is coming to her and her illness is now manageable. She also understood there is more work to be done and wants to be more accountable for her recovery process.

*“I’m just finally realizing that I do have more of a handle on this. And I have been skating along and just coasting. And there is more to life than being able to do that and I think the quality of life can be so much better. So, I am trying to take a different tack and be more involved... It’s not rocket science.”*

Josh shared his lived experience in recovery for a bipolar disorder and also an addict. He described his story is ‘full of missed opportunities to be diagnosed with the right thing’. Josh shared that he comes from a family that had problems with both mental illness and drug addiction. He learned about his father’s drug addiction and his mother’s bipolar disorder at a very young age. At nine years old he was diagnosed with ADHD and saw a counselor who told Josh he is very smart but had this illness so let’s see what they can do with it. The school put Josh in what’s called a gifted program where there’s less people in class and it was more focused on more individual basis than regular class. He had this plan where he thought he could play sports to take the excess energy out and not take the medication and it worked.

In college he noticed he could not pay attention in class and started feeling the same way he felt when he was nine years old. He went back on medication for his mental health illness. In college, he was self-medicating but did not understand at the time. After graduation, he started working in sales but was still taking opiates which, he explained was not good for him because of his addict genes. He started to take a little more every time until his breaking point. He ended up going on methadone because it was the right choice for him to make. He was on methadone for four years was able come off of it as well. Unfortunately, he started to hear voices to the point where he stole a car. He was later diagnosed with bipolar disorder.

Josh shared that throughout his entire life he was running scared of bipolar disorder because he knew that it was possible for me to have it because of who his mother was. But he is not running anymore. He accepted the facts. He explained further on why thinks his journey was full of miss opportunities:

*“The reason why I said missed opportunities is because I did commit crimes here and there. Instead of a psychological profile, they just threw me in county jail for a today. Threw me in intake for a day. Threw me here, threw me there. And it wasn’t until I did something severe like stealing a car that they actually put me in a mental health facility and said you need to get this man some help.”*

Josh wanted to add that his support system, his family, came back into his life after he got diagnosed with bipolar disorder and he is grateful for that. He also shared one final note on his experience with recovery while being homeless.

*“I was homeless for a couple of years and the lack of a steady home can really make the biggest difference in the world in your recovery from either an addiction or mental illness. If you don’t have a steady home or a solid foundation, it is almost worthless to try to even get into any type of recovery because it’s not going to work or it’s not going to work well enough for you to move forward and gain those things.”*

Walter shared his story of growing up with an abusive father and how that affected him. He started to see things and hearing voices. In school, he was treated as the ‘bad guy’ and the teachers didn’t want him. In 4th grade, he had a wonderful teacher who gave him the benefit of the doubt and taught him so much. Whenever he thought everyone heard things and saw things like ghosts. Despite the obstacles, he always tried to work harder to receive extra credit to pass the classes and graduate from high school. He worked with City Year after graduation and started tutoring students. He once tutored a student who was going through the same thing as he did. He remembered his time with the 4th grade teacher who helped him, so he worked hard to help the student.

He described how he was working at all these different jobs but was always getting fired from them without understanding why. For example, he worked at a job where he started hearing voices telling him to steal from work. He would later go home and regret it. He was always stealing from work but could not understand why. Things got worse and he called Providence Center to ask for help. The police came and instead of taking him to jail they brought him to the hospital. After explaining his symptoms of not being able to sleep, feeling confused and lost, hearing voices and seeing things, he was diagnosed with schizophrenia. And once he got diagnosed, he took the medications and he woke up feeling better. It was like starting a whole new life. He started working with animals. He now works at autobody shops and in his cleaning business. He also attends college and educate people about schizophrenia. He also helps out in the neighborhood by helping them take out the trash.

