

**Report: White River Junction
BIPOC and LGBTQIA2S+
Storytelling for Health Equity**

2023

Introduction

This report is a compilation of stories and themes that were told through stories during three virtual storytelling events for Black, Indigenous, and People of Color (BIPOC) and LGBTQIA2S+ folx living in White River Junction and surrounding areas in Vermont. The storytelling events were made possible by funding through the Vermont Community Health Equity Partnership. This report outlines the purpose, themes, limitations, and excerpts from the stories told at those events.

Purpose

It is crucial that health systems create intentional space and time to listen to the communities they are responsible for serving. This storytelling series was designed to honor and share the stories of underserved populations. They were thoughtfully facilitated and attended by combinations of community members and BIPOC and/or LGBTQIA2s+ health providers. There were opportunities for storytelling and listening in small and large group settings throughout the two events.

This intervention was open to all BIPOC and LGBTQIA2S+ community members who wished to share their stories about their experiences with barriers to health access and racism and prejudice experienced when seeking healthcare.

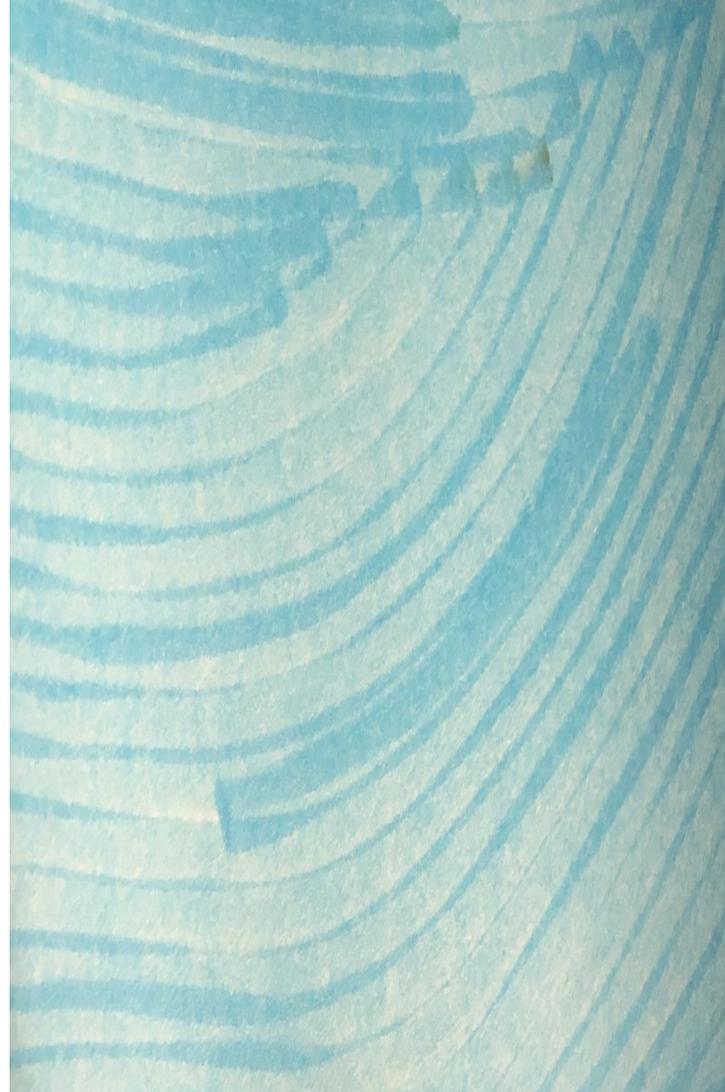
This program was developed with the belief that humans are innately drawn to stories. When we hear stories we are compelled to empathetic action. We live in a moment when data and health science are often mistrusted, but stories connect us to others. Through witnessing these stories, the medical community can learn about the expressed needs and experiences of those they are responsible for serving and can inform policy change through this empathetic lens.

