

Hiding in Plain Sight: A Conversation with Makalynn Powell

Makalynn Powell:

In the film *Hiding in Plain Sight: Youth Mental Illness*, it's fantastic film, if you haven't seen it yet, please watch it. It's a very eye-opening, raw perspective on what it's like to live with mental illness in America, but especially as a young person. I think that a lot of times we forget that young people go through things, too. It's very hard to navigate this world as an adult, but it's even more difficult as a child whenever you're living with mental illness. So please, please, please, watch that film. It's still available on pbs.org if you get the opportunity.

I first want to thank the Alliance for organizing the summit and encouraging this extremely necessary conversation about mental health. It still surprises me that organizations ask me to participate in events like this and think that I have something worthwhile to say, because I'm simply a person with lived experience. But if I've learned anything through this journey, it's that listening to individuals with lived experience is probably the most important thing that we can do. Letting somebody else dictate the policies and the programs that we have in place hasn't worked thus far, so it's time to try something new.

My work in advocacy started when I started volunteering at a program at a maximum federal facility, so I was working with inmates. I met incarcerated men and women there who resembled people that I encountered daily on the outside world. The only difference between these individuals and the people that I experienced was the fact that we called them inmates, the fact that we used a label. We called them inmates.

I'm going to go ahead and start off really quick by saying, I've never had to do this one-person keynote speaker thing in front of a bunch of professional people. I'm usually sitting in that chair with a moderator who asks me a specific question, and then I answer that question and then we move on from there. So bear with me. We're going to double back really quick.

So I was working in a federal maximum security prison with people who were just like the people that I met on the outside. They were people from underserved areas who suffered very traumatic events. They had untreated mental illness. They often suffered from substance use disorder, PTSD, different things that I saw on the outside. But again, the only thing that made them different is that we had this label for them and it was inmate. So it was very discouraging to see, but I quickly realized how important it was to have a conversation about labeling theory, and to discuss the effects that we often face when society reduces us to a singular life event or a diagnosis.

By outcasting or othering people from vulnerable populations with words like minority or schizophrenic, we begin to quantify them rather than recognizing and addressing their needs as individuals. It's no secret that populations from certain areas or ethnicities or age groups tend to experience similar hardships, but to assume that a one-size-fits-all course of treatment is the answer is often more damaging than beneficial. It only reinforces the stigmatization of mental illness and discourages people like me from seeking help.

So a little bit about me, again, if you haven't watched the film, please do. You will learn a lot more than I expected anybody else to know about me, but again, great film. I was labeled as defiant, disrespectful, and generally a troubled child growing up, when in reality, I was just experiencing textbook symptoms of bipolar disorder, so low self-esteem, inability to maintain relationships in any capacity, high highs, low lows, feelings of helplessness, irritability, lack of focus, you name it.

But the adults in my life decided to focus on my outward circumstances. I was a child with an absent father, growing up in an income-based housing project with a single mother who worked three

jobs to make ends meet. And as a result, I was reduced to that reality, and inevitably fell into a self-fulfilling prophecy. I began to self-medicate and eventually found myself in a state-funded facility at 17 years old.

Now that I'm older and understand what an effective treatment plan looks like, I can confidently say that that treatment center was nothing more than a poorly run daycare center for teens who have been cast aside and didn't necessarily fit the mold that our society has built for them. The staff members were only required to have the equivalent to a high school diploma and basic first aid training. So essentially, they were not equipped whatsoever to handle the many challenges that we thought we faced as clients. And of course, my story is very different from a lot of the other clients that were there. They faced hardships that were far more detrimental than mine. So I can't imagine how their experience was, but I'm sure it was a lot worse than mine.

We were completely isolated from the outside world, so we attended school at the facility. We held group therapy services in our living room, and we occasionally played intermural sports in our gravel parking lot. So my experience with inpatient treatment being in total isolation, essentially crippled me. After 11 months, I left treatment and quickly realized that I had become institutionalized. I was not at all prepared to re-enter society whatsoever.

The only sense of normalcy I found on the outside was when I started to attend Narcotics Anonymous meetings. And I can confidently say that 12 Step programs saved my life. And I truly believe that that's because these are programs that are created by the very people who need them. These are people with lived experience who had to learn how to live life without using drugs. And they recognize the value of peer support.

After a year and a half clean, I was finally diagnosed with bipolar disorder, and this meant starting the very grueling journey of finding the proper treatment. So my psychiatrist and I tried about seven different medications within a year, and it was very difficult. It was extremely difficult. The side effects that I experienced physical, psychologically, and mentally were very difficult to navigate at a young age. We finally got there, and I finally found the perfect combination of medication and therapy and was stable for about two years.

