

## Oral History with Isabel Williams

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## Interview with Isabel Williams

Session 1 (4/15/2020)

[00:00:00]

YIU: Here we go. Okay. Hi, Isabel. I'm Nic and I've been corresponding with you. Thank you so much for taking your time out today to talk to me. How are you doing?

WILLIAMS: It's a hard time. But I'm healthy! So that's great. How are you?

YIU: I'm so happy to hear that. I'm doing okay, as well. I'm quarantining with my cat and my partner. We've just been managing to stay indoors and learning all kinds of crafting so we aren't too bored. Yeah, it's definitely a different time than what we imagined when we first started scheduling for interview.

WILLIAMS: Yes. That's true.

YIU: Yeah. So I wanted to ask if you have any questions regarding this oral history project and/or the legal agreements that we will send to you in the mail. I'll send out this piece of mail from my home because we're no longer going into the office, but there will be a self-sticking envelope and we're still respecting the fragrance-free policy.

WILLIAMS: Okay. I don't have any questions—nothing that I could be articulate about because it's hard for me to put my thoughts together a lot of the times because I have Lyme disease so I'm battling a lot of headache and kind of fogginess all the time. I don't know if you've ever talked to anybody else with Lyme disease but, you know, it takes me a while.

YIU: Yeah, that's completely fine. There's no expected pace at how this interview should go. And I wanted to put it out there that, at any point, if you wish to stop or pause to get a drink of water or just a momentary silence, we can certainly do that. I can either call back within five to ten minutes, or we can schedule for another call at another time since this will be a much easier schedule for me, given that I have all the time.

WILLIAMS: Okay, I appreciate that. Like I said, I'm going to stop at some point. I don't know when that will be but normally, I have a hard time on digital devices. I think I'm pretty good for about fifty-five minutes to an hour and then afterwards, I just can't—I need to get off the phone.

YIU: Yeah, which is completely understandable. And so I'm going to keep that in mind and check in when it hits that hour mark. And feel free to tell me whenever you feel like you would like to take a break.

WILLIAMS: Okay. I can do that.

[00:03:39]

YIU: So, if we can go ahead and get started, I would love to get a sense of when and where you were born.

WILLIAMS: So I was born in El Salvador in 1977 during the civil war. And it's a really long story—it's a very long story. I could write a book about it and I'm trying to but I never know how to, like, summarize it but I was eventually separated from my family because our village was raided (by) the National Guard at that time. So I was separated from my family and many of them were killed but my older sister and I were taken to a hospital of some form and from there, we were sent to an orphanage. We spent about a year there and then we were adopted by an American woman who was single at the time and we went to live with her. We grew up in New England, near Boston—we moved around a few different places there. So this was--yeah, so it was myself, I was almost (inaudible) at the time of the adoption and my older sister was about six years old and we were adopted together thankfully.

YIU: Right. I remember you writing in your pre-interview questions—thank you again for that really well done narrative—that you crossed it out. And you mentioned that you were adopted in 1981, is that correct?

WILLIAMS: Yes.

YIU: And you said that you had this safe—you grew up in this safe, quiet neighborhood with an Irish American family. Can you tell me more about your parents?

[00:05:59]

WILLIAMS: My mother was single when she adopted us. And it was really, really great. It was really magical and enchanting. It was ...it was just great for a while. And we lived with our grandparents for—I don't know how many years. We ended up living with them for a while so it was just like my mother, my sister, and my grandparents. It was really loving, I was told, and it is a—we were living in (inaudible) at that point. It was--and I think about it often--really a great neighborhood, a tree-lined neighborhood. Ten minutes from Boston; often it's nice and quiet. Yeah, it was just really, it felt safe to me, it felt like a safe place.

YIU: Yeah, so it was not exactly urban downtown but it's not rural, either.

WILLIAMS: No, it was a suburb so it wasn't a city. When I got older, I would take a bus and the train into Boston, and then it would get gradually—like there would be more people and more pollution and more of everything. But it was a really nice, quiet suburb. It was not rural.

YIU: Right.

WILLIAMS: Because there wasn't--there was the average amount of pollution, I guess. But there wasn't too many--there weren't too many cars on the street. It was quiet, I could ride my bike. It was a safe neighborhood. It wasn't near any type of industry; it was a small main street. Yeah, it wasn't—there was no pollution that I can think of.

YIU: And so this suburban community that you grew up in, did you stay there for a long time? Or did you move soon after?

[00:08:06]

WILLIAMS: We stayed until I was about twelve years old, and then life changed a lot. My mother got married. And this man took us away from our family. He moved us all the way over to Indiana. We lived--we moved to a farmhouse (inaudible) out in farm country--we lived on ninety-nine acres. Some years, it was corn; the other years, it was soybeans. It was very rural, very rural, very racist.

And it was--I mean, that's where I contracted Lyme disease. I would walk out into the field by myself because I will try to get away from a very abusive household. I would go walk in the field, and during one of those walks, I got bitten by a tick. I was only about fifteen years old. And so they were like--I thought about this a lot because I wonder how did I become so ill? And this was where it started. It was--like being in an abusive family, getting bitten by a tick which gave me Lyme disease, and other tick-borne infections. There was also the constant smell of fertilizer and pesticide. It was so strong. I smelled it, it smelled like yeast – it was so sick(ening) and overpowering. It was disgusting. I didn't know anything about these. I was only fifteen years old--I was just a child. You know, when something like this happens, you are just like, "Okay, that's a part of the landscape" and you just accept it. But it was really overpowering, the smell of whatever that was, pesticides or fertilizers. And it was also a moldy farmhouse. And there was black mold in the basement. Yeah, that was not a good time in my life. I got very, very ill.

[00:10:15]

YIU: Yeah, before we move on to talking about that incident that you wrote in the pre-interview and you briefly talked about when you were fifteen and being bitten by a tick, could you tell me more about this house that you moved into in this very rural and racist community. So, you mentioned there's black mold in the basement. What was the house like, other than the smell of pesticide? What other scents do you remember?

WILLIAMS: In the house?

YIU: Yeah, in or near the house.

WILLIAMS: The house was very small. It was, you know, it was hard to stay safe in that house and it was very tiny and it was just an old house. We lived hard. My mother eventually--she had the attic redone to give my sister and I--Kind of a safe place to get away. So, it's really nice that they (inaudible) was created upstairs in the attic and it was newly painted. I thank my mother for that. I mean, at least she did try in some ways. I love her very much. I mean, I love all that she has done. But she had a hard time keeping us safe, but it's okay. But it did--it added to kind of like, the breakdown of my body because I couldn't deal with all that stuff.

YIU: Right, and so, do you remember particular products used at home at the time, like cleaning chemical?

[00:12:07]

WILLIAMS: Oh my goodness, I mean we were poor. We were very poor--we relied exclusively on the income of my abusive parent. And that was not enough. We ate pasta--I mean the cheapest pasta and spaghetti--like, almost every night. We hardly--that's about what all we ate.

Sometimes we'd have chicken. Yeah, there was lots of pasta, sauce. Then I would eat at school. So I'd leave for school, I'd have that lunch meal there. And then I used (inaudible) hair products to wash my hair like the cheapest product you could get. It was Suave and I would use a lot of it because I had a lot of hair. And so we were living very cheaply.

I mean, I remember already feeling ill at that point because I was fifteen and I got the Lyme disease. I remember the chemical allergies started then but not in full force. I remember going to the store and being very happy because my mother would get our clothes once a year. We went to Montgomery Ward and I got these black jeans and I remember feeling ill when I put them on. Like, I remember realizing it must be the dye on the jeans as like too much dye on jeans. I remember that was the first time, I think. I remember getting ill from something like synthetic pants.

YIU: And so you mentioned that you were fifteen, so a dumb teenager walking in spaces where you got bitten by a tick. Can you tell me more about that and how you originally perceived your sensitivity under illness that became an onset you described?

[00:14:15]

WILLIAMS: I don't remember exactly what I was doing, but I do remember waking up one morning and doing my usual routine and going down to the basement full of black mold and going to take my daily shower.

