

## Oral History with Sossity Chiricuzio

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Interview with Sossity Chiricuzio  
SESSION 1 (4/19/2019)

[00:00:00]

BLOOM: It's April 19th, and this is Molly Bloom, conducting an oral history over the phone with Sossity Chiricuzio. Sossity, can you tell me where and when you were born?

CHIRICUZIO: I was born in 1970, and grew up mostly in Arizona, but five years in Florida, in very poor and working-class neighborhoods, and I feel like that probably has something to do with my health in general. Especially in Florida, they would spray the entire apartment blocks with poison for bugs. They had mosquito fog trucks going around at dusk and, my mother kept us in. But there were other kids that were out dancing around in it because people just didn't really have an awareness of the level of toxicity, or that poison for bugs does not mean not poison for people. You know, there's a lot of ways I feel like industry in America has just overused chemicals, for cleaning, for poisoning, for whatever word they would use for that pesticide, or for crops in the cities or what have you. But my mother also frequently cleaned houses for a living, which I also helped with, and the chemicals you used for that—there was also a lot of exposure in various ways to chemicals, which I think contributed to it. But actually, women in my family have had a chemical sensitivity, specifically to scents, colognes and perfumes, and cleaning products. Not essential oils, but chemical scents, back to at least my grandmother, and it was sort of a mid-twenties onset for just about all of them. And I'm not entirely sure what that means, as far as that it was true for all of us. Like, is there a genetic component to it as well or is it just that we've been working-class women for generations? It's hard to say what the specific cause was especially because it was probably a combination of things. Let's see, before I go on, do you have any questions about any of that?

BLOOM: Yeah, you said you were born in Arizona, is that correct?

CHIRICUZIO: Yes, yes.

BLOOM: Okay, when were you born?

CHIRICUZIO: Nineteen seventy.

BLOOM: Okay great. Yeah, and I also just want to get a sense of your childhood. What was your house like, maybe when you were young and then as you moved, and what was your relationship with your parents or siblings or any family members that were around?

[00:03:04]

CHIRICUZIO: Sure! Unconventional would be the basic answer to all of those things. My mother was just seventeen when she had me and was definitely a flower child. In all the best senses of the word, by which I mean really questioning the status quo, and questioning how things are supposed to be. So, I actually grew up in a wide variety of houses and an ashram or two. I believe there was a school bus somewhere along the way. All very safe, but definitely unconventional, frequently groups of people, so there was a lot of shared childcare. Several times—I was mostly raised by my mother, but also my grandmother and my aunt. My uncle—there was our extended family that way, often lived near, if not with, each other. And then other small family groups would frequently get multiple apartments in one complex for example, and that made it easier to share resources and to share childcare and things like that. Always rentals, with one exception. We always lived in rental units, so it's really hard to say what condition the place is in, in terms of, lead paint, or asbestos, or any number of things like that. It was usually older houses, really close-knit family. Great relationship with my family, then and now, lots of involvement in each other's learning process. I'm the oldest, and my parents both worked swing shift, so it was frequently me and the other kids after school. So we were, you know, we were probably even more a unit than other siblings might be because we were all looking out for each other.

And we lived in a lot of low-income housing. Which comes with all sorts of things. Like I said, lead paint and various things like that, you just don't know what you're dealing with really. We did own one house for a period of a couple of years in Florida, but it had been—someone had done a very cosmetic upgrade on it. By which I mean, after a couple of years there was a hole in the bathroom floor that you could see down to the outside through, and lots of peeling of paint, and things like that. So, my parents were as careful as they could be to keep an eye out for environmental things. But when you don't have a lot of money, and you have a large family, sometimes you have to take what you can get when it comes to housing. I'm not sure if I'm covering the basis that you're looking for with this.

BLOOM: Absolutely. I do have a follow up question. Because you mentioned that, in your pre-interview, you mentioned that the women in your family have this sensitivity. So, how was illness or sensitivity to chemicals perceived in your family? Was it accepted? Not accepted?

