

A Cry for Community

When a health care professional asks you if you are safe, they are actually asking if you are a danger to yourself or others. Yet, I have learned that safe is a word that means so much more than that limited definition.

Most people take safety for granted. They think that it's the norm, and that this is everyone else's experience too. Well, except for people in war-torn countries and other places like that, places foreign and far away.

Let's travel back a moment to 2006 when Mohammed Reza Taheri-azar drove a silver SUV through the pit on UNC's campus and injured 9 people. The feeling of safety on campus was shattered. A vigil was held to regain that safety "take back the pit". How could someone do something like this? Who was this person? He was described as a good student, shy and socially awkward, a loner. Even the members of the community he claimed to be a part of, denied him. Was he simply a religious zealot? Was he mentally ill? Be patient. I promise that this is relevant to my story.

Have you ever been in circumstances too big for you, that no matter what you did you were not enough? Did you ask a family member for help, or a friend? What if you had no one, or even just felt that way? When you face life alone, you aren't safe. You are like the lone antelope that got separated from the herd and is about to be devoured by lions.

I don't know why he did it, and I wasn't thinking about it then. I was studying abroad in Lancaster England and attending my first Friend's meeting with another curious student from my biology class. She said it was interesting but didn't go back after that day. I continued to attend almost every week. After that first meeting, I realized that I had found a place where I fit, and where everyone didn't have to be the same to belong. Students at school made me feel the same way. I was usually described as a good student, shy and socially awkward, a loner. Hmm, where have we heard that before? For the first time ever my academic life was not going well, but for the first time ever I was socializing, on purpose.

When I returned to UNC, I realized that students at UNC were not as inclusive as the students in Lancaster. If you didn't already know people or weren't an extreme extrovert, socializing was hard. It's easy to get lost at UNC, and I mean among other students, not just figuring out your way around the constant construction detours (pause). I missed my friends in England. But, I found out that Chapel Hill has a meeting house. Tom Munk was doing some outreach to UNC students. He was the first person I really got to know. I started going on a regular basis. I attended some of Tom's game nights and potlucks.

School was going well. My grades were good. I was working part-time as a tutor. I was having fun doing a lot of extra-curricular activities like peer mentoring for the Carolina Covenant program, being the secretary for Carolina Music Outreach, learning aikido, and several other things on top of that. Dean Woodard said that I was the poster-child for time management. People could see that I was doing well.

I was doing well, but there was also a lot that people didn't know. They didn't know that growing up there was abuse and a lot of neglect. They didn't know that I had left home when I was 16. They didn't know that when the dorms closed for break that I didn't have anywhere to go. They didn't realize that my scholarship covered my food at the dining halls, but that when they were closed, I had no access to food. Almost all the money from my part-time job went to buy groceries for my five younger siblings.

Most people didn't know that I have learning disabilities. I was diagnosed second semester of freshman year. I couldn't finish my tests, and they counted for a lot more of your grade than they did in high school. I was evaluated and they said that I had non-verbal learning disorder. Many people don't realize that yes you can be gifted and have a disability at the same time. And, it affected much more than my grades. Spatial distance concepts are hard. People didn't know how horribly lost I get, and this time I am speaking geographically. I can't read a map. I can't get myself around on the bus system. Not, unless I have some help. So even if I wanted to get to a grocery store, I wouldn't have known how. And, I didn't know that I could ask for help. I thought that I had to do everything on my own. I'm independent. I'm an adult. It sounds weird to admit to someone that you never leave campus because you don't know how.

One thing I wish people would have let me know is that I could ask for help, not just with things people think are the big things like a crisis, but also everyday things.

Anyway, I got sick my senior year. I kept going to student health and they kept telling me that it was stress, and if I hurt just take some ibuprofen. I was very sick, but everyone kept telling me that it there was nothing wrong with me. One doctor thought that I was just trying to get out of exams. It turned out that I had Rocky Mountain Spotted Fever. I had to withdraw. I was only one semester away from graduating.