The basement was almost always--it was always flooded. There was probably about like, five inches of water I think. Always, there would be water up to my ankle in the basement, and then we had a shower, a standing shower, it was just made of plastic and it was a terrible basement. There was one light bulb that you had to walk in the middle of the basement to get to put the light on so you had to walk through moldy, sandy water in the basement every single morning. And I'd go and take a shower, there'd be black mold all over the walls of this standing shower we had and it was very dark. I could barely see anything.

Then, one morning, I walked up the stairs after my shower and I almost want to say that I felt something on my toe. Like, as I was standing in the water, I think I felt something on my toe and I go, "I don't know what that is." And by the time I got there, up to the top of the stairs, where there was light, I looked at my big toe, and it was a tick on it. It was just huge and engorged and I took it off. I remember thinking to myself, "Oh great, now I have Lyme disease," but then going on with my day because I was just a teenager and I need to get out of the house, I always needed to get out of the house. I needed to go to school. And I went on with my life.

Then, I don't know if it was within a week, I got so ill, I got so sick. I couldn't (inaudible). I don't know what to call it, but I couldn't--my stomach fell apart and if I had to go to the bathroom, I would have to go immediately. My mother eventually wrote a note to all of my teachers telling them that they have to allow me to go to the bathroom as soon as I have to go, I would have permission to leave and go. And it was scary because I couldn't control my body for the first time. And it was painful and humiliating and embarrassing. So that was the first thing that happened. And I still didn't know anything about the Lyme disease. I still hadn't been diagnosed.

I still hadn't gone to a doctor. I knew that, all of a sudden, I had this huge problem with my stomach and it was embarrassing. Yeah, I mean, I remember crying uncontrollably the first time because I didn't know what happened to me. And I was just thinking, "Okay, I've got some extracurricular activity after school with my sister" and then I got sick into the bathroom and I had no help. Nobody. Like I had no help--nobody knew what was happening to me. I was just a kid with other kids. I mean, it was tremendous. Yeah.

[00:17:37]

YIU: That definitely didn't sound like the best environment for a young child to be in, as you described, rural and racist within that school and alone. Could you tell me more about, because you said a week after, you got very sick after the tick bites. Did you make the instant connection at the time between the tick bite and, (as) you described, the inability to control your body?

WILLIAMS: No, I didn't know anything about Lyme disease. I remember, like, thinking Lyme disease in my head because--I don't know where I got the term from--I got it somewhere, but it was not spoken about. I didn't see any information about Lyme disease anywhere so I didn't know anything about it honestly. And no, I did not connect my stomach problems with the Lyme disease. I had no idea what was happening. I had no idea. I didn't know anything.

YIU: Right, and did your mother know anything, or did she talk to you about what she thought it might be?

WILLIAMS: No, she didn't know anything about Lyme disease. And we were barely speaking to each other. It was a very stressful household. I blamed her for bringing in an abusive person into the household and I was trying to stay safe, so I did not have a very good close relationship with my mother in those years. We really honestly didn't talk a lot. But it was obvious-- I had to tell her that I had this problem and that I was getting sick. She did take me to the doctors once or twice.

YIU: And this was the whole time in your teenage years after a tick bite at fifteen, you have only gone to the doctors twice?

WILLIAMS: Yep, I went twice. And--

YIU: Can you describe to me those experiences of accessing medical care when you were a teenager?

[00:19:41]

WILLIAMS: I only went to the doctor twice. That was it, only those two times. Like I said, we were very poor. I don't think my parents probably had any money to send me to the doctor or if they did--I don't know what happened. You know, it was an abusive household so I wasn't getting cared for in a way that would have been ideal. But yeah, I only went to a doctor twice. One time to the gastroenterologist, and he was very patronizing. And he said that I must have opened my mouth too much when I ate food and that my stomach was upset. It just was ridiculous. I was--it was a terrible appointment. He didn't talk about Lyme disease at all, he

blamed it on me, treating me like I was--It just was terrible. And then I went to a second doctor, and I don't want to talk about that.

YIU: Okay.

WILLIAMS: That is something I don't want to talk about. So I didn't get any diagnosis--I didn't get a diagnosis for many years. And I was acutely ill with that stomach problem for like, a year at least. And then it sort of went away. I mean, yeah, my history is a history of Lyme disease. It's so tricky because, it'd be acute sometimes and then your symptoms kind of like, decrease and then they'll show up in another part of your body. I've been struggling for twenty-six years with it. I tried to go on with my life.

YIU: Yeah. When you mentioned that--before we move to the part where you said you didn't receive a diagnosis for many years--when you were younger, though, how were you navigating these symptoms while being in school because you mentioned you were dealing with feelings of shame because you were unable to control your body for the first time? Can you walk me through that more?

[00:22:07]

WILLIAMS: How I navigated going to school? I just got that one accommodation, where the teachers allowed me to go visit the restroom anytime I needed to. It didn't affect my studies or my brain in any way, so it didn't affect my learning. I was just in a lot of pain. And I just pushed through it.

YIU: Right. And did your friends at the time know that you were ill? Did they try to accommodate you in any way?

WILLIAMS: My friends?

YIU: Yeah.

WILLIAMS: Is that what you're asking? Oh. No, I mean, as most teenagers, I think I just didn't want anybody to know. I don't think I told anybody, because what would I have said? I didn't even know what was happening to me. So I don't think any of my--No, none of my friends knew that I was sick. None of them, only my sister. And my sister would take me on very long walks. And it wasn't--we would go on very long walks. I thank my sister so much every day for having her--She would take us on these--like, we would go and walk in the woods for like four hours almost every day to be out of the house, to be away from the house. So that's what we would do. And that actually helped, I'm sure with that first sort of symptoms. I'm sure it helped my body to get rid of some of those toxins. So, my sister was really my only help.

YIU: Yeah, so your sister was a huge part of your support system. You mentioned earlier that your history of illness is really a history of Lyme disease because sometimes it's acute and then your symptoms shows up in a different part of your body; what were some of the signs and sensitivity when you were a teenager? Or how did that change over time?

WILLIAMS: So I only remember that one time, with those pants that I got from the store. Otherwise, I didn't have any sensitivities for years, many years. I only had acute multiple chemical sensitivity for the past eleven or twelve years. I think--I keep on getting older and not wanting to acknowledge that but I think it might be twelve years now. Yeah, so-- I mean, because I often think back on this and I think, "Yeah, it's only been about eleven or twelve years since I've had MCS." And so I remember times when I wasn't sick. And I could take planes and airplanes and travel and wear new clothing. Yeah, I remember, I remember those times. So it hasn't been very long that I've had MCS.

YIU: You mentioned--so going back to earlier that you didn't receive a diagnosis for many years, when did you first receive your diagnosis of Lyme?

[00:25:35.00]

WILLIAMS: I don't have my files in front of me, but I think it was about six years ago, no more than six years ago. I finally went to a doctor in Massachusetts, which is, you know, the state right beside ours, and he was a doctor of Environmental Medicine. It was a very long time of going without a diagnosis. Instead, I had the diagnosis of rheumatoid arthritis because that's what the rheumatologist couldn't ignore. Like, for a few years, by the time I was nineteen, suddenly, I had severe rheumatoid arthritis for no reason. And it doesn't run in my family. Obviously not in my adopted family, but also not in my birth family. That was primarily how Lyme disease showed up in my body, for most of the time, as rheumatoid arthritis.

YIU: Okay. Wow, it really was a long time when those twenty-six years that you've lived with it, for many of those years, you didn't know the causes of your illness. Is that right?

WILLIAMS: Yep. I mean, I didn't--I thought I had rheumatoid arthritis. That's all, that's all. Nobody ever talked to me about Lyme disease which is crazy because I live in Vermont, a rural state. Now people talk about Lyme disease, now it's an epidemic and everybody talks about it. But for years, decades, I didn't know anything. I was not exposed to any information about Lyme disease so I didn't know anything about it. Nobody ever mentioned it to me. Not doctors, not friends. Nobody for a long time.

It was just six years ago that I went to that doctor in Massachusetts. I mean (when the diagnosis was received), I didn't have some, like, outpouring of rage or anything because of the injustice that nobody had told me about this. By that time, I was just so weary. I was just so tired of being sick all the time. And I wasn't surprised to get a diagnosis of Lyme disease but I still didn't have any faith that all of a sudden, there was going to be a cure. I'm glad that I did get the diagnosis though. I'm glad that I have something I can look into books about and try to get more knowledgeable about it. But I know there's still no cure, so it wasn't like some saving grace. But I'm glad that I have it. Glad that I know now.