[00:06:38]

CHIRICUZIO: Oh yeah, I mean to people's sensitivity I would say, you know, pretty much we didn't wear cologne or perfume. We were really mindful about the smells that we brought into the house. Lots of, like I said, flower children, so we were already inclined towards the baking soda, vinegar cleaning product route. Being aware that if you were wearing perfume and you hugged grandma, she would get sick for the rest of the day. That was part of the understanding in the family, paying attention to those things. And it was tricky because we also all really loved

scents, like incense and potpourri and things like that. (Those) are things that we really loved in that hedonistic, nesting sort of way, but a lot of it would make us sick, so we had to be really careful about that. So I think we probably had more of an awareness about things that you could burn, like incense, that wouldn't make people sick, kind of a thing. Or how to clean with vinegar instead of Lysol, because you could make someone sick. So, and it was kind of an adult onset thing for all of them, and they are all very close in age, so like I said, my mother was seventeen when she had me, her mother was twenty when she had her. Most of our lives that we spent together, that was something that was an issue and something we were all very careful about. Letting our friends know about bringing stinky things into the house, or if people were wearing a lot of cologne, giving them the heads up about not hugging people it would be an issue for. These were very normal things at our house.

BLOOM: And when did you first show signs of multiple chemical sensitivity (MCS)?

CHIRICUZIO: I started noticing it in my, I would say in my mid to late twenties. And I had already been aware of it, like I said, as an issue for other people. So there were things that I could do at home, like burn incense, that I couldn't do in a shared space, but I started to notice it was affecting me too. And so then I became very careful about only (using) essential oils, and natural things like that. But then something that wouldn't bother me, like a lump of raw amber, it would be fine for me, but would actually make my mother sick. Like something, increased sensitivity for her. So, at a certain point I just stopped. There's almost no scent in my house at all. Because if perfume is going to make me sick and essential oil is going to make someone else sick, I want to have the awareness for other people that I'm asking them to have for me. So our households generally, and generationally, have been really free of things like Febreze, or air fresheners, or perfume, or scented dish soap. Lots of those things that people just don't think of when you tell them that you're sensitive to things, people don't necessarily think of all of the things that have a chemical in them, which is most of the things that were sold. Which doesn't seem to be lessening (in) any way, as I've (seen) through the years, like household products, even the ones that are now marked unscented. They don't actually mean there's no chemicals in them. They mean there's a chemical in them to block its smelling like anything, but it's still a chemical, and it still sets me off, so I feel like it's actually gotten harder as I've gotten older. The world has gotten more poisonous in that way.

[00:10:32]

BLOOM: Right, and in your mid to late twenties when you first started to get these signs of multiple sensitivities, can you sort of provide a context for your life? What did it look like, what were you doing? What did it feel like when you first noticed those sensitivities?

CHIRICUZIO: Yes, definitely. For me, it mostly results in a migraine. So it became evident pretty quickly and it would affect my entire day. So, the incentive to figure it out and work around it was pretty high. It looked at first like me clearing my own space of anything that would set me off, and then having to start to figure out how to have those conversations with coworkers, with employers, with friends, with partners about what I needed to not be sick. And I had my own business doing web and graphic design, so luckily since I worked from home I was able to avoid a lot of that in my day-to-day, but it also led to a lot of feelings of isolation. Anytime I go into a public space, I'm gambling. You know, any new person I meet, I have to give them the heads up so they don't hug me without knowing and now I'm stuck with their perfume on my face for the day. So it looked like a crash course in self-advocacy. It looked like a lot of educating people about the difference between essential oil and chemical scents. It looked like a lot of leaving spaces early, figuring out what were the most likely places that there'd be high concentration of a smell, like a movie theater or an elevator or a public bus, which is tricky because I, up until this last year, have been entirely on public transportation, so every time I leave the house, I'm going to run an obstacle course. And that was a lot harder to manage.