Discussion: Discussion after the panelists shared their stories included the following points:

* How can we get people’s problems recognized/diagnosed earlier?
	+ LEAP method is important.
	+ Having a trustworthy provider was important for many panelists. The unwelcoming environment of offices and negative attitudes of staff members towards patients can impact patients’ trust towards providers.
	+ From Jean’s experience, there are only a handful of good providers.
	+ Penny felt that there was this ‘gigantic boulder’ preventing her son from getting a diagnosis even when she was an advocate. Part of the problem was having to navigate the system herself to even find doctors who would listen. Another problem is that mental illness is stigmatized.
	+ There are not enough psychiatrists and that is a big problem in the first place.
* Continuity of care under one provider is helpful. Having to tell the story all over again to new providers is difficult.
* There are SUD coaches on the recovery side. Why don’t we have a mental illness navigator?
	+ Certified peer recovery specialists learn about substance use and mental health disorders so should be able to respond to both.
	+ People can actually now bill for peer recovery specialists to Medicaid and perhaps to BCBS as well. But it’s a matter of do the hospitals want to have that person there.
* Mental health screening tools are inadequate.
* People who are having some sort of mental health or SUD crisis can go to BH Link and they will help you get the help they need. It will be in a less traumatic environment.

**4. Feedback and Discussion**

Discussion from the second panel continued and the following points were shared:

* When you see a general physician, cardiologist, or other types of physicians, do you feel like you are getting adequate care?
* When an individual reaches the age of Medicare eligibility, the resources available plummet. This is a real concern and there is some stigma attached to long-term care. What’s the plan?
* There’s no formal support for the families. If a family has a very ill or dysfunctional child, it is going to disrupt the entire family. We talk about the engaging in the community for natural supports, but families are the natural supports who can help individuals stay in recovery. Research models can be helpful in informing this issue.
* While under-developed, family members can also become peer recovery specialists to help other families. This is a terrific step, but doctors also need some training too.
* Stigmatizing language towards individuals with SUD and mental health issues is still a problem that needs to be addressed.
* Self-medication and its effect on patients are also a potential research topic.
* While it is true that peer recovery coaches are trained in both SUD and mental illness, it is difficult for a coach with lived experience with SUD to help someone in mental illness due to the lack of lived experience. This is true both ways.
* There’s so much fragmentation in the system. There are so many different organizations that it is difficult to navigate. Is there an umbrella organization to help people find the right resource the need?
* It is difficult to navigate the system. BHDDH is revamping its website so that should be a helpful resource for people. BH Link can be a helpful resource as well. They have a hotline and triage center itself.
* The peer movement is very important because the more people talk about normalizing different types of mental illness, that really helps people break down the stigma. Behavioral health is the only thing one can be blamed for having.
* Health Homes is a great online resource containing information from sober housing to hospitalizations.
* It was hard to hear people are having difficulty getting diagnosed. Most people who are diagnosed eventually with mental health conditions, it manifests by the time you are 14 years old. It is happening when people are young and there’s a fear of identifying people to get the help they need.
* There needs to be some research done on why we don’t have 30-day (or long-term) treatment programs anymore.
* General public can benefit from educating providers. Having a curriculum for new physicians and nurse practitioners about stigma, SUD, and mental illness and how they can help in breaching those challenges can be very helpful.
* The people making the decisions (stamping denial) at the insurance companies do not necessarily have the knowledge to make decisions on mental illness. This is true for people we talk to even before getting to that decision. People answering the phones don’t even know what mental illness really is.
* Again, often providers don’t have a welcoming environment for patients, and this negatively impacts people from getting a diagnosis.
* Long-term treatment is happening when people are in crisis. This needs to be approached way before that, even before 30-day treatment is needed. It needs to be in the doctor’s office. It needs to be screened and addressed by the family doctors.
* From Nick’s own experience, some of the most vulnerable people he worked with have been people with serious mental health issues who have been incarcerated. The way that the system responds to them is outrageously cruel and deserves a special set of attention. We are talking about guys from young age without supportive home environment to lean on. Rather than being diverted out of the system, they were criminalized for a crime while they were under the influence of psychosis. If people didn’t have support, there really would be no other option other than criminalization due to the complicated process of navigating the system to receive treatment or be reimbursed for treatment. Not only is this cruel, it is the costliest way to go about this.
* There needs to be more research for people who were incarcerated. It is a particularly costly population of need.

**5. Closing Remarks**

We have reached halfway through the four symposia and have demonstrated two things. There is a lot of interest and very articulate contributors. We will need all of this as we go forward on this project.