I stayed with my dad at this motel and then in a crumbling abandoned house where I got all my stuff stolen, I stayed with a friend's family, I stayed with my grandparents, I stayed with an Uncle, and made it until it was time I could return to school.

When I returned, I was still having health issues. I was having seizures. The school required that I get medical testing if I wanted to continue. I was on probation. They could call me with no warning and say you have an appointment in 15 minutes you are required to be there. I ran because it would take 30 minutes to get there if I waited and took the bus over. Then, they decided that theses seizures were actually a mental health issue. They were pseudo seizures now termed non-epileptic seizures or PNES. I was required that I see a councilor at student health. I started getting a different perspective on the things that had happened in my life, and remembering things from my life that didn't seem like they could be true, like I was making them up. I started having nightmares, while my happy UNC life was also starting to be a nightmare.

I had a seizure in my dorm, and they kicked me out of my dorm because they couldn't be held liable if something happened. They gave me a week to leave. I'm still not exactly sure if that was legal. They expected that I would go home to my parents. They didn't realize I don't have a home to go back to.

I went to use my OneCard at the dining hall and it said that I was not currently enrolled. The school of education withdrew me from school without my knowledge. According to the woman who helped me re-enrolled, that is the first time that has happened to a student in the history of UNC. I seem to frequently be in situations where people don't know how to handle it because it's a first.

I requested a clearness committee here and it help me think through some things. I dropped to an underload and switched to two other classes mid-semester, with the expectations that I still complete all of the coursework that I missed. As for finding a place to live, a friend on my clearness committee knew someone that was looking for a roommate, and I moved in with her. Meeting her was pivotal. At this point, I was ending up in the ER quite a bit. It shocked her to know that she was the first person to sit with me through an ER visit. I didn't know anything about dealing with doctors or my health care. She taught me to advocate for myself. She taught me how her mother had taught her, and from all her experience advocating for herself as someone who is blind and disabled. I've never known a smarter more capable person. She made me realize the sharp distinction between having a disability and being disabled. Anyway, I finished my two classes, with A's in both. After fighting so hard, I still ended up having to withdraw again. I started UNC in 2004. I didn't end up getting my degree until 2016.

Does any of this surprise you? I want people to know that you really don't know what other people are going through. I also want you to know there are things you can do. Don't be quite so polite and afraid to offend (as long as you are coming from place of love and not other reasons). Be nosy. Ask questions. I have found that people would rather have someone ask them questions than be distant or awkward. Get to know the people around you on more than a superficial level. Be the first person to initiate a conversation. Check that people are all right.

Everything feels disconnected, especially since COVID. Everyone seems to be busy. The attitude is that other people are not your responsibility. Let someone else handle it. Leave it up to the experts. In my experience that is the worst possible advice, and I think my story will demonstrate why.

I was hospitalized for psych over 200 times in 14 years, so I'm sure you understand why I can't go into a lot of detail, but I will share some of the highlights.

The first time that I tried to commit suicide, I had recently moved to a supportive apartment program. I overdosed on one of my medications and then was so scared about what I did that I called 911 myself. The police came. They mistook me for my roommate who could get violent when she had episodes. They said that I was dangerous. They put me in handcuffs and were not gentle about it. They talked to me like I was a criminal. While in the waiting room at the hospital, I had a seizure. They thought I was faking and pulled on the handcuffs so hard that it broke my wrist. I tried to tell the nurses and the doctor. They wouldn't listen to me. They ignored me the whole time I was there, like I was just trying to get attention. After being discharged, I had to wait three days to get a Medicaid cab to go back to the hospital so they could do x-rays. When they asked how I broke my wrist and I told them, they said that it couldn't have happened

that way. If the doctor thought that my wrist was broken, he would have x-rayed it while I was there before.