When I was younger, I didn't have the experience that I have now of advocating for myself, so it would sometimes look like getting sick because I didn't speak up for myself. Because for whatever reason of not feeling empowered in that situation or feeling intimidated in a situation or not having support. You know, lots of employers aren't interested in everything it takes to get a fragrance-free workplace, so I've had a lot of low-grade migraines in my life because I needed to go to work and pay rent. Yeah, I think it's something that most people don't even think about that much if it doesn't affect them.

BLOOM: And just, where were you living when all this sort of—

CHIRICUZIO: When it came on?

BLOOM: Yes.

[00:13:49]

CHIRICUZIO: Tucson, Arizona. I had graduated from the U of A (University of Arizona), and was living there and doing my graphic and web design business.

BLOOM: Okay. And how long did it take you to figure out that it was scents that were causing your migraines?

CHIRICUZIO: Not very long, since I knew historically that it had been an issue for other women in my family, it was pretty easy to put together like, "Oh it's that thing!" It's my turn. I

kind of knew that might happen at some point. So, once I started getting migraines in that way, it was pretty easy to put together, “Oh, I was burning incense and now I feel sick.” Or, “Oh I went to a friend’s house and they use a lot of Lysol and now I feel sick.” It wasn’t hard to figure out, because I had already had such a background in seeing that as a cause-and-effect situation.

BLOOM: And it wasn’t hard to figure out, how did you deal with it emotionally?

CHIRICUZIO: I was pretty bummed. I feel like my family of origin was a huge head start in many ways. Like, negotiating for myself was a skill I was taught as a child, which is not true for most of us, which made some things easier in this sense. I was cognizant of the fact that it’s my right and responsibility to take care of myself and negotiate for what I need. But you complicate that with matters like class and access and capitalism and patriarchy, and all the things that create the container that we’re actually living in. So figuring it out, and figuring out what to do about it, are two separate things. I figured it out pretty fast, but figuring out what to do about it and how to manage that on a day-to-day basis, has definitely been a long and ongoing process. Because people have to meet you partway. I can say, “I’m sensitive to scents, please don’t hug me if you’re wearing perfume. Please don’t bring scents into my house. Please let me know if the space you want to go to has a lot of scent.” But, until someone has actually seen the impact on me and sickness, they may or may not remember. They may or may not make that allowance. They may or may not let me know ahead of time. So it’s been, it’s a very isolating thing. To take the best care of myself, I have to avoid most people.

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BLOOM: When you first began to advocate for yourself, what toll did that take on your relationship? I’m asking toll because you mentioned it was isolating.

CHIRICUZIO: Yeah, I mean luckily my partners have been understanding. And they, of course, in that situation, you see really clearly the effect on somebody. And I’m slow to move in with someone, so they were well aware before we were sharing a house what I needed around that. So that way, that wasn’t too hard. With friends, it was a little harder, sometimes. Because scent is a really personal thing. It’s often cultural. It involves money. You know if you tell someone, this body product you use is making me sick, that could be shampoo or soap, lotion, face wash, hairspray, it could be a whole bunch of things that maybe they can or can’t afford to replace. Or can or can’t easily find replacements for. Especially when you’re dealing with people of color there’s already less availability of products. You know, there’s a lot of things that go into the scents that are on a person. So trying to have a sensitivity and an awareness around what I’m asking someone to do. If I ask them to not have a scent or wear chemicals around me, it’s not just about how it impacts me, but also how it impacts them, and how it impacts the space that we’re in. So, sometimes it’s gone well, sometimes it was really tricky. Sometimes it turned into a

compromise—I could hang out with someone, but I couldn't hug them. You know, we could hang out outside their house, but not inside their house.

I don't feel like people were—it wasn't that there was a lack of sympathy. It's that it's complicated to try to find a solution and what made it a solution for me was often a large compromise for someone else. You know, once you replace all of your cleaning products and all of your personal products and all of your things around the house you like the smell of—that's a huge ask. So I guess the answer would be, it has varied in many ways. I definitely recognize it as somebody agreeing to do a lot of work, and expend the energy and resources to meet me where they need to for me to be, safe and comfortable in their environment. Sometimes it's hard. Mostly people visit me at my house. I'm also allergic to animals, so it's just, you know it's very hard to find other places I can go and hang out and be comfortable. So mostly people come to me, so that has an impact too, I don't get to experience other friends' homes that often. That means they're the ones taking on the bulk of the responsibility for travel. It complicates things for sure.