The benefit of this intervention is threefold and compounding: the storytellers are held within a safe, empathetic, often cathartic environment by a community that shares their experiences and desire for change; the events are a trust building exercise between BIPOC and LGBTQIA2S+ community members and providers that encourage health seeking behaviors through relationship building; the widely shared reports harness the empathetic, transformative power of storytelling that influences policy and procedural change at all levels of the health system to serve BIPOC, LGBTQIA2S+, and, ultimately, all community members more equitably.

Every community is the expert in their own health and needs. When we listen to BIPOC and LGBTQIA2S+ voices we eradicate racist/oppressive constructs like “empowerment” and move into a space of deep understanding that each community has the power and brilliance to achieve equity. It is racism and marginalization that stand in the way of these achievements. A platform for storytelling and listening recognizes this brilliance and creates an opportunity for BIPOC and LGBTQIA2S+ individuals to share firsthand knowledge and experience of how they can be better served by health systems. Storytelling dismantles power structures and creates an innately human trust-building exercise between communities and health systems. These events lead to equitable policy change, deeper understandings, and – as mentioned above – increased trust.

Themes

The themes of the stories told during these sessions were largely centered around: individual BIPOC and LGBTQIA2S+ experiences in the healthcare system; collective experiences of BIPOC and LGBTQIA2S+ communities; what is needed to build trust with healthcare providers and the healthcare system at large; and the impacts of intersectionality for QTBIPOC folx.



Limitations

These events took place during three storytelling programs held virtually to increase accessibility. They were held in the evening, which makes them inaccessible to folx who might be caring for others or who work beyond what are considered traditional working hours in Vermont. That said, individuals were offered 1:1 opportunities to tell stories if they chose to do so and had the time and capacity.

The events were open to all BIPOC and LGBTQIA2S+ community members. There was feedback from participants that the events would have been more comfortable and accessible if they were held as individual BIPOC affinity spaces and if all LGBTQIA2S+ individuals would have been included in a separate event in order to create a BIPOC affinity space for at least one of the events.

Outreach for these events was conducted virtually and by word of mouth, so likely did not reach individuals who may not subscribe to newsletters and listservs and/or have limited access to technology.

Going forward, events of this nature should be hosted at different times throughout the day, and with a mix of virtual and in-person options.

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Author

This programming was created and implemented by me, Murphy Barney. This is a process I have designed and facilitated as a part of the Harvard Ministerial Leadership Program in Ethiopia; with displaced persons in Greece; and with StoryCorps as an Account Manager throughout the United States.

Additionally, I am a Two Spirit Shoshone woman who was raised on stories and studied storytelling as a tool for health equity during my Masters of Public Health training at the Harvard T.H. Chan School of Public Health.

Stories

Below are excerpts from stories shared during the three storytelling events hosted in White River Junction. Storytellers are kept anonymous for their safety and comfort. I invite you to read through and witness the stories and solutions to health inequities that are revealed within.

Individual Experiences

“As a Black trans man, I have to constantly educate my providers about the dosages of things they give me. Like so many times I have been prescribed doses of hormones and things that would have seriously harmed me if I hadn’t been the one doing the research and making sure that I knew what was going on. It is not only dismissive, it is also dangerous. I feel like I have to do the job of also educating others and making sure the same things don’t happen to them. I should be able to go in and get careful medical attention, and instead I have to go in and teach my providers.”

Individual Experiences

“When I first moved to Vermont, I had to change providers, and they made me take a full drug test in order to get testosterone. That had never happened to me before and I had never had a problem getting testosterone. I am in recovery from a substance use disorder, so it was really challenging to be tested and go through all of that. I have been sober for a long time, but knowing that this provider just saw me as a drug user was upsetting.”

Individual Experiences

"I haven't been able to find a provider who understands and respects polyamory. There is so much judgment and so many harmful things have been said to me by providers when they find out I am polyamorous. It has stopped me from being as proactive about my health as I would like to be because it is just too exhausting."