But of course, I was once again, met with the issue of stigma and labeling. It seemed like the minute I informed someone that I had bipolar disorder, that was all they could see. My justifiable emotions and reactions to life were often met with, "Well, have you been taking your meds?" Or "Maybe you should call your therapist." And for somebody who was raised by a very, very strong, independent single mother and was taught to stand up for herself no matter what, being viewed as less than or weaker was absolutely unacceptable, absolutely unacceptable.

I wanted to completely shed that identity as a recovering addict with bipolar disorder. Unfortunately, living with a mental illness does not come with the privilege of turning your symptoms on and off whenever you want. I quickly realized that I didn't get to choose when and where my diagnoses presented themselves. So I had to relearn how to be vulnerable and remind myself that I'm not just an addict and I'm not just someone who often experiences mania. I am Makalynn, and sometimes I have bad days.

I had to continue to advocate for myself to preserve that stability I had worked so hard for, and my journey of mental health recovery has been relatively successful. I was able to graduate college twice and now have the opportunity to advocate, which I absolutely love. Thankfully, I have a provider, a fairly stable provider now, and I'm able to receive the medications that I need in order to maintain that stability. I still experience issues from time to time. For instance, when insurance companies decide that they no longer want to cover a medication that I've been taking for years, and it's time to maybe try

something new, or I have to wait to receive medication that I've been taking, again for years, for a prior authorization from a doctor. These are just a few of the issues that I face.

I also am from a college town, so the hospital that I go to is a teaching hospital, which means that I only have the same psychiatrist for about a year before I get a new one. And each time you get a new psychiatrist, you have to go through your entire mental health history over again. And I often spend the first two to three months convincing them that, "Yes, the current plan that I'm on, the current treatment plan that we have in place is successful and I don't want to change anything." But again, other than that stability, I feel like I'm very fortunate compared to other people that I know.

The cycle, honestly is exhausting, and sometimes it does leave me considering whether or not I can simply manage my symptoms on my own. But of course, I know that is not an option. I personally have symptoms that are fairly easily managed, but that isn't the case for everybody.

Now, I mentioned earlier how important 12 Step programs are to me, because I believe it is paramount to include people with lived experience in the discussion on how to improve our mental health system. The need for inpatient mental health care is necessary, but the therapeutic value of realistic follow-up care is what truly helps people like me adapt to real life.

And that, of course, then brings up the issue of who has access to which resources. So for instance, 12 Step meetings, 12 Step programs are beneficial because they're free, anonymous, and available worldwide, with the operative word being free. Poverty is one of the strongest social determinants of mental health. So typically, if you're poor, you're more likely to experience a mental illness. Also, if you're poor, you're less likely to be able to afford mental healthcare, so this creates a cycle of widespread untreated mental illness for communities that have no other choice but to live with it.

And I'm sure, as many of you know, sometimes a mental illness is just not something that you can live with. It can become unbearable. It can result in very low lows, and it can lead to feelings of despair and hopelessness and feelings that there are no other options.

So this is a very unfortunate system that we have in our hands right now. It's safe to assume that everybody in this room agrees that mental healthcare reform is absolutely necessary, but I think it's time that we start including mental healthcare as just healthcare, not separating it. It's important to focus on it 100%, but it needs to be included in lists of resources. There are plenty of insurance companies that will cover a handful of appointments with a therapist. For instance, my grandmother has an insurance company that covers 20 appointments with a therapist, 20. For somebody like me, 20 is not enough. I need more than 20. So having the privilege to stand up here and speak in front of a room full of people who are professionals in the field and have the ability to affect real change is an absolute honor to me.

And my biggest takeaway here is that we continue to listen to those with lived experience. It's easy to look at something from the outside and pinpoint problems and assume that we know the answer, but until you've lived it, or until you've seen it firsthand, that's not as easy.

And also, my success is a testament to some, but my story is not typical for everybody like me. Like I said earlier, I grew up with a single parent, income-based housing. My father himself is an addict. I grew up with some poor circumstances, but I was successful in life, thankfully. But that's not typical. There are plenty of people like me who look like me, who come from backgrounds like me, who don't get these opportunities that I was given. But because of my success, I now have the chance to stand up on platforms like this and speak for them, speak about them, and try to encourage others who don't quite understand to make changes for them. And that is all I have.