YIU: Yeah, you mentioned that meeting this doctor in Massachusetts--how did you come to know about this doctor? And how did you come to think of environmental illness as a practice that you should link to your illness?

[00:28:42]



WILLIAMS: I don't actually remember how I found Dr. Wakaba but I think that probably my naturopathic doctor suggested him. I've talked to doctors a lot and I've been talking to doctors for decades and telling them very specifically, all of my symptoms, and nobody's been able to piece anything together, except that I'm pretty sure one of my naturopathic doctors was the one who mentioned Dr. Wakaba. Otherwise I wouldn't have known about him, he's all the way in Massachusetts. I go to a clinic here, I've gone to this clinic for a long time, and they're very knowledgeable about Lyme disease there. They weren't always knowledgeable about Lyme disease, but now they are.

YIU: I see. So this naturopath that you have been seeing, can you tell me more about them? How long have you been seeing them?

WILLIAMS: I don't know how long but it's been a really long time. I think I was--

YIU: Oh, so you still see them?

WILLIAMS: Oh, yeah, yep, I still see this doctor. So, I want to say, I've been going there for like ten years.

YIU: That is a really long relationship.

WILLIAMS: It is, yep. My doctor wrote a book about Lyme disease actually; it's available online.

YIU: And how were you able to maintain this relationship with this doctor over the course of ten years?

WILLIAMS: I don't know. I just kept going back. I keep making appointments.

YIU: Right. So they're not dismissive?

WILLIAMS: No, thank goodness. And I think that the biggest factor in that is that she's a woman. I've had male doctors be so condescending to me, and tell me that I'm delusional and crazy, and I never had a woman doctor treat me badly. And so, I tried to seek women doctors. Now I know I need to see women doctors.

YIU: I think that's such an interesting observation of how gender plays a role in medicine. Right. Can you talk more about this interaction and what you think about it? Do you think it's because you're a woman?

[00:31:38]

WILLIAMS: Oh, definitely. So I apologize, I'm getting tired right now. But yeah, I mean, this is a huge issue. I just have horror stories about how male doctors have treated me over the years. Like I said, I was first diagnosed with rheumatoid arthritis when I was nineteen. But I had already--I mean, it was a crisis immediately. It's never good to go to a doctor when you're in crisis because--I don't know how to explain it. But yeah, male doctors have been awful to me over the years.

I have one good male doctor now, but I mean, my rheumatologist, at one point—he eventually mailed me my file because I asked for it and he was about to retire. Anyways, this was like my second rheumatologist. When I looked at-- through my files, I saw his notes and I saw that at one point, he actually called me “delusional”, quote unquote delusional. I mean, this is ridiculous. Like, I am a very intelligent person-- I'm very intelligent, but I couldn't believe that it had to do with the fact that I was always sensitive to the medicine that rheumatologists put me on.

When you were asking about when did my chemical allergy began, I'm just remembering now that medicines are chemicals and that I've actually been sensitive to chemicals for a long time, for as long as I have Lyme disease actually. Yeah, that means I need to note that because that is where my chemical allergies came out.

I would be very sensitive to all of the anti-inflammatories that the rheumatologist put me on. And then I would get blamed, or I could just feel like these doctors blaming me for being sick, or for being sickened by the medicine, which is so wrong because for one thing, women's bodies are different than men. So when they're giving you a medicine, the medicines that they give you and the doses that they give you are often made for men. Men are much bigger than women, and I'm a very small woman. I'm only barely five feet tall. My grandmother had the same problem with medicine. Every single time a doctor tried to give her something, she would cut every pill in half, because otherwise she would get ill.

[00:34:17]

The doctors that I've seen over the years, and I've seen many doctors--like I regularly go to the doctors, I have a chronic illness with rheumatoid arthritis--they blame you. If you have a problem with the medicine, then you're--I forget the word--non-compliant. I've been called non-compliant at times by doctors because I said, “This medicine is making me ill. I can't handle the side effects. This is too much, can I take less?” I'm constantly having to advocate for myself.

To put it bluntly, I think male doctors often, the ones that I've had, have god complexes. Every time I'm trying to tell them that this approach is not right for me or it's not gentle enough, they don't want to hear it and it's part of their god complex, but it's also the fact that medicine is so intertwined with the pharmaceutical companies that, I mean, it's really corrupt.

Let's see, I think it was like twelve years ago, ten or twelve years ago that I had a major allergic reaction to a medicine ten or twelve years ago. I can't really get the years to be that specific but I started becoming acutely allergic to the anti-inflammatories that the rheumatologists put me on. I got so ill that for an entire year, I could barely breathe. It was terrifying. I could barely breathe. My eyes were literally crossed because my brain wasn't getting enough oxygen. I couldn't--I was so dizzy and lightheaded. I didn't leave my apartment for five years. I was bedridden, I had--It was just excruciating pain. And I'll never forget that because it was so traumatic. I was bedridden for five years. I could barely do the basic things and I just can't believe that you can be in that much pain and not die. It was terrible. You know, I lost those years of my life after this allergic reaction that I had to a couple of medicines actually. I tried a few. And all my airways just became incredibly inflamed. I could barely breathe. And then doctors--I just couldn't go to doctors anymore because they didn't know what was going on with me and they would just be

punitive and blame me. I kept on saying, "I can't take any more medicines, I can't take these medicines, they're making me so sick." So I just didn't go to a doctor for years. My body just had to take a break from those chemicals, my body couldn't get rid of those chemicals. I couldn't metabolize them.

[00:37:20]

Sadly, that is when arthritis overtook my hand. We're not doing FaceTime or anything so you can't see my hands but my hands are very deformed. Like I have the hands of a grandmother. Nobody--my rheumatologist, he has compassion for me. This one that I have now is a good one. Five or six years, and he says he's never seen anybody with hands like mine. I mean, he's more like, "I have lupus." It's like he sees hands like mine on people with lupus.

Anyways, yeah, these chemical sensitivities and the Lyme disease have had me on a very terrifying solitary path for many years. And I just--I mean Dr. Wakaba, the environmental medicine doctor, he was the first doctor to really believe me. He was the first one to say, "I'm going to test you for Lyme disease." He asked me--he gave me a huge questionnaire, it was pages long, and I checked off all the symptoms. And he was the first doctor to finally, like, believe me. Not that the woman doctor didn't but she didn't have the knowledge at that point about Lyme disease, which is probably why she gave me that referral to him. So gradually, I've been, I don't know, I'm getting better. I'm on medicine again. Very strong medicine, and I often have to wonder when the other shoe is going to drop. Am I gonna have another allergic reaction again? I don't know. I don't want to think that way, I don't want it to catch fire but it's precarious to ... live on medicines like this when I have MCS and multiple drug intolerance.

YIU: Yeah, I'm really conscious as well about, you know, the time we're spending today, it's almost been forty minutes now. I want to check in and see how you're doing and perhaps whether or not you would like to schedule for a second call instead or take a break.

WILLIAMS: I probably got about like five more minutes that I can do and then we should probably have another phone call.

YIU: Perfect, sounds good. I think you are obviously such a smart person, as you said, which has been dismissed by the doctors, and I think your intelligence comes out in this critique of what you call the intertwining of the medical industry where male doctors have a god complex, but also the corruption of (the) pharmaceutical industry. So I wanted to go back to there and ask you a little bit more about your general view on the medical industry, where it's not only sexist, but also capitalistic at the same time.

[00:40:35]

WILLIAMS: What did you say? Capitalistic? Yeah. Yeah, the medical industry is very corrupt. I just wish that I didn't have to depend on it, and I do. I see naturopathic doctors and I have to go to the rheumatologist but it's very corrupt.

I mean, like I said, I went through--when I became sick and acutely ill from those pharmaceuticals that I was taking, there was no way that there was any doctor working in the

mainstream medical industry that would listen to me about that because those are their tools. They get paid to like write out these prescription, my medicines, all of which is extremely expensive. I have procedures done every six months in arthritis that costs thousands of dollars. I mean somebody's making a lot of money off of me. I'm not paying because I have Medicaid and Medicare because I'm poor. So there's one good part about that is that like, because you're very poor, if you're very poor, and you've got this paid insurance, sometimes you get very expensive procedures and medicines because somebody is getting very rich off of the medicine you're getting. Not me, you know. They're CEOs and all kinds of people that are getting very rich from the procedures and pharmaceuticals that are the mainstay of like, medical practice, industry.