BLOOM: Yeah. And what about work? So you mentioned that you were a graphic designer after you graduated from University of Arizona. What has your work life looked like from that point over the next few years?

[00:20:34]

CHIRICUZIO: Pretty variable. Being self-employed, while having a really strong work ethic around keeping my prices accessible, meant that I often had to have a part-time job to make up the difference. I've done a lot of food service. I did house cleaning, before college, but not so much after because of the chemicals. Food service is also hard. People are often wearing perfumes and things like that. So I transitioned to doing more counter service than table service. That way I at least had a counter's distance between myself and anybody I was interacting with. But it was still tricky; I would often end up with a low-grade migraine after a couple of days of work. From there, oh, let's see, that was kind of what I was doing when I was in Arizona.

I moved to Portland, Oregon, in 2004. And at that point I was still mostly self-employed, so it was much easier to manage in those moments, but I worked in a furniture store for two to three years. And customer service is definitely, definitely a gamble in that way. You've got to meet a lot of people; you've got to shake a lot of hands. You know, the store (was) owned by a small business owner who was sympathetic, but couldn't make it scent-free. So I would just have to, I'd wash my hands and face a lot. Stand near the open door when possible. Go for a walk when possible. Just to try to get some air that I could breathe comfortably. And then I hurt myself at that job. I've got some sort of arthritis type of situation I've had since I was eighteen, and it had (been) exacerbated with that kind of work. I had to try and find something else to do, and I ended

up at a chiropractor's office four days a week for a while with the injuries that I had sustained, and while I was there, recognized the need that they had for someone to manage their place and ended up getting hired there.

So I took a complete left turn into the healthcare field, which is something I had avoided for a long time. Most of the women in my family had worked in medical settings and, as you probably know, those are hugely full of chemicals and scents, so I just knew that would be a tricky place to try to work. But there was important work to be done, and advocating for myself had given me a really strong skillset in advocating for other people as well. So doing patient care and support through front desk work and through negotiating with various providers and things like that, made a lot of sense and really played to my skill set. I've also found pretty quickly that in that setting, there was more of a willingness to talk about chemical sensitivity and environmental factors in health and more of a willingness to address that. So that was the first place that I was able to make some leeway in terms of scented products. It was a wellness (business) so there were chiropractors, and massage therapists and acupuncturists and things like that. And some of them, they use candles, or there's high traffic areas, so there were Lysol wipes. You know, scented laundry detergent being used on the premises and things like that. But I was able to quickly negotiate and educate so that we moved to scent-free laundry detergents and vinegar wipes and, you know, no to the scented candles. Things like that. So, it was really refreshing and obviously much healthier for me, and I feel for other people too.

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It's one of those things that a lot of people don't really realize the impact chemicals are having on their health because it's not a huge impact—it's not something they can put their finger on and be like, "It's so strange that I have this headache that happens, or that I feel sick to my stomach this way or whatever, and it's this Glade plug-in in my office space." You know, like a lot of people. If you don't know that that's a possibility that that might be what's happening, and there's obviously not been a lot of public education about that. It's not something that people will always put together, they're just like, I don't know why I always get these headaches. Just leave that plug-in plugged in because our house is supposed to smell like fake cherries, that's how it works. Or clean smells like fake pine trees, we've bought into this, we've been sold this, and we've bought into this, and we don't have enough information to know to question it. But I find often once I start talking to people about these things and they make a change for me and then realize, "Oh, I haven't actually had that headache for a couple of weeks," or "I don't have that headache when I'm at work, but I'm starting to get headaches when I'm at home," you know. It kind of gives them a chance to observe and experience that impact for themselves. So I feel like some of us are super sensitive and so we are really aware of it because we have to be for survival. And other people are sensitive and don't realize it because they are never given a reason to think that might be an issue, you know? Why would you think that chemical smells



would be a problem when there's entire aisles in the grocery store that smell like that because that's what cleaning products smell like?

