

4/10/23

Senator Donna Bailey

Representative Anne Perry

Committee on Health Coverage, Insurance and Financial Services

State House

Augusta ME 04332

Re: LD 1304 Resolve, to Establish the Task Force to Study Barriers to Achieving

Behavioral Health Integration and Parity

Dear Representative Perry and Senator Bailey, and Representatives Brennan, Dhalac, and Madigan:

I am asking for your support of this critical emergency legislation to establish a task force to study service barriers to behavioral health treatment in Maine.

Insert a few sentences to describe your personal experience with insurance roadblocks to BH treatment or access.

Throughout my entire childhood, I survived extreme ongoing traumatic experiences and abuse. These traumatic childhood experiences caused significant mental health issues for me as an adult and as a child. In 2016, these mental health issues became significantly worse and reaped their ugly head. I began to experience many mental health symptoms that I could not yet identify because I had never received any mental health treatment prior. 1) because I did not know these services existed 2) because mental health treatment is extremely stigmatized 3) and because I could not afford mental health services.

In 2016, my life completely changed, and my mental health quickly went downhill. I struggled with suicidal ideation, self-harm, extreme memory loss, debilitating anxiety, hyper-vigilance, dissociative experiences, and many more mental health illness symptoms. My first psychiatric hospitalization was in 2016 due to a severe suicide attempt. While at a psychiatric hospital, I was referred to establish a local therapist. However, the therapist that I was referred to was completely booked six months out or longer.

Because of the personal life changing circumstances that occurred, I was forced to resign from my job and therefore lost my insurance. I attempted to reach out to several other therapists in my area. However, I was unable to find someone in my region and someone who I could afford. I was in the process of applying for Mainecare, however, had not been approved yet. During this process, I felt completely defeated and alone. I had no one to help me navigate the very broken and foreign system of state insurance and mental health treatment. In 2017, the only therapist that I found who was accepting new patients and Mainecare, was online from Psychology Today. However, this experience was more harmful than helpful. She was undereducated and caused more trauma. This created my mental health symptoms to continue to spiral out of control. Since I had zero experience with any mental health services, I did not understand or know how much harm she was causing.

Each time becoming worse. In my gut, I knew something was off with this therapist but each time I would attempt to find a new therapist they would be booked out 3-6 months or not accept Mainecare. And quite frankly, I could not afford to pay for individual therapy due to my current life circumstances. I was stressed out to the max, all while, continuing to live my life while feeling hopeless and like my life was

not worth living. The only mental health treatment I received was, while I was in crisis, at psychiatric in-patient units. Acute psychiatric in-patient hospitalization do not provide any individual therapy during that time.

After several years of attempting to find a new therapist, I finally found an equine therapist that lived over an hour away from me. However, I did not care because she was trauma informed and accepted Mainecare. In total, I spent three hours each session just to make it to therapy. There were many sessions I had to cancel due to the inability to drive there because I could not afford the gas to get there. I finally found a therapist, however, there were so many barriers that it felt impossible to be consistent with therapy. I lived in a rural area and my internet capabilities were also extremely limited causing zoom sessions to be inadequate therapy sessions. Also, equine therapy requires you to work with animals and that requires you to be there in person.

My symptoms continued to significantly decline. I continued to be psychiatrically hospitalized over the course of the next seven years. I had MANY more suicide attempts. The process too even become admitted to an in-patient psychiatric unit is hell on earth. The longest I sat in a hospital emergency waiting room, waiting for a bed, was 15 days. This is completely unacceptable. That is only one of my hospitalization experiences. The adult psych emergency unit and children's psych emergency unit were side by side. Every time someone was forcefully put into restraints or into seclusion you heard and saw it. Every time a child was screaming and put into the seclusion room you heard and saw, because the seclusion room was on the adult side. There are not enough resources in the state of Maine for individuals both young and old suffering from mental health problems and crisis's to help those who need it most. The lack of resources further only causes more trauma on trauma.