I am thankful for these medicines when they work for me and they don't make me sick but when (inaudible) or when you're getting sickened by some of these medicines, it's sacrilege to say, "This medicine isn't working for me." So, pretty shocking at the time when all of a sudden I was acutely ill and the doctors couldn't help me and not only were they not helping me, they were acting like I was being noncompliant or telling me I was being noncompliant. All of a sudden I became like an enemy for (inaudible). And I'd always been a very like, compliant patient. I always took the medicine that they gave me, so--

[00:43:19]

YIU: Yeah, I think it's very interesting the keywords that you've mentioned as like noncompliance but also, perhaps you didn't use this word but what I'm getting is that, they're describing you as hysterical--Oh, he used the word delusional, as you described, in his doctor's notes. It sounds like what you're saying is there are some connections being made between women and male doctors describing them as mentally incapable of understanding what's going on with their body.

WILLIAMS: Yeah, I mean, it was just terrible because I will try to tell these doctors that I can't breathe. And it's not even with just doctors. I went to rehab one day. Right after I had my medicine and all of a sudden, I was having the reaction again, and I was with a man, my rehab person, and my case manager didn't even believe me. I said, "I can't breathe well right now, I need to go. I can't breathe right now. Can we stop this meeting? I need to go home." And he wouldn't let me leave. I had to finish that meeting with him. There's something so wrong sometimes about men doing their job and like, I don't know what it is. I mean, like, I wonder what is it like? I'm just this woman, and I don't--You can't see when I'm telling you I'm sick. I can't breathe and like I don't understand, (inaudible).

You know, it's really it's scary that like, you can be so ill and people don't notice that about you. That's actually a pretty common experience for people with Lyme disease because we look healthy. We look healthy. You can't see how sick we are or tired or whatever is going on with your body unless you're limping or living in a wheelchair. People don't really see that you're disabled or sick. Anyways, I've had terrible experiences with men not believing me when I tell them that I can't breathe. Yeah it's been awful. Yeah, I don't know what that is. I don't know why.

[00:45:58]

YIU: That definitely sounds like a terrible combination at once. I would love to talk more about your involvement in the community in terms of the meetings at the local center that you attend. But also you mentioned earlier about the self-advocacy work that you do within medicine. And so if we can schedule for a different time on another day to talk more about that, that would be so great.

WILLIAMS: Okay.

YIU: And should I email you to schedule a time or would you like to set a time now?

WILLIAMS: We can do it now.

YIU: Okay. I would be free next Monday, any time before 1 PM PST, which would be I think 11 AM your time, or after 2:30 my time, which would be 5:30 your time?

WILLIAMS: I can do the 5:30.

YIU: Okay, so on Monday the 20th at 5:30.

WILLIAMS: Yes, I can do that.

YIU: Great, thank you Isabel. I'm going to give you a call at 5:30 again on Monday, April 20th. Thank you for your energy today and for sharing your story.

WILLIAMS: Thank you.

YIU: Take care and-

WILLIAMS: Thanks.

YIU: Yeah, take care and I'll speak to you soon.

WILLIAMS: Thanks. Bye.

[00:47:46] (End of April 15, 2020 Interview)

Interview with Isabel Williams  
Session 2 (4/20/2020)

[00:00:00]

(pre-interview phone set up)

[00:00:59]

YIU: Okay, well, last time, we were talking about the invisibility of Lyme disease and how you were talking about how you can be so ill but people still don't know that about you because you can look quote unquote healthy. So I wanted to know more about your experience of being ill and how that has affected your social relationships with others.

WILLIAMS: Oh my gosh! It has such a huge effect. I don't--Yeah, I mean, because, like, I think that the culture like expects women to do everything and be everything to everybody and overachieve. I'm always judging myself by that and, it's painful because I can't. I don't have the energy to do that. I can't work full time. I didn't have the life I thought I was gonna lead, and I wasn't able to have a family. I'm often undependable, even, in my friendships. So it's--yeah.

Having chronic illness, it affects every single relationship I have, including my family, like the most important relationships that I have with my family and even with them, I'm always the one who's needing help, especially right now. Because now we're in a pandemic. I have two wonderful sisters--one's in New York City. She's doing very well and taking care of herself and staying safe. And I'm really thankful for that. I never have to worry about her. And then I have an older sister who lives in my town, and I still depend on her greatly, you know? She brought me groceries yesterday, and so like I still depend on my family. I'm the one who's like, ill, I believe--I think that's the one like, when you're taking on roles in your family, I'm the one that often needs help in getting groceries or getting my medicine in the store. I'm not the one that you can depend on, whereas I have two very overachieving sisters.

And I think that's the way that all women are supposed to--I see that all women are still supposed to be like that. They're doing everything. They look after their children, and they're working and doing all the emotional labor and they're doing it all. That's what I see, in my community and in the media. And I can't be that person. I was raised to be that person: a very independent, strong woman who owns her own business. She had just this outsized personality, and I could never follow in her footsteps because I got this illness. It's just--it's tough, everything. And periodically, it's just disrupted my life. Like I--I've spent years bedridden, and then I come out of it, and then I try to live as much as I possibly can, do as much as I possibly can. And I could probably hear that from a lot of people that it's time to leave, and then we do too much, and then we suffer, and then we're in bed for days or weeks or months, because we've done too much. So I can't push myself like most people can.

[00:04:28]

With regards to friendships, they're just difficult because I can't--like, I can't do the things that I wish that I could for friends. Right now, I have a friend with cancer. I would love to be able to go to her house right now and help her with anything--cleaning, getting something for her, cooking something and bringing it over. But I can't. I can't be that friend because I'm disabled and I can't drive because of my hands. I can't really grip a wheel. I can't do these very basic things that people do in order to stay connected to their friends, family, and community. And, like, this is like the foundation of friendship is how can you like--how can I depend on you, or let me help you out. I can't watch my friends' kids; I used to do that. So, it's very difficult. I feel very invisible, very invisible in the world because I don't fit into any role. I don't fit into any role. I'm just a (disabled person) or I'm just a friend or a sister. But yeah, so it's been very painful. And there isn't much space in the culture for people that are chronically ill and can't do above and beyond, can't push themselves to the limit and go on and do beyond my twenty-four hours a day. I can't.

Sometimes I just can barely--I'm so tired I can't even think straight. And, it's just frustrating. Right now, because we're in pandemic crisis, it would mean me going online and having Zoom meetings and I can't even do that. I missed a meeting yesterday. I'm probably going to miss another meeting tonight, which was like—I had to go to a meeting tonight for the local chapter of the statewide People of Color Caucus. I'm probably going to miss that because I can't do Zoom and I can't be—I can't be on the internet or be on my phone for very long. People don't understand what EMF sensitivity is. There are so many things about my illness that are just sort of like—I personally think they're exasperating for people. They don't understand it and they think maybe I'm just being difficult or I'm trying to control situations, and I certainly don't want to do that. It's just that, you know, I will get there when somebody is wearing cologne or if I have to get on the phone for too long or—I don't know.

I don't fit many roles that are—Yeah, I just don't fit into many roles in society and I just can only be myself and I can only—if I show up, that's like the whole battle... if I feel well enough to show up. And so, I need people in my life that understand that but yeah, I don't see myself as ever being a person to like depend on. I'll never be able to walk to anybody—like I saw my grandparents (inaudible), my mother (inaudible) or my sisters. Yeah, it's been heartbreaking and I've had to define my own humanity in ways that are much different than how everybody else would in the world.

[00:08:10]

YIU: Yeah, I think what you just said now, thank you. You mentioned a couple of times of how there's a culture that manages this expectation of women to do everything and friendship being one that is of mutual care. I was just wondering if you can clarify what culture that is, do you mean the US patriarchal culture, or what do you mean?