Individual Experiences

“I haven’t been able to find any mental health providers who understand the experience of trans folx. That is really hard because I don’t want to have to educate my providers or answer constant questions about my identity. I need a therapist who gets me so we can start from a place where I know I can come to them with the challenges I am facing without fearing that they won’t understand me or constantly ask me to define or clarify what I am talking about.”

Individual Experiences

“They put me in a wheelchair, whipped me into the room, locked me down, and ran all these tests. And they planned to do a procedure, but I've had enough experiences in hospitals that have caused me to have not as much confidence in what they're saying. So, I'm sitting in a room, 10:00, 11:00, noon rolls around. Nobody even shows up. No one's letting me know what to expect, so I said, “Hey, I'm out of here,” and I went home. Made an appointment to go to a different hospital.”

Individual Experiences

"I feel like we're just a number, an appointment, and a paycheck. On several occasions, I felt like my race played a factor in my treatment."



Individual Experiences

“He told me what the side effects would be. And at that point I said, okay, let's, let's proceed. So that was the extent of my open discussion with my doctor. It was a discussion where I listened to him, could not offer any feedback or assume it was really in question because of my lack of knowledge.”



Individual Experiences

“This is very, very important topic of equity in my work of being autistic myself, or how individuals that are neurodiverse and also trying to navigate, you know, from the systems, from childhood transition to adulthood.”



Individual Experiences

“Because it is hard enough for a regular individual to access their needs. But a person like myself, um, a person of color with a disability is actually extremely hard. Yeah. Because it's made for, you know, the average individual is made for a medical profession or legislator and or elected official, and that's across Vermont. It's like it's made for the hierarchies, but not all the individuals are not part of system went by just to let you know we are part of that system, right? Because we need to have our service. We need to have our service needs met with individuals.”

Individual Experiences

"As a kid, going to the doctor was a last resort because we didn't have a lot of money and no health insurance. Both sets of family also didn't trust doctors and I had traumatic experiences with doctors. We didn't have people in our personal space who were doctors and definitely perceived them as either scammers or hosting gross clinics for poor people. The good care was only for the ultra rich. Now, my doctor was new to working with trans people but had the motivation to learn. I had a negative experience with having to be drug tested before I could get access to my hormones which hadn't happened in the last ten years that I had been taking them. A few years ago I was involuntarily detained at the psych ward. I was not told what was happening or that I wasn't free to leave and was physically restrained multiple times, told to leave and then restrained again by police and security staff outside. I was pushed to the ground with a knee on my back. Overall, my experiences as a trans person was okay, with one issue at the end with a diagram given to me to understand my UTI. But I felt the system was really violent and punitive of someone navigating complex PTSD, mental health, and physical infection. It was a horrible experience and I tried to hold the hospital police accountable and gave up after two years of pushing."

Individual Experiences

“Growing up as a person of color, particularly with the roots of, like immigrant parents and mixed status or undocumented. Like, we avoid the doctors unless we're dying. You're not going to see us at a doctor's office because cost is often too much. So yeah, I was like that and I felt like I was dying. Like the poison ivy was so bad, like it was keeping me up at night. Like it had been a few days of exposure and I couldn't sleep. So I had to go to Urgent Care at this point. And I was barely making any money. And I had expenses that I feel like other people typically don't have. I also had a loan that had to go to help out my parents. So I was like really, really tight on money and that \$300 bill really set me back. And I even delayed care because I didn't plan for it. I looked up my health insurance. I asked if this was going to be covered and how much was going to come out of pocket? And the only reason I convinced myself to go was because there was this app that said I wouldn't have to pay.”

Individual Experiences

“It really sucks because one of the appeals of being in the Upper Valley was that it is such a small town. I wanted to get to know who my primary care provider was and establish a relationship. I haven’t had that before. I was looking forward to consistency. The fact that I didn’t have that in the past was a barrier, and it was really frustrating. But eventually after trying for so long to find someone in the area, I gave up. I couldn’t find anyone who provided the care I needed.”