One of my attempts was so close ending my life ending and I had was driven by ambulance to a hospital down in southern Maine. After, I spent a week recovering in the ICU and several days in the regular psychiatric hospital, I realized that Maine did not have the resources that I needed. I needed intensive residential treatment and the only way I was going to receive it was by going out of state. I then spent the next 9 months of my life at an out-of-state residential treatment facility. However, this was almost impossible to find a RES out of state who accepted state insurance. The problem with going from out of state treatment to in-state treatment is the discharge. There is no linear cohesiveness from one facility to another. After 9 months of RES, I returned home and several months later had another attempt because I had no supports or resources in place.

Often, my experiences at in-patient psychiatric hospitals were horrific and unhelpful in the long-term. I often felt unheard, ignored, and not believed. Many psychiatric providers (on numerous occasions) told me that the symptoms I was experiencing in my own body were incorrect. Also, that I should not be feeling that way, because I should be starting to feel better. 9 times out of 10 they did not help me access the mental health providers and treatment that I desperately needed. I'd be discharged from the hospital yet, still have the same issues at hand.

While at one of the hospitals, I was told that if I continued to cry and experience dissociative symptoms (while I was curled up in the fetal position in a corner crying uncontrollably) I would be immediately discharged from the hospital for "unsafe" behaviors if it continued. I was not harming myself nor anyone else at this time. They proceeded to tell me that other more critical patients needed my bed.

At this hospital, I was stalked and attacked by another patient who attempted to hit me over the head with a guitar. After I told staff and providers how scared and unsafe this patient made me feel they still did nothing to prevent it. They told me to "keep my distance from this patient" and that they would try to be more watchful. Numerous times, I asked for help from them. Numerous times, I cried because I just needed someone to listen and help me. And still little to no help was given.

After my seventh suicide attempt, (five days into my in-patient hospitalization), this hospital wanted to discharge me. Several times I told them that I did not feel safe being discharged into the community. I knew if I was, I was going to kill myself. They continued to tell me that I alone only had that power, and they were not responsible for that. While that is true to a certain extent. I was still in crisis. I was self-harming, still extremely suicidal, and planning to kill myself that night if I was discharged. I told them that. They continued to threaten me by saying that “I obviously didn’t want to get better”. These words caused more harm to my overall mental health treatment than I can even begin to explain.

They have a zero-tolerance policy for violence. They consider self-harm to be self-violence. Because of the abuse I survived, I am diagnosed with a dissociative disorder, and I did not remember or know that I had self-harmed until afterward. They did not believe in my diagnosis and told me that I needed to stop “faking my diagnosis” and to stop pretending that I didn’t know what I had done. They threatened to discharge me if the self-harming behaviors continued. This caused me to feel scared to be fully honest with providers and staff about how unsafe I was really feeling. I ask, how can patients desire or want to receive mental health treatment if they are being threatened and not believed? How can they want access to a system that is going to stigmatize, belittle, and dehumanize them?

During this long in-patient hospitalization, they said I needed to be discharged because hospitalizations were not long-term solutions. While I agree, acute inpatient hospitalizations are not created for long-term care. I believe that they need to create safe and effective discharge plans for the patient. Every patient’s specific treatment needs are different. This isn’t a cookie cutter solution. This isn’t a cookie cutter world we live in. However, a safe, personalized, discharge plan was not a solution they were providing me. They instead insisted and wanted to discharge me to a women’s shelter. I refused and told them that I could not keep myself safe alone and that would only further cause more trauma for me, especially since I already had trauma from shelters. The second option they gave me was to discharge me to a hotel room temporarily. This once again was completely out of the question, and I firmly declined their insistent demands.