BLOOM: Right. And I think you already alluded to this, but did you find over the course of dealing with those multiple chemical sensitivities, did you find a community of other people with sensitivities and what does that community look like?

CHIRICUZIO: It's—I would say yes in the sense that I'm queer and that community is already inclined to share knowledge and resources and insights, and probably lots of communities are, but this is the lived experience I have. That we have to look out for ourselves, so we tend to share what we find and I feel a little more empowered to discuss my needs and findings in that community than the community at large. So, and I feel like there's also a disproportionate number of queer and trans folks living in poverty, doing jobs that other people don't want to do. Being really impacted by those economic factors that can lead to a lot of exposure, of work injuries or repetitive injuries, or just (being) overworked in general. But generally speaking, my community has had a lot of people dealing with various kinds of chronic illness and disability issues. So most of my personal close circle of friends, at this point, are very much a part of that. We are all dealing with various levels of health issues, you know. We understand that someone's going to need to be able to sit down. We are used to making sure wherever we're going to hang out can accommodate a wheelchair and scent stuff and various things like those. Those are very standard operating procedure in the community that I'm a part of.

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And a lot of that community is also electronic, sharing all our resources through social media, resources of awareness. So people learn something, they share it with someone else, they share it with someone else, and some people get together and they put together a resource guide and then we all share that with each other. There's a lot of information sharing of that sort, so I feel like our awareness of those issues is pretty high. For me and both the close circle of friends and the general, larger, often internet-based communities that I'm a part of as well. I don't belong to any specific Facebook groups, for example, "Folks with Chemical Sensitivities (sic)," mostly just because I do a lot of work online anyways. The work I'm doing for the organization I'm at now is operations and also marketing. So I'm online all the time, plus I'm a writer, so then I also live in front of the computer. So I don't tend to do a lot of group joining, because I'm already overwhelmed with the amount of time I'm spending on social media. But I know that they're out there, and it's really good to know that I could if I had a specific question or was feeling a particular need to be able to commiserate or brainstorm; those resources exist.

BLOOM: Can you talk about how you started the job that you do now, and sort of what the organization is, and what you do?

CHIRICUZIO: Yes, so, to do a quick timeline. So the chiropractor, the wellness center that I started doing that kind of work at, I was there for three and a half years as office manager. Which, class-wise, opened up some more doors to me in terms of job opportunities. Not having to do service work in quite the same way. And from there, I went to a queer- and trans-specific healthcare center for a year and a half. And did a very similar job there, office management, patient care. And then when I left that situation, I started with the organization I'm at now, which is ORCHWA, which stands for Oregon Community Health Workers Association. Community health workers are advocates from within a particular community. Usually they help with accessing services, with interpretation, translation, with going along with folks to doctors' appointments or doing in-house visits around health things, usually specifically physical health, but also mental health and social services. So this is work, as a queer person, it's already the kind of work I've been doing for decades, advocacy, and resource sharing, and you know, just being part of the system, though not officially, in many ways. CHW (Community Health Workers) bridges that even further and (I) can actually be paid for doing that work that really needs to be done and can really make a bridge between marginalized communities and the healthcare system. So it's really incredible work that I didn't know was a thing, even though it so much mirrored what I did in the world on a day-to-day basis, just as a matter of personal survival and community organizing. So I took on the operations and marketing role with them as a chance to share the skill sets that I have to support that work. I am hoping to actually do some formal CHW training myself and get more into the community work of that, but right now, just being part of a team that has that awareness in the healthcare industry is really important. It feels like really important work to do and also has turned out to be a group of people that has more compassion and awareness of health equity and accessibility than any place I'd ever worked before.