I can tell the number of lies I've told on my hands, but the pattern I discovered was that our health care system starts by assuming that there patients are lying, while trying to get patients to talk to and trust providers. Providers no longer know their patients. They rush to get to the next one. They try to fit in as many as possible because they think it is more effective. They are strangers forced to collaborate on very personal matters. Doctors expect patients to trust them based on the fact that they have a degree, and not by building a relationship of trust. Mistrust and miscommunication abound. It reminds me of what my aunt says all the time "the hurrier I go the behinder I get".

I have also come across another pattern. If you have a mental health diagnosis, if they can't immediately see a physical problem, then they assume that you are lying and manipulating, trying to get attention, or you're sick or crazy, just part of your mental health issues. While simultaneously trying to be professional and put on a front like they aren't doing that.

At one point, I started feeling really sick. I went to my doctors. She said that it was depression. One of the things I was diagnosed with is bipolar, but I knew this was different. I spoke up, but I was ignored. They wouldn't believe me until almost all my hair fell out. They asked why I hadn't said something earlier. It was like student health telling me that my problem was stress when I had Rocky Mountain spotted fever.

I was also dealing with other systems like social security. If you are in a facility, like a hospital, for more than 30 days your money goes to the institution to help pay costs, not to you. That makes sense, right? You are being provided for, so why do you need the money? I was in the hospital over 200 times, a lot of them were over 30 day stays. If you don't live in a place where someone else is responsible for the housing cost and you go in for one of those long stays, you won't have the money to retain your residence. While in the hospital, the place where you are renting can get rid of all of your belongings, and when you leave the hospital you will have no place to go back to. Hospitals are not supposed to discharge you without somewhere to go, but they can put down that you are being discharged to a shelter whether or not you actually plan to go there. I chose to live in a tent in NY in the middle of winter because the possibility of freezing to death seemed like the less traumatic choice. I'd say that these systems are not cultivating the sense of safety and well being you see on the brochures.

I moved a lot. People told me I needed to stop running from my problems. I knew what I needed was a stable long-term place to be. What I didn't know was how to make that happen. I was in so much agony 24/7 that I couldn't stand to be in my own skin for more than 30 seconds at a time. I was exhausted, terrified, angry, couldn't think straight. It felt like when you get caught up in the undercurrent in the ocean and it keeps tumbling you over and over in the water where you can't get air and you pray that you can just wash back up on the shore before you drown.

After being chronically suicidal for 14 years, being diagnosed with bipolar, PTSD, dissociative identity disorder, and functional neurologic disorder...After being in and out of hospitals, group homes, and homelessness...After people telling me I just need to have more faith, that I needed

to be grateful, saying that I didn't really want to get better or I would have done it by now, and all the other negative judgements and the ill treatment that followed from that line of thought... there was a turning point.

My sister and my mom found out that they can't eat gluten. My sister said I should talk to my doctor, who told me to stop eating gluten and see what happens. At first, I felt like I was dying. I didn't know that stopping gluten can send you into withdrawals similar to going off opioids. Apparently, that's not well known to health care professionals either. I ended up in the psych ward again. After being discharged, the agony I had been in for so long stopped. I had more energy and I could finally think clearly again. Problems that had started to raise red flags—high blood sugar, high blood pressure, high inflammation level and white blood cell count, anemia, vitamin D deficiency—all started improving within a month. I also haven't been an inpatient in a hospital since then. 80% of the problems that were really making me miserable went away.

I am not saying that gluten was my only problem. But, it was the problem that had to be fixed before any of the other ones. It was the bleeding that had to be stopped. Unfortunately, it took 14 years to figure out the problem.

7 months later, I got another diagnosis. I was diagnosed with autism. Unlike the other diagnoses, this one was actually helpful. I realize from my experiences that a lot of people who don't try to get help may want help, but they know how harmful it can be to interact with the system. They are already people who are different whether from the way they think or the things they have been through. They are called lazy or liars, dangerous or crazy. They don't want any more labels that can be used against them. But, the autism diagnosis helped my providers understand a little more, and helped me understand a little more too.