My provider gave me homework which was to write a list of all the ways I could keep myself safe in the home and community. I could not come up with any because I DID NOT FEEL SAFE in the community or at home by myself. I had already attempted suicide six times and been in the ICU twice. In turn, I wrote my provider a 30-page handwritten letter about why I didn’t feel safe and what supports I felt like I needed. Those supports were getting into a group home and/or going into a state hospital. The next day that I met with her, I asked if she had read my letter and she said that she read a little but felt it was more important we discuss how I could be safe in the community and home by myself.

I was strongly discouraged from being placed in a group home by saying that I was “too independent” to be placed in a group home. However, I wanted and needed to be placed in a group home, because I understood how inadequate and incapable, I was of keeping myself safe by myself. I needed safety, security, and someone else to hold me and give me my medications. I had already overdosed several times and all the preventive measures my family and I had been trying at home were failing. I had been doing the same thing for seven years and nothing that the mental health system had been doing was helping me to heal me in my recovery. I was someone who did not struggle with substance use, therefore, there were many treatment programs that I did not qualify for.

They also attempted to discharge me two days before I was supposed to be placed in the group home. While I was in a dissociative state, I signed a green paper stating that I wanted to leave the hospital to go and hurt myself. After this dissociative state passed, I met with the head psychologist, and she informed me that I was being discharged immediately. I was confused because I did not remember anything. However, she did not believe me and she didn’t think I was a danger to myself, that I had just said that statement for attention. She proceeded to tell me that she was going to continue with the immediate discharge. Her words were “I cannot blue paper you”.

I was not told in that meeting that I could rescind my green paper. However, thankfully a very diligent and kind staff member told me that by rescinding my green paper, my formal discharge plan could proceed. This plan was to be discharged to the group home. I feel that specific treatment team members of this hospital did not care about my safety or welfare. They strictly, just wanted my bed to be free. They wanted their money. I was just another patient to them. However, for me, this was life or death. If I was placed in any of these discharge plans that the hospital wanted I believe I would not be alive today. Thankfully, I had other people on my team. So, with the help of my therapist, the CCU, and my family support, I was able to be accepted and placed in a very supportive and healing group home.

Since leaving this hospital, I am thriving at the group home. I feel safe. I feel like I am finally beginning to heal. There are good people in the mental health system and it's up to us, those people, to make the changes so that others don't have to suffer like I and many others have had to. For the first four years after 2016, I struggled to find treatment providers because of lack of resources and complications with insurance.

Insurance companies don't see humans. They see price tags, diagnoses, and numbers. The cost of mental health treatment with out-of-pocket providers is astronomical. How can we expect people to get the help they need and deserve when it's almost impossible to find available providers? How can we expect people to want to go and receive the help they need when an in-patient hospitalization can cost them thousands of dollars? How can we expect people with the highest needs to get the help they need when they are being stigmatized, belittled, and abused by the system? Insurance companies don't see the hearts and souls of individuals like me. These broken systems need updates. They need to allow individuals better access to mental health services and treatment. They need change.

I have been to every in-patient psychiatric hospital in Maine. Each one has helped me stay alive at certain times in my life, for that I am unbelievably grateful. I understand that this is not a perfect system and that even providers are not perfect people. However, I do expect providers and staff to believe their patients above all else. I expect to be treated with dignity and respect. I expect the broken mental health system to be held accountable for its lack of access to appropriate treatment. I also expect providers to pave new paths to dismember the roadblocks that so many other patients' mental health and lives have been impacted by. I expect change to the barriers that is placed on the behavioral health system.

By developing this task force, Maine can understand the barriers that insurance providers place on BH treatment services. When insurance companies cannot provide an adequate network of BH providers in an area, they are effectively discriminating against people seeking care.

Today, most Maine residents wait long periods to receive treatment, travel great distances to see an in-network provider, and/or pay higher costs to see out-of-network providers. Understanding these roadblocks will help us address the shortage of services and improve our state's ability to provide BH treatment to people of all ages.

Respectfully submitted,

Your Signature

Name:

Position

Organization

Contact Information