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I work most days from home because that's better for my chronic pain conditions. But they make sure, when I'm at work, (that) it's a fragrance-free environment. I have an ergonomic working situation. I have accommodations for being able to do what I need to do around said stuff. You know, if somebody comes in with a scent thing, then I just go ahead and go home and work for the day, so I don't end up with a migraine. Their awareness around it is singular. I have not had an experience like that working before. I didn't have to try so hard with them because they were like, "Oh yes, I've heard of that." You know they already had some knowledge of it with working with the healthcare systems and working with marginalized populations who are already dealing with a lot of environmental factors. Folks who are doing a lot of the so-called menial labor, house cleaning or cleaning in general, or farm work, or various jobs where you just, that's just the way it is, you know. Whether that's about fragrance or workload or the hours that you're working. So there's already a population that's been very affected by those kinds of environmental factors, which means that the people working with them have awareness of those

factors and the impacts that they have. Is that sort of? I'm talking around the topic, but I'm not sure if there's something more specific I could give you.

[00:35:36]

BLOOM: I think I would like to know how did you bring up the topic of fragrance-free, what were those initial conversations like?

CHIRICUZIO: Absolutely. They started with—so I'm sensitive to chemicals. I also, my body has a lot of special tricks, I'm also allergic to garlic and onions. Including when they are being cooked and when they are in the air, or when they're heated up and they're in the air. I have an asthmatic reaction to that. And the place that I work is very culturally mixed, and they used to have a lot of food potluck situations, where they'd order in a bunch of food, food that I wish I could eat, that I used to be able to eat, and I can't eat anymore. This allergy came on in my early thirties. That was a special decade. But, it came up pretty quickly, because we were having a meeting in a small room, and they had ordered food, and it was very garlicky, and I actually had to excuse myself from the room because I couldn't breathe. So I had to have a conversation pretty quickly with my supervisor about that. And, luckily her reaction wasn't, "That's ridiculous," or "I've never heard of that," or you know, "There's nothing we can do about that" or whatever. It was, "Oh, I'm really sorry to hear that, take care of yourself." And they stopped having potlucks at staff meetings, which was very sad, because it's such a beautiful thing to do to share food and to share culture. It's very hard for me, as white person, to ask for that and in that particular context as well. Like, when the impact of what I need is particularly taxing on people of color or communities of color. It's a hard—it's loaded. Just no matter what, it's a loaded thing. But I have to be honest about the impact, because otherwise what they have is an employee who's sick a lot and that could be prevented, so that I could stay productive and part of the team, and luckily they had the same feeling about that.

So, I had a conversation with my supervisor, and then had to go ahead and send out an email to my coworkers to just be like, here's what is the truth from me: If you're wearing perfume, please don't hug me. And by perfume, I mean also all these other things. If you're not sure if something's going to make me sick, look at the list of ingredients, and if it says fragrance or perfume anywhere in it, then it's poison for me. So people becoming aware of it, and that really made people start thinking about what they were using and looking at the list of ingredients and thinking about what that meant for themselves, as well as the impact it was having on me. And then, collectively, we decided that a fragrance-free policy was the way to go, not only for myself and another staff, another person who worked in the building who hadn't said anything much up to that point, but was definitely also being affected by chemical sensitivities. But also the best thing, as a healthcare organization, knowing that this is a healthcare issue, that the most equitable thing to do would be to make our office fragrance-free, so then we wrote it into policy. And it

happened pretty quickly, which was surprising and really unique in my lived experience. And I don't know how much of that is about the social justice equity lens of the organization and how much of it is the healthcare part of the organization, but I'm really grateful. And since we share a building with other healthcare-based organizations, we had to have a conversation with them as well, because it doesn't do us any good in a big open air space to have a fragrance-free policy, if the folks in the cubicles across the way don't as well. So, they all adopted that as well. So there were four different organizations, and now I think it's five in the new space we moved into—(there) are some of the same people and some different people—so it turned into a fragrance-free policy for up to five different organizations.

[00:40:04]

BLOOM: Wow, yeah that's impressive.

CHIRICUZIO: It's—yeah.

BLOOM: Yes. And, I'