Individual Experiences

“Then another thing that I want to name is my experience trying to access mental health services. I was going through some really difficult things, like mental health stuff at one point and I had an employer that offered it as an employee assistance program. So I was able to access that to get mental health services. And that felt most accessible to me because I was overwhelmed at the level. Where do I even start? And I like the employee assistance program because it gave them a call and they gave me like three recommendations of where to start, which helped me not feel too overwhelmed. Yeah. And they paid for like the first six sessions or something like that. Um, so I did have a good experience with that. They helped me navigate a difficult situation I was facing. But then a few months later, I was facing another very difficult situation which was around just racism in the workplace. And I was the only employee of color at the organization. It was in the middle of the whole George Floyd, like Breonna Taylor, like national attention on this. I felt like I had no one aside from my friends to, like, talk to about this. I didn't know it at the time, but I was experiencing things like panic attacks and felt myself like slipping into depression mode. And I did not seek services because I was like, I already used up my six sessions for my employee assistance program. I'm going to have to pay for this. I don't even know where to go. And also because it was like the challenges that I was experiencing were so directly tied to me being a person of color and having had experiences of being dismissed and being treated like I was the problem here. Like I was the one that is not being patient. That I was the one that's making a whole big fuss out of nothing. Like, I was afraid to talk about what I was going through for fear of hearing the same thing: this isn't a big deal or like, get over it. Yeah. Like I had to quit my job for my mental health. Yeah. It was a really fucked up thing.”

Individual Experiences

"I went to the hospital here, I was literally bleeding to death. And I told the doctor that something wasn't right. And because of whatever his personal beliefs were, he decided to send me home and tell me to make an appointment with my doctor. By the day that it was time for me to see my doctor. I had almost bled to death and I had to have, like, a surgery and two blood transfusions. Because the doctor just did not want to check me. He didn't want to help me. He didn't want to do his job. He just wanted to send me home. I don't know. But I just know that he almost cost me my life. And it literally took me to keep passing out in the bathroom before I even knew what was going on. By the time I got to the hospital, I needed two pints of blood. They want to charge our insurance. They don't want to do any job. Like I asked them to run a test to see if I had, like an infection or anything. He decided he didn't want to do anything. Like it was his decision to not help me, even though I clearly needed help. I was desperate and I told him I don't want to die. I think something is wrong and I just don't want to die. And that man sent me right out that door. And within a couple of days, my face was pale white."

Individual Experiences

"I came here as a domestic violence survivor and I was pregnant. One thing was that there's not a lot of access to health care here. Because when I went into labor they didn't have any kind of ambulance to come and get me, let alone a signal for me to call out. So I actually stayed in the first and 2 hours waiting for a coworker to get there just so I could, you know, get to the hospital. Oh, and that happened after my doctor had just sent me home and argued with me and told me that he was going to keep my baby in me as long as he could. And I went into labor badly. I learned a lot of stuff when I moved to Vermont. Yeah. But I never knew exactly what it felt like to not have equal access to health care or be treated some type of way to where you can't get the care you need. Yeah. And fortunately I've had some really, really good providers like my providers as far as mental health and regular, you know, wellness, check those. But the scariest doctor was my OB. Yeah, I guess it's like he didn't care. He seemed like he was a nice guy, but I didn't know about racism in healthcare either. So I was just trying to wrap my head around all of this. My nurses and my mental health provider, my primary care physician. They've all been great and always respected my decisions. Yeah. You know, never made me feel like I was getting inadequate help. But my OB was different. Like every time I would see him do things to me that he wouldn't do to other patients. It made me very uncomfortable. You know, I've had three kids before, so I feel like I know when something is weird or, you know, I need to be, you know, looked after. And I just remember that day like I was trying to tell him that I thought it was time. He said: no, I'm not going to do this. You are going to keep that baby in as long as you can. And I told him I was going into labor. Like, I know that I'm going to have this baby. And that night when I got to work, I went into labor and there was no access. He wasn't on call. Yeah, I had to have a different doctor deliver my, and I appreciate her for delivering my baby, but she's a very rough doctor, so it wasn't the loving experience that you would want for delivering a baby. I had my coworker holding my legs and comforting me, and, you know, I have to work with. Oh, my goodness. Hmm. Holding my hand when we're delivering a baby while there are two nurses holding my legs that are kind of like cussing me out. I had a plan that I had set forth so that it wouldn't be so traumatic for me. Yeah, it was a disaster. I had a health care plan. Yeah, but it wasn't followed through, and I didn't get anything. I had to push a baby out with no medicine, no nothing. Yeah. And then, you know, just the way that they handled me in the hospital, like I had the nurses that were really nasty to me and one nurse that didn't want to take my baby so I could go to sleep, or the fact that they only took pictures of the white babies that were born, but not my baby.