I wanted to find a support group for people with disabilities. I had been in the mental health group here at this meeting for a while and wondered if Ithaca meeting had something similar. I reached out to a friend who directed me to someone in New York Yearly meeting. I found out that the differently abled friends and allies subcommittee (DAFA) had been formed within the last year or so. I also found out that it wasn't active. Right then it hit me that I could help with that. I'd never done anything like it. I didn't even know what it would look like. But, I knew I could get something going just by creating a space, an opportunity for people to come together and talk about all things disability related. I also realized that the point wasn't going to only be about things like increasing the number of handicapped spaces in front of the library. They group would be for everyone, whether they were diagnosed with a disability or not. I've learned that the biggest disability is disconnection. Everyone has something they have trouble with, some more than others. There needs to be more awareness, more connection, more community. As one DAFA member from the Ithaca meeting said, "if we take turns functioning, we can get it done."

Immediately after I started feeling better, I also stopped going to therapy and I dismissed my home health aide. I still needed one, but you can't have a home health aide and be a home health aide at the same time. I started working full time as an aide for my friend's mom who recently moved into the complex. I was told that I shouldn't be working. Remember, I still had that list of diagnoses, and yes I would consider them correct diagnoses, if I were going by the medical

model. But, I don't go by that model, so I'm not trapped by its limitations. The idea being reinforced was You can't help people. You are disabled. You should just think about your own problems. You don't have time to worry about anyone else's. But, my friend's mom had no one to help, and she said she would rather die than go back into the abusive situation at the nursing home. Unless you know someone, you are more likely right now to win the lottery than find a home health aide. I was the only thing standing between her and that awful place.

They say, you just can't help some people. It's not your responsibility anyway. You would think about that statement differently if the person they were talking about was you.

I may not have been in therapy, but I worked on a lot of things. I started by trying to strengthen my almost non-existent support network, starting with reaching out to extended family members that I had gotten disconnected from. My family moved to NC when I was 8. Child protective services was going to remove me and my siblings from our home. My parents found out somehow and moved us out of state without telling anyone where we were going.

I was working for my friend's mom, brushing her hair. It made me think about my cousin. He was the only one I would let willing brush my hair when I was younger. I had been wondering how to start reaching out to people. I decided to start with him. That was last March. This March, he's going to be my home health aide. How did that happen, we'll get to that.

My friend's mom did go back to a nursing home, just not the same one. It's still bad, but I try to help by cooking her three days' worth of meals every Monday and her daughter takes them the food to her. I can't go. I can't wear a mask. I had to fight in order to get a mask accommodation so I could even get medical care. That's a story for another day. I have a lot of stories.

Because of my seizures I am not supposed to ride public transportation, and I'm not within walking distances of much of anything in a town population size 523 and doesn't even have a gas station. I can't get to a job. I can't even not work at home because flexible at-home jobs are not flexible enough. However, writing is something I can do. I am currently attending Southern New Hampshire University online for Creative Writing. I have a lot to say, a lot more than I can express in this forum, but I also know that the best writers are people who have something to say, and I hope one day you will stop at a library or bookstore and care enough to pick up one of my books because the purpose of my books is to get people to care.

It's amazing how many people don't seem to care, or the ones that do don't think they are worth being cared for. One thing that struck me about my friend's mom was that she was amazed that someone was helping her. She felt like a useless burden and couldn't believe that someone actually cared about her. These feelings are things I have witnessed in other patients I have seen in the hospital, and feelings I have felt myself. They don't start in a person. They start with the voices of others telling them, just like people saying I shouldn't work because I was disabled. The system sends the message that you are either able to be and independent contributing member to society, or you aren't. They are designed as if people function like machines, and don't account for human diversity. There are too many experts at distance level too far away to be effective and not enough people doing the hands-on part. There need to be more boots on the ground. We need more people using their gifts, not side-lining people. People have things to

offer no matter what their circumstances or level of health, if they are given the right circumstances. But, most of the time society doesn't create those circumstances. I know they are working on it, but we have a long way to go.