WILLIAMS: I mean, I live in that so I can't get away from that, but I think it's just—isn't that what friendship is? I mean, because I see there's the reciprocity, like you go over and you help somebody, friends with their garden, or there are things that's expensive, and friendship is about reciprocity. It's hard for me because I can't give the traditional things, like I can only give myself when I'm there. I need people to just be thankful that I'm well today and I will be able to come

and like to be with you and I can't do—maybe it's just my culture, I don't know. I just can't—okay, so I guess to be more personal, I come from like a rescue culture. And this is just our personal level because as you know, I was adopted. I was adopted by this single woman at the time. She was extraordinary. She was an extraordinary business person. She was very successful. She was like, featured in Time Magazine as one of the most successful women in America and she would be on the Today show, the local news station, she was in the Cosmopolitan magazine. Like, I had this very huge ideal to live up to with this very successful woman who was also an even more important, and even more importantly, she was so kind and compassionate and loved everybody. So I come from that culture and I've heard stories of all the other women in my family who also have a bit of a culture of like, rescue—a rescue culture in my family. I read a lot. I see a lot in my community, because I'm also like—I finally learned racial and social justice so there's a lot of like rescuing going on. Yeah.

YIU: Right, when you talk about this rescue culture, there's the sense of maybe uneven power relations. Can you talk more about this rescue culture and what you think of it?

WILLIAMS: I'm trying to break free of it.

YIU: You're trying to--

WILLIAMS: Just break free of it, all the expectations because I can't- I can't live up to those standards. And then I'm trying to find mutual, equal kind of relationships. Sorry, I lost my thought after that. I'm not sure.

YIU: Yeah, I mean, we, we were talking about rescue culture and you were saying that you are trying to kind of escape from the rigid boundaries of that.

WILLIAMS: Yeah. Yeah.

[00:11:41]

YIU: So what are some ways that you do that?

WILLIAMS: Well, I mean, I just try to bring my voice into like, whatever gathering I go to, and I just try to be myself. I mean, I try not to depend on anybody other than family members. And I don't know, I'm just trying to like I try to make do—I do depend on a lot on like social services. So maybe I'm not like, completely out of that rescue culture. Because I do depend a lot on the social services. I just sort of switched over from depending on people or friends to depending on social services. But what else could I do? Like I depend on things like food stamps and the visits from a visiting nurse from the Vermont Nursing Houses Association. But I don't know--but that's not rescue culture, that's like acts of like social service culture and I need it. I have an illness. Otherwise, like in my community, I don't know—I just show up, and then I'm just mental. And I try not to be in crisis, but at times it has happened. And it's because of my illness. I remember losing—well, being in a coma for a few months, although technically I wasn't. That was a few years ago, because it just got very dangerous in my public housing for me and it had to do with my MCS because the person that made me unable to live there anymore knew that I have that



condition. He did everything he could to make me ill so that was a pretty scary time. But otherwise, yeah, I'm just being myself. And I'm not trying to depend on people more than I have to. And I think I'm finding a pretty good balance, I think.

YIU: You mentioned that you were not living in your home for a few months. Can you talk more about that?

[00:14:08]

WILLIAMS: Yes, it was really upsetting. Boy, living in public housing is really difficult. I live in public housing, for like eleven years now. And I grew up poor...living in subsidized housing, and there was a lot of—oh my gosh, I don't know how to describe it. There's so much anger and mental illness, as well as physical disability. Everybody's having trouble. If they didn't have a troubled life, they wouldn't be living in subsidized housing. I'm living in subsidized housing because I have arthritis. I've lived in a building with—they were single units so there are people that did not have families of their own. So it was individuals, every single one of them had mental illness. Every single one. It was crazy-making; it was terrible. It wasn't safe. I had a neighbor who harassed me and he ended up assaulting me. This is not something that I run into a lot in my life and I try to—I'm very shy and quiet and I keep to myself, but I... I couldn't protect myself from this person. I tried. So that ended, because of all that harassment and then assaulting and all this stuff, I had to leave. I had to leave, it was dangerous for me. I had to go and walk over to the clinic—and get a letter from my doctor explaining what was happening to me and then I sent it to the landlord. And I went and stayed with a couple of different people, and I stayed with a friend on the street for like three months, two or three months.

YIU: Wow.

WILLIAMS: It was a nightmare. It was winter time. I felt very victimized and disempowered. But I also should just—I try to focus on how well I got myself out of that situation. And I advocated for myself and I went down the path that nobody had gone down before because I had MCS. It was a lot to try to help people in housing understand what I was going through. I mean, it's hard enough—I had to contact the local Women's Freedom Center and that's for women who experienced domestic violence. I talked to them about my situation, but then they couldn't help me because my abuser wasn't my partner. He certainly wasn't. And because he wasn't, they couldn't help me.

[00:16:58]

And then when I called the police, I ended up calling the police a couple weeks later. And then, you know, it was a male police officer and he said, “Why didn't you call us earlier? Why didn't you call us before? Why didn't you call us two weeks ago?” So instead of saying, “Okay, we're on it, we're gonna help you,” they punished me, humiliated me. They made me feel like it was my fault. I didn't do the right steps, I didn't call on time, so I must be fine, or what, I don't know. But I didn't get empathy or compassion from the police officer. So it was really terrible.

All the women that I spoke to, every one of them, every single one of them—they all had empathy for me and compassion, but they weren't the people in power, of course. It was a nightmare. But eventually, I talked to my case manager in housing, like my local housing authority and he was helpful. He believed me, thank god. And I got myself into the apartment I'm in now, which is much healthier for me even though there's a lot of conflict here too. But it doesn't have to do with me, thank god.

But yeah, I'm very proud of how I got myself out of that situation because I was doing, I was having to—there were no depths for me. And I'm not the only woman this was happening to, which made me more upset, because I was like, “How could you be giving me such a hard time?” I mean, “What are you doing with all the other women?” Like, there's so many women that, like, run into trouble. And I didn't get the help that I needed. But I forged my own path, because I had to, because it was necessary. So yeah, I got myself into another apartment as soon as possible and yeah, it's very hard to advocate for yourself as a woman or disabled woman or a woman of color or a foreign woman. And for me, all of those identities are mixed into one.

YIU: Yes.

WILLIAMS: Yes. So actually that—my job is often things like that, but I don't earn money. But that's my work in life essentially, show up, bring my whole self, represent who I am and like, the other people who could identify with me. And yeah, that's really my work.

[00:19:42]

YIU: Yes. I really loved how you described self-advocacy as work because it is surely a labor. Can you talk more about experiences and self-advocacy that you're proud of? Now that you have mentioned the housing experience where you self-advocated for yourself, do you have other experiences in your life where you're like, “Wow, I really showed up and advocated for myself”?

WILLIAMS: Well, for myself, I guess I've done a pretty good job with my doctors and my healthcare. Because, as I already said, I have a lot of difficulty. And I've been pretty abused by the medical system over the years but I'm doing a really good job now. And I'm proud of that. Like I already told you I have a woman doctor, she's a naturopath and I've been seeing her for ten years. And she's been helpful and I see women doctors and I'm on a better path now. I feel more heard, even my rheumatologist listens to me; he did a talk in Science News on arthritis (and Lyme Disease) and how they're connected just last year. And he was glad to tell me that the last time I went to see him because he knows I'd be happy about that because that's what we talk about. Because I've been seeing only doctors that were not believing me when I say, “I got this arthritis from Lyme disease. This is not something that runs in my family.” So I only have those like small victories but they're important because, like, I want to get to a point where I can advocate for other people. I want to get to that point. But it is hard.

I have a niece, who I tried to advocate for last year when she was—I mean, it's a very long story, and it's sad. It's sad, and it doesn't have a good ending, but I tried to advocate for my niece who was also in an abusive situation and still is, very sad. I tried to advocate for her and actually I think I did a good—it was good that I had to go through something similar myself and to live in a

town for such a long time where I knew who, you know where the resources were to be able to try to advocate for her. But it was—oh my gosh, it took so much energy, more energy than I had. I mean, it is so exhausting to try to help a woman who's in trouble because you have to be everything to them—you have to be their therapist, nurse or doctor, the police person, their first responder. You are their first responder—I was doing all of it but I don't get paid and it's my family member. A lot of people are like that, because when women are in trouble, they're not going to go to the police because they don't get help there. So usually they're going to go to their family members. Or, I guess friends. Anyways, I want to be able to advocate for other people. But currently I just do it for myself and I'm just learning skills. I hope that I'll be able to use them again sometime in the future.