Collective Experiences

“And there is not a doctor ever in my life that would take that time. Asking me not just about what was happening with my heart but what's happening in my life because realizing that all our systems are connected, you know, and one thing can affect another. I can pinpoint what we hear far too much in women, specifically women of color, particularly Black women, that they are undertreated, underdiagnosed, and many a times silenced. And as a result, these are the outcomes that we're seeing.”

Collective Experiences

“And so those chronic illnesses, even if your socioeconomic status increases and improves over time. You still deal with the chronic health issues that you've had over a long term effect. And I think that that issue, that inequitable access, will continue to plague us until we really, really understand it and make significant changes to help address that.”

Collective Experiences

“And I feel like I've seen the kind of remainder, the footprint of that kind of still existing in the way that Black patients, that patients of low income that brown patients, recently immigrated patients still face. That's frustrating to transition into.”

Collective Experiences

“If you have people who are taught by those people still thinking that Black pain is not as important or does not need to be treated with the same gusto. Effectively, you have generations of people whose pain is being ignored and who are simply suffering every day.”

Collective Experiences

“Why on earth should your doctor have to be Black for you to get the care you deserve? For you to survive. Especially keeping in mind the fact that Black doctors are what, 5% of the medical workforce? So, the likelihood that you're going to get a Black doctor is fairly low. So this country has essentially said: it is all right for all of these people to get inadequate care. We're not going to teach non-Black doctors how to give adequate care. We're not going to train enough Black doctors to provide adequate care.”

Collective Experiences

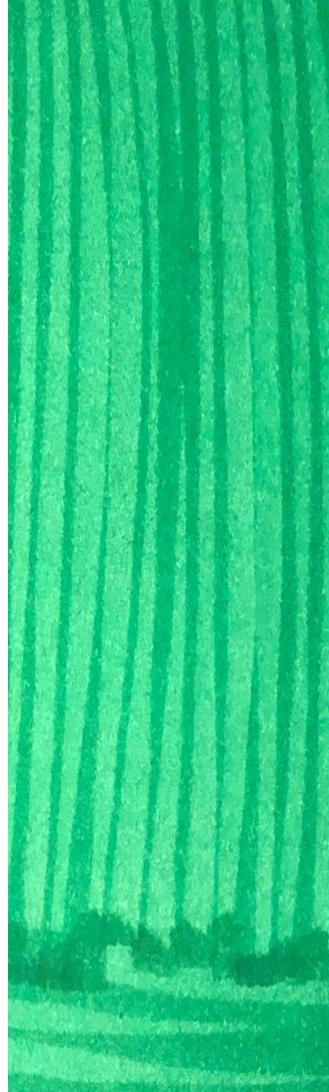
“And so if I was going to make a change, I would want to create a space in the community where physicians and other health care professionals can truly be part of the community.”

Collective Experiences

“There's not many resources out here in general. I think it makes it difficult to feel connected in the community.”