American culture equates your worth with your productivity, usually your job. It's amazing how many people see me differently now than when I was sick. When people saw that I had gotten a job, they commented on how they were glad I was finally working on things and getting myself together. They didn't realize I had to work so much harder when I was sick than when I did when I was working 40 hours a week. Plus, all of a sudden I somehow gained credibility in others eyes and didn't have to deal with as much stigma and ill-treatment.

I have come across a lot of different people trapped in our systems. Most didn't have the miracle I did when my sister figured out the gluten issue. They also may not be as stubborn and I am. I am definitely a fighter, and I still tried committing suicide on several different occasions because things were too much. Some people who have tried to commit suicide look back and wonder what they were thinking. I look back and realize that life was intolerable, and no one is that strong. I needed outside intervention. I needed support. I need to not be alone. Our system doesn't help with that. Having people, having a community helps with that.

My experiences taught me that whether you are marginalized because of your mental health, religion, race, culture, or any other labels people use as an excuse to hate someone different from them, it takes away the safety that most people take for granted. It makes me wonder what Mohammed Reza Taheri-azar went through that he would hurt those people. I don't know. I do know that people, when they are drowning, will pull anyone next to them under too. Unfortunately, many people stopped taking the time to stop and throw out a lifeline. And, as a result there have been too many casualties.

However, the people being helped also have a responsibility. They have to accept help and do it in a healthy way. Learning to accept help was hard because I've seen what passes for help. Real help is someone caring about you, where someone is not looking down and judging you, where you aren't just a client.

My experiment to help my friend's mom remain in her apartment may not have worked out. But, it was worthwhile. I think I taught her that it was ok to accept help when it was genuinely offered, where the person was there to help in the way that is best for you, not just what's most convenient for them. But, it goes both ways with teaching and learning. Some cultures only have one word to describe both. She didn't let me continue to work when I didn't feel well, even when I wanted to. I learned what it felt like for someone to care about me, and not just about what I could do.

I didn't totally learn to accept help until I re-connected to my cousin. We check in with each other every day. If I don't respond, he knows to check on me. I left the group home I was in against medical advice because they thought it was too dangerous for me to live independently. They were right. I could be unconscious lying injured from a concussion and no one would know. I could be catatonic for days and die of dehydration because no one would know. But, I still thought it was better than the alternative. My experiences in places like group homes are

also a separate story. My cousin made it safer. He is not over here 24/7. He has a job. But, just a text to check in and knowing someone would be there in case of an emergency, that just changed my life. He also made me feel safer going to doctor appointments. I don't have seizures and get taken in a hospital because I can't speak for myself and they don't know what else to do with me. He also helps me communicate when I can't. For all my words, autism presents significant communication issues, especially with the fear accrued through my experiences with the healthcare system. Sometimes I literally lose my words. I now have an AAC device, but it's much easier to have someone who can be my voice.

Now, I have finally learned what home feels like, what the word safe feels like, and what having a dependable family member in my life feels like, for someone to speak for me when I can't, and to not be alone. I'm creative, but those things are much better than anything my brain could come up with.

I see a lot of lonely people around me. I live in an apartment complex for elderly and disabled. There are a lot of lonely people right next door to other lonely people. It doesn't make sense. I can't leave my apartment complex and participate in activities in the community, so I recently decided to start up some social activities right here. I am the unofficial community activities director. I even started a newsletter. There is now bingo once a month, a potluck once a month, a movie night once a month, and at least two other activities once a month. I can't do everything. There are three buildings here, and each one now has a representative.