[00:23:08]

YIU: Yes. You've mentioned now—I'm sorry, there's a garbage disposal truck that just drove over so you might hear some noise. And that if you can't hear me clearly, please let me know. I wanted to ask you more about this—you have mentioned several times now, the structural access issues because of gender, because of class, as you said. These multiple layered experiences because you were a disabled woman of color whom is poor, so I wanted to ask you more about this very specific experience and how you navigate that.

WILLIAMS: Well, I mean—I don't know, I've done a really good job. My mom used to say, "You should write a book about how to live well, when you're poor" and it would make me laugh. I think people would really read that. And I'm proud of myself. I have set up a really good life for myself even though I'm poor and disabled, and a woman of color living in a predominantly white state. I'm sorry to say it—there are a lot of good things about Vermont but if you look at the population specifics, it is tough to be here and to be a person of color, let alone a woman, so I've done a really, really good job. I'm really proud of myself.

I mean, especially with housing, I did a really good job. Despite the fact that like neighbors ...have a lot of mental illness, I have a beautiful apartment, it is beautiful. And like, there is an art school downstairs. And so, I have a relationship with those people. I spent a lot of time working at the (inaudible) still. And I just made a lot of really great connections. And, it's because—I may be poor, but I'm educated which I'm really proud of. I'm a very educated person. I was like the second person in my family to go to college. And I mean, you talk about my birth family, they don't even go past eighth grade because there is no school where they live in El Salvador. I've been very proud, and my older sister has been such a hero to me. She was also very disciplined, even more than me. I've done so well for myself as a poor person.

And I don't actually feel poor---don't actually feel poor and that's huge. Because I felt poor in the past. But I don't—I know that I am seen as poor, because I can feel the condescension sometimes in certain groups. But I don't feel poor and that is a huge triumph. Because it breaks you down if you feel poor all the time. But I have what I feel that I need. I have food in my fridge; I have enough to eat. I have actually a beautiful place to live. It's really beautiful: there is a balcony and a huge yard and a Victorian house, and two bedrooms. I mean, I've done really well for myself. And part of that is education but a lot of it is also just because I'm a friendly person. And I'm honest and genuine. Right now, people appreciate that. So, yeah I think--

[00:27:06]

YIU: That's beautiful, because I think what you really managed to highlight is that this is not just the knowledge in terms of, obviously you're extremely smart in terms of how you're educated, but also, this knowledge of survival that you have managed to accumulate over time, including how to self-advocate for yourself in terms of housing or medical access. Yeah, so now I want to kind of move towards talking about more, revisiting—earlier you mentioned that a lot of people don't know what EMS is, which is I'm guessing, electromagnetic field sensitivity.

WILLIAMS: Yes.

YIU: Can you talk more about your experience with EMS?

WILLIAMS: Oh my gosh, it makes me very, very ill. And I feel guilty because the whole world is online. And all I can do is have this little phone and it makes me sick for the entire time that I'm on it. And I remember when I first got this phone. It was brand new, but when it was brand new, it was off-gassing, and I was on it for like, five or six hours because I was so enthralled by it. I thought, "Oh my goodness, I have everything at my fingertip, internet, email, calling friends, this is great!" I remember thinking I was like wild. I was like, "I love this." And then I got very sick. That night, I got so sick, I was throwing up. I couldn't keep anything in. I was laid on the floor for, oh my gosh, a long time. I think I passed out for a few minutes. I started to sweat. I had this feeling of like toxicity going throughout my entire body. And I was shaking and sweating and, oh my god, it was terrible. I felt so sick. And I knew it was because I had been on the phone for too long. I wasn't going to call an ambulance or anything, but I just had to get through it.

But because this is—and this is what's so terrible like it's so troubling because I can get so ill from something like a phone, but people use their phones all the time, and they're on their computers all the time. I mean, they're on it all day long and I can't even wrap my brain around how you can do that and still stay healthy. I mean, I have acute illness if I spend too much time on the phone, and I see people are just on their devices all the time. And there's so little research on how it affects people's bodies. All these devices—they have all these chemicals and minerals in them, and rare earth or whatever they're called, that are like not supposed to be on our fingertips, in our skin, going into our bloodstream. And I do believe that they cause things like diabetes and cancer. But there's no way that industry is going to ever be accountable for those—to that. And it's just the beginning of just an explosion: you're interconnected to this through electronic devices. So I feel like anathema sometimes, and I feel pretty misunderstood.

[00:30:39]

But yeah, I become acutely sick, and I can't have internet because I can't have a router in my apartment. Nobody understands that if I tell them over and over again. They'll just automatically say, "Please join in this meeting" or this or that, and I have to tell them over and over again, I don't have internet; I can't have a router in the apartment. If I bring a router in the apartment, I get completely disoriented and confused. And I can't think straight; I can't make any decisions. I start having numbness in all of my limbs and my arms and my legs. And my throat starts to swell

up and my tongue starts to swell up and I start to taste chemicals in my mouth and I can't—I start to feel as if I'm about to pass out. It's terrible. I have no protection against electromagnetic waves or whatever they are. They just go straight into my neurological system. I don't know why, but that's just the way it is. So I can't have a router. I tried to get a cable box in here, the same thing happens. I tried it.

I don't know what it is but I know our bodies are made of chemicals and also made of electricity. It's kinda crazy to think that you wouldn't have a reaction or that it's not affecting your body. Like, I know I've only had MCS for like twelve years now but (inaudible) and how people can't understand how they'd be affected, or their bodies are affected just because they can't feel it. I don't—but they do. I talked to my sister a couple days ago and she's a teacher, and she's on Zoom all day now because she has to teach now online, and she's getting headaches. She's getting migraines. She got a migraine couple days ago; she's getting chronic headaches. Her eyes are bothering her. The same is happening to her husband. It's too much computer, it's not healthy. I'm not the only one having problems. But myself and other people have enough sensitivity—we feel it much more acutely and immediately.

YIU: I think something that's really illuminating that you brought up in both this interview and the last is actually how this COVID pandemic have made a lot of people think that our lives are now exceptional because we have to stay home a lot. We have to connect to people in different ways where we can't be in person, but you have commented on that and said, in fact, it hasn't really changed your life that much because you have to stay at home. So can you talk more about the combined experience of having EMS and MCS and how COVID may or may not have changed your life?

[00:33:41]

WILLIAMS: Yeah, COVID-19 hasn't affected me. It hasn't affected me in a dramatic way. I think, as dramatically as other people because, like I said, I've spent years bedridden and isolated and had no one to help me. Nobody, no friends, no doctors. Nobody could do anything for me. And when you're in pain like that for so many years, five years straight, doing nothing but crossing the street and going to the grocery store and then coming home—I don't know how I survived. But there was nobody to help me at all. Friends don't really want to hear every day, how much pain you're in. It starts to be—if they're not experiencing it, and they don't have any empathy. So, yeah, I've gone through years of being very, very isolated and having just the barest minimum of like, social interactions. And it always comes down to my oldest sister, she's always been there for me, it's our relationship. She's always been the one who helped. And also my mother. But anyway, yeah, so COVID-19 is not changing my life dramatically.

Although I am suffering because I'm not seeing anybody and because I have EMF sensitivity, I can't go online and talk to people and see people on screen. But then that doesn't really do it for me. It's really not the same. I feel kind of offended—or maybe offended is not the right word—but I think people are starting to use the term physical distancing, as opposed to social distancing. But I still feel it's social distancing between (inaudible). For example, I have family in El Salvador. And sometimes, once a year, about once a year, I Skype with them. I can't go

there, I can't travel because of my MCS, so we Skype once a year. It's not the same thing. It's not the same thing.

My (biological) mother came here and we had a reunion in 2015. And she was here for two weeks. It was amazing. And I can't put it into words but to actually have your mother that you haven't seen, I hadn't seen her in thirty five years—and I thought she had died—so to actually have that human contact, to hug her. She held me for weeks. All she wanted to do was to hold me; I was just a baby when she left. So it is not the same. It's not the same to be on a computer looking at a computer screen. That will never measure up to being with people and sharing space with them energetically and physically. It is social distancing, to me, that's happening right now during COVID. It's not just physical distancing; it's social distancing. It's going to change us in ways I think that we haven't even really thought about. It seems temporary, but I don't think it really is. I think it's really going to have a lot of reverberations—it's gonna affect the social stratosphere somehow even after it ends and who knows when it's going to end, until they make a vaccine. I'm going to be pretty scared about that, because I'm immuno-compromised. It's a whole new landscape for me. It feels like when people start going outside again, things have changed, I think, for us—I don't know, I think a lot has changed. It's not going to go back to whatever normal people are thinking or hoping.