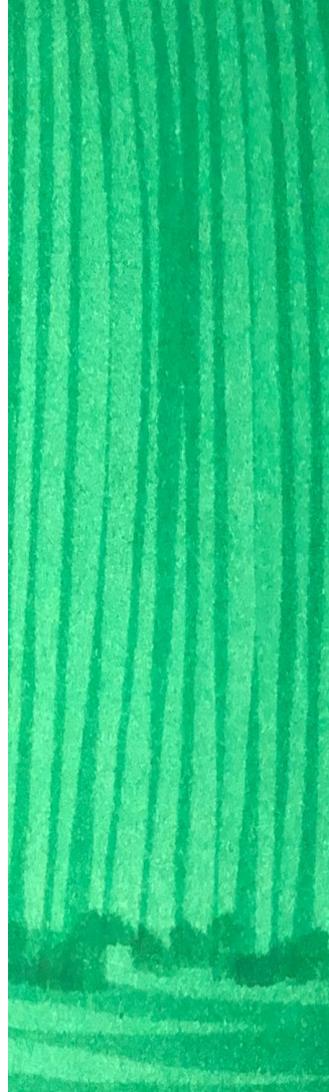
Solutions

“Right. Like we're talking about health, but we're talking about everything because it's all so related and it all ties back to health and our communities abilities to access health care.”



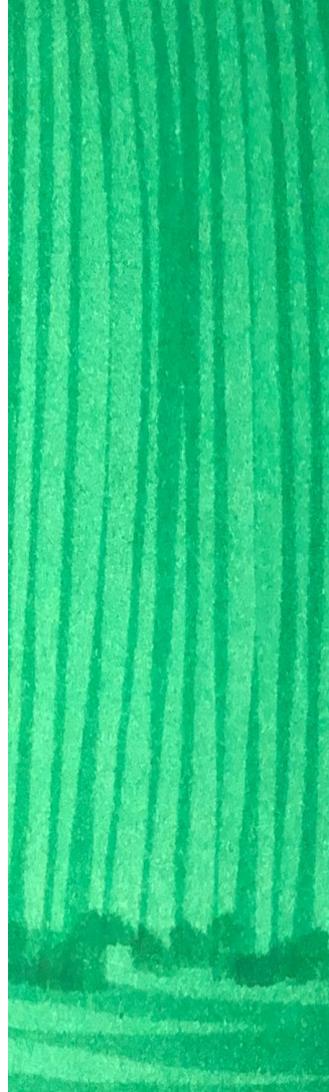
Solutions

“I think about so much of what you're saying about, you know, the Vermont government not picking it up. And then once they do, they don't actually talk to marginalized communities and then they create all these solutions, but they haven't talked to us about them. And so then they're not actually solutions and they're not actually helpful.”



Solutions

"I think we've been at the same table over and over and over again. It's about time to say, You know what? To hell with all of it. We're going to create a new table because this is not working."



Trust and Hope

“Planned Parenthood became the only place that was accessible to me. And so that's where I went. And I did have positive experiences seeking treatment at Planned Parenthood. And I think it's just the nature of the organization. Like they know the type of challenges that their demographics face and they remove those barriers. They work to try to address those barriers.”

Trust and Hope

“But then the good thing was, is that, you know, the way the healthcare system is supposed to work is actually how it ended up working out. And it was a beautiful experience because the doctor that I was supposed to see happened to be on call. She actually did my surgery. But it was the compassion issue. So for me, it was the way that the nurses moved around and how everybody was communicating with each other. And she was communicating with my doctor, even though she didn't have to. Yeah. And she held my hand until I fell asleep before the surgery because I was so scared that I was going to die. Yeah. And it was just a beautiful experience at the end. Like, it was scary. The fact that I almost died. And I have kids, you know? Right. But the way that it worked out at the end is exactly how the healthcare system is supposed to work. It was supposed to work beautifully like that. The way that that doctor handled me, the way those nurses handled it, they were just so gentle.”