It sounds great, but like my DAFA meetings, attendance is low. Maybe people have forgotten how to be a community. I hear from a lot of people that the things I'm doing are great ideas. They don't show up. They see it as a nice extra that they don't have time for, not as something that could be vital in bringing joy and health to their lives. I was invited to speak because of the article about DAFA that came out in Friends Journal. I was going to focus on telling more about the group, but I needed to let people know some of the backstory. I needed my story to paint a picture for people to know how urgently we need change, urgent enough for me to brave public speaking. I know it feels so big that most people don't even try, but there are things you can do. And, if you are truly interested in DAFA and want to know more, show up, or at least get in contact with me. Sometimes if you don't know what to do, the first thing is just to reach out.

That's what I did. After several traumatic experiences at a local hospital, I decided to try to do something about it, another story in itself. The result was that I wrote a letter to Dr. Patch Adams, a recent Nobel peace prize nominee, who's life story was done as a movie starring Robin Williams. Maybe you've seen it. I couldn't think of what to say in the letter, so I asked him to call me. He did. We have been talking regularly since. I'm glad that he is my friend. He says he has never done any patient of his the dis-service of giving them a mental health diagnosis. His trifecta of health is family and friends, nature, and the arts.

I mostly talk about the mental health system, but our overall health care system and other systems offering aid, need to be more human. Things have gotten too big to be effective, and too few people are taking on the load. The system doesn't only need to change for people who aren't getting care, it is also needed for the providers and staff who do this work because they do care

about people. They are overworked and burnt out. It's not fair to them either. After all I've said about the deficits of the health care system, know that I am talking about the system and not about the caring, passionate people who work in it. We need to remember that people who are carers also need care.

After all my experiences, I concluded that mental illness does not exist, this is not based on my ignorance about mental health issues, but my experiences with it. This doesn't mean that I don't believe in psychology, or the suffering that people are facing. I'm still dealing with things myself and I do believe that the patterns of behavior and thinking in the DSM are real. I don't agree with the conclusion that all those things are deficits, or illnesses. I believe that what being human means goes beyond the DSM. Unless there is a medical abnormality like a cancer ravaging someone's brain, people's brains are doing what they are supposed to be doing. They are reacting normally to abnormal circumstances. The mental health system creates a cycle that keep people trapped in it unless there is outside intervention like family and friends, unless people can get what they need be it physical, mental, emotional, or social.

Mental health professionals harp on concepts like mindfulness. By themselves, they are some helpful concepts. Everyone could be more mindful about the way they think and feel, but not because they are ill, because striving to grow and become aware is part of maturing as a person. In addition to people trying to strive and grow, If people were to start connecting and being able to get their needs met, we might start to see this mental illness pandemic start to die out. We should be taking it just as seriously as COVID, after all it kills a lot more people.

Patch says loneliness is our biggest health issue. From my experiences, I'd say I agree. He as a very different vision when it comes to health care. A description of his hospital, Gesundheit, and how it runs, and what he has been up do can be found on his website, although he doesn't use a computer. If you want to contact him, write him a handwritten letter and send it by snail mail. He responds to every letter himself.

Patch has been working for over 50 years trying to get funding to build a free hospital, and a system that actually allows for people to be human beings. The health care system we have now is not sustainable. It will eventually fail. You can't work within it. It's like a broken cistern. No matter how much you pour into it, it's not going to work. The question is, can we prepare and begin making changes now, and not wait for things to get worse? Patch has been dealing with the same problem I have at my meetings, only he has dealt with it for much longer. I actually made him a certificate for perseverance. While everyone has said he has wonderful ideas, when it comes time to contribute, no one is showing up. No one is donating. If you are interested in helping...please consider donating. The link to his website can be found in the chat.

I have had a lot of experts in my life, but no one who was really there, not someone in my daily life whom I had a real relationship with, who knew me. I was surrounded by people and all by myself. They tried to help me with things I didn't need help with and couldn't help me with the things I needed the most. It wasn't their job. I'm glad my cousin doesn't feel that way. We do need experts sometimes, but they should be supplemental to the support the person receives from their community. Everyone seems to be relying on experts nowadays, and there aren't enough of

them to go around. This doesn't have to end up being a crisis. Not just anyone can be an expert, but anyone can be a friend.