[00:37:05]

YIU: Yeah, I think in your pre-interview, you also mentioned that you're trying to write a memoir about this, this memory of reuniting with your birth family. And also in the same paragraph, you wrote about how, your journey in life is to heal. So, in thinking through maybe some of our final questions I wanted to ask you, what does your journey of healing look like and how have you been carrying out that journey of healing?

WILLIAMS: Well, I've done a lot of healing. My whole life has been like a healing journey. I have an older sister that we were adopted together, but it's interesting how different our journeys have been. She's a much different person than me; like she has actually—on the surface, it looks like she's done a lot better than me because she married someone and she has two children and she has a full time job and she's this kind of a superwoman, like most women are.

But then I'm very different. I've always been one of those highly sensitive people. So, like, I feel the world, and feeling the world is very dangerous to somebody who lives in a war zone. So, I have decades more—I will never be fully healed from the things that I witnessed or experienced in the war and separation from my birth family, but I've done a very good job. I'm artistic and creative, and I'm a writer, so I need to express them that way. And a lot of it's been just really personal and I haven't had the courage or the confidence to share myself with the community in ways that I wish that I could. But I am not done yet. I'm only forty-two, I (inaudible). So I got some help. But again, I've done a really good job. And my life was pretty—it's stable. And that is a lot. That's a really big accomplishment, not that my life was ever unstable due to like my own self. Yeah, my life is pretty stable.

But in the future, yes, I would like to be able to share myself more, and my experience more with other people even more than just writing a memoir, because if I put my memoir out there, those

are words and some people are very affected by words, i.e. me, because I'm a writer, so I'm very affected by some of the memoirs that I've read. But I would like to have more of a public presence someday and be able to get up on feet and talk to people. Because my writing self is one thing, it's a very personal thing with my writing self—very confessional and personal. But then, I wouldn't necessarily be out in public talking about that because I would be embarrassed or feel like I don't deserve to have my voice heard. So I would like to move beyond the feeling of not being good enough to be in front of people and to be heard.

[00:40:39]

And so, someday I would like to have more of a voice and be able to use my voice in community and have deeper friendships with people who can empathize. Like other people with physical disability because right now in my life, I don't have a lot of them. My friends are very, like... cheerful people with lots of energy. But they're not physically disabled. And then I have a group of people that I see sometimes at this place called the Inclusion Center. Those are physically disabled people as in in-wheelchairs, and other things that are very visible. And I don't—I am glad for that community, but I can't relate to that community either as much because I'm somewhere between.

As I said, if you see me in person, I have a lot of energy. I think, I'm pretty like, I don't want to say charismatic, but I'm somebody with—I don't look like I'm unhealthy; you can't really see my disability. So, it's hard to like be, yeah, I live with Lyme disease or like MCS. I'd like to bring more of me out into the world and actually have a physical ability to do that, because it is hard for me to be in public places. People are wearing things, there's new carpeting on the floor, there's apples on the street, maybe there's like a new painting in the building. I have a very hard time being in public places because of all the chemicals. And I want to be—I want to heal from that someday. Yeah, so it's a lot to heal from. It's a lot and it's all connected. It's not like, “Oh, there's MCS here on one end of my life, and then here's the, PTSD over here.” These things are connected, like my body has felt a lot of stress throughout my entire life. And I mean, from in utero—my mother didn't have enough to eat. She was terrified, my birth mother. So my whole life has been like this struggle, and it's changed me, it's created me like this. Yeah, my whole life is about healing. And I will always be doing it and someday I'd like to be able to, like, live my life purpose, which is really to love and be loved, you know? Have really deeper, like intimate friendships and more connection in the community and yeah, things like that.

[00:43:26]

YIU: Yeah, I mean, you've mentioned you're a very creative person and that you write but other than writing, what other creative outlets do you use to cope with your current life?

WILLIAMS: So writing a book, I'd love to do more of but I can't because of my hands; (I'm) working on that. But I love to sing. I absolutely love to sing. And I never really knew why. But then when I reunited with my birth family, my mother told me that my father sang. He sang in church; that was one of the things he was known for. And it was so wonderful to find that out because I--suddenly it was like connected, like, I have lineage, you know? I wasn't just this like person that all of a sudden existed once I came to America. Finding out little things like that after

I reunited with my birth family that like, oh, my goodness, my love for singing and my ability to sing comes from this man who gave me this voice—it was amazing. So yes, I love to sing. And I love to dance. I love dancing. And I'm very good at it actually, despite my physical disabilities, which is another thing. Someday I'd really love to dance in public. And I don't mean—I would love to be able to perform someday. Because I think it's really special that like, I'm physically disabled, but kind of a reputable dancer. So yeah, those are things I love to do. And I'm just—I do things like yoga and I meditate. And those are also creative and artistic, somehow. So yeah, yeah, I have a lot of outlets, I do. I'm really fortunate actually that way.

YIU: Yeah, definitely dancing is a creative outlet that helps stretch your bodies in other ways. I'm trying to think of the name of this company, which hires dancers of varying abilities. But if I come up with it, I will definitely email you and let you know because that would be really great.

WILLIAMS: Thank you.

YIU: Sorry, I thought I heard something else. Yeah, earlier we were talking about your EMF and how the new rates of Zoom meetings as a form of socializing does not work well for you because of your EMF. So actually, one of the main things that caught up with most participants is that they have found folks with similar experience online. Having not have the ability to go online, such as going to Facebook and things like that, how do you—do you manage any relationships with folks who share your experiences or illness?

WILLIAMS: I'm on Facebook and Instagram so I do actually spend a lot of time on social media and it actually has not—it's not improved my life I have to say. Yeah, it's really not a good thing for me, but I do—like, I am part of this like group on Facebook. And we all have MCS and so there's posts up there and sometimes I put posts up there and people like communicate but not all of my stuff—I'm much better in person. I really don't feel comfortable with things that are online. Yeah, this new culture of like being online and doing everything online it just doesn't feel like real life to me. It doesn't feel like we're improving humanity by moving our lives online. That doesn't mean I'm like—I'm not a machine and I really value person-to-person contact and being in groups and congregating and like just the human experience—does not really look like it happens online for me. But I am, I am online somewhat.

[00:47:36]

YIU: So do you have any relationships with folks with MCS or those with Lyme or Lyme-induced arthritis on these groups?

WILLIAMS: Online or in person, there are not a lot of people that I know that have Lyme disease for one thing. Apparently, it's an epidemic and there's a lot of people here in Vermont who have it, but I haven't met anybody who has it. As long as I have, I have not met anybody. There seems to have been like a surge like ten years ago, I think, of Lyme disease. And a lot of people that have connected with them had it for ten years, but I've never met anybody in person who's had it for like, twenty-five years like I have. So there's still this belief in the culture that it's something that is easy to treat, and you will only have it for a few month or a few years, and then you'll recover. That has not been my experience. So over the years, I've met some people



with Lyme disease, but every one of us is different. And I've met a lot of people that—everybody I've met, every person with Lyme disease I've met here in Vermont, are healthy enough to work. So I haven't really met anybody who I can really relate to.

YIU: Has meeting people with at least some degrees of your experience been helpful?

WILLIAMS: So with the Lyme disease people, I have like one person that relates to me and I can relate to her and I like to see that she's doing well. She's an artist and she has her paintings and artwork in a local studio here. But otherwise, like I had gone to a group on Lyme disease, people with Lyme disease and it wasn't helpful at all. People were asking more—what's the word I'm looking for? Like they were, they were talking about, "Take your antibiotics, and you will get better." And they were all like, a lot of them were like, "I'm fine now; I was sick with Lyme disease for only a short amount of time and now I'm fine; I'm doing everything so don't lose hope." That didn't help me. Because I needed to be around people, I still need to be around people who have Lyme disease, and it's chronic, and we're trying to live the best life that we can. I wasn't helped by people who came in and said, "I've been lucky with antibiotics and now my life is fine again." That didn't seem real to me, that didn't seem relatable in any way.

[00:50:14]

And the people with the MCS, I'm only connected with people online, on that online forum for people with MCS. And I have to say, it's a difficult bunch. I'm not saying personally I have difficulties—I'm just saying MCS can make people very odd. Like, I have (inaudible), because they'd been so isolated out of necessity. I think a lot of people with MCS are very isolated and sometimes very antisocial. Because if you're like—I don't know, I don't know, but I've heard this from other people who don't have MCS who meet people with MCS, MCS people can be very odd sometimes. And I'm not one of them but I felt that, like I see that. And I think it has to do with like spending too many years alone. You forget how to relate to people. It's bad but I can see how that happens. So yeah, the MCS crew is a hard crew to even—we've never been together. I've been on this online forum for years now, and we have never been able to say, "Let's all go to the park together!" We've never had that—I've never had face to face with any of those people, so it is hard to connect, at all really, with people with MCS other than online.

And then people with EMF, like I have it but not so severely that I can't be on the phone with you for 45 minutes. There are people who are living in their cars. Sometimes there is this one person that checks in on Facebook every now and then, but it's terrible because she's always saying, "I have nowhere to go. I'm in my car, there's COVID, it's winter, can somebody please help me?" and nobody can ever help. It's a terrible, terrible—I don't know what to call it. Do you call it a disorder? Do you call it a disease? If it's a disease, it's just a disease of the modern world. It shouldn't be that word, disease. But anyhow, she struggled with it so much. She's constantly homeless, and no one can help her. I couldn't even tell her to come here because she would get sick by the (inaudible) in my apartment or whatever. So it's really hard.

There are also people that have EMF sensitivity and MCS that you never hear from, which is why I feel like I've got to talk more, because there are people living in their closet, or living in tents in the woods. And you never hear from them. They're not on social media. They're not even

going to the store. Yeah, when you're talking about how does COVID affect somebody with MCS, people that are much sicker than me, they're out there, but they have no one to help them. It's very sad.

YIU: Yeah.

WILLIAMS: So, yeah, the world is sort of like, moving because it feels like the world is moving and we're all lagging behind. And what about us? We can't come along on this ride of electronic revolution. But we should also be listened to because these things are causing us to be sick. Like I said, I have a friend who has cancer. She's my age. She's my age and she's so healthy. We live in Vermont, and we all eat like granola and organic food and we live in the woods. We're so healthy. How did it happen that these young women that I know get cancer? And I don't want to blame anybody or anything, but we are all on our devices. They're all on their devices constantly. So yeah, we have a different way of being in the world. And it's important for people to like know that there's people who have a different way of being in the world.

[00:54:06]

YIU: Most definitely. To wrap up this interview, I wanted to ask you, what are some steps that you believe could change our society, like contemporary relationships with chemicals right now?

WILLIAMS: I think we have a hell of a lot of reconciliation that we need to do with people of color in this country. And I can get pretty fiery about this. But that's people that are dying, people of color. We're usually concentrated in more poverty-ridden areas and in more urban areas where so much of the pollution is. The rates of like asthma and heart disease and diabetes much more so in like Native American cultures, Black people, brown people like me. We need to like humanize people of color and women, I think, because those are communities that are not being reviewed at the doctor's office, at the social services offices and housing offices. If you listen to those people, they're going to hear sicknesses and talk about pollution in their community. People of color and women, we need to be listened to, we need much more of a voice. Because, for instance, women are raising children, and they know what's going on with their children's health, with their own health. So yeah, it's about listening to certain populations that are very silenced in this country. I mean, the Native Americans, I mean, like they're constantly on the lines, on the frontlines standing up for things like water rights. And, they get met with bullets and water hoses. Yeah, there's a lot of violence in the country, dehumanization. So listening to people of color and women. We need less of a consumer society, for sure. I live in a very local life, which I think is very, like—I prefer it because I know where everything comes from. I go to farm stand to get food or I go to a local cooperative market. We're always trying to buy locally, so I know where everything comes from. I'm not trying to continue the enslavement of people like my brother who works on coffee plantations in El Salvador. I tend to know where my food is coming from. I buy only secondhand clothing, because not only does new clothing make me ill, but also because I'm less of a—I don't want to like trade in anymore of these things. I'm trying to reuse and recycle and live locally, and all those things. And I know that not everybody can do that, but some of us can. And that's the life that I'm leading now.

But otherwise, I'd like to move to the city again at some point. And actually soon, I'd like to live in the city again soon, but I might get really sad. I'm not sure. I don't know—I haven't found balance between meeting the community again, like a community that I can relate to, people of color, but then also not wanting to get sickened by living in a city where there's going to be all kinds of EMF everywhere that would only make me ill, so I don't know. Yeah, because I have these two experiences of, like, I grew up in the city, but moved into the country because it was out of necessity. So I'm not in the know when it comes to “How can the urban society become less toxic?” I'm not sure if I can talk about that because my experience is that I live in a small town. And yeah, I live locally, and pretty close to nature.

[00:58:30]

YIU: Right. Thank you so much for our interview. I wanted to ask one final question because what you've just talked to me about—as you said earlier, these things are connected, they cannot be separated from one another, whether it's the consumer culture or the ways in which you are demanding reconciliation, so can you end by telling me more about these interconnections that you have observed?

WILLIAMS: I'm not sure, I'm not sure. I come from—the only things that come to mind is that like, there are things in my life that I don't know if there'll ever be an answer, or reparations or reconciliation, and that's my experience. For instance, you know I was adopted and that I reunited with my birth family in 2015, but I can't change their lives. So this is like a tie that I have; I have this very strong attachment to my birth family, and they're desperately poor. So everything that I left, that I was supposedly rescued from, it's still there: they are still dirt poor. They don't have any medical facilities, they don't have any infrastructure, they don't have an education. It's still a war-like society. I've always struggled because I thought how can I possibly help them? Like, how can I bridge my life with theirs in a way that isn't like--isn't condescending? Or how can I just—I have these two realities in my life and how could I ever help them? And how could-- how can their country ever be helped? How can we get everybody who's in that same situation, almost everybody in that country-- and it has to do with our politics and our consumer culture here in the United States and other larger, more powerful countries. So that's on that level. And with that issue, I feel powerless. I don't know how to help them. I can't change their system. What I could do was reunite with them. That's what I could do. Like I helped us to heal on that level. And that means a ton because they can live without money. They do the best they can without money, without enough food, without medications, without education, without all of those basic things that they fought in a war for. But without love it's nothing, like love is like the most important thing. So I feel like I did the best that I could, and let my mother know we're still alive. And I brought us back together again, that's like the best thing. I'm getting emotional. So, yeah, I mean, we can afford to be more compassionate in the world. That's like the most important of all.

[01:01:33]

YIU: Wow, thank you for that. I can't wait to read your biography. I can already see it coming, just even thinking about the multiple things that you have discussed, including community, love, mutual care and support and compassion for this world. So thank you for giving me much to

think about, Isabel. Is there anything that I haven't asked that you would like to add for the record?

WILLIAMS: I don't think so. I don't have anything right now. But it seems like it's been a really good interview.

YIU: It really was, at least for me. Thank you for your patience and for narrating your story with such clarity and critical engagement of the world. It's much more than I can ever ask for. So thank you again for your time. Do you have any questions about what happens after this?

WILLIAMS: That's a good question, but I don't—yeah, I don't have anything right now. But I can think about it.

YIU: Okay yeah, please contact me. Yeah, please contact me if you have any questions. You have my email. I definitely will send you, in mail, a legal agreement form which we need a hand signature so it will be in the self-sticking envelope and we'll also honor the fragrance free policy that our Center has. Once you receive it, that there should be a stamp inside, in which you can then mail it back to us. And if and when you receive that legal agreement and you have any questions about that, you can certainly contact me as well.

WILLIAMS: Okay, sounds good. Great.

YIU: Okay. Perfect. Thank you so much for your time. And if you have any questions, please just let me know.

WILLIAMS: Okay. Thank you. Thank you for your time.

[01:03:43] (End of April 20, 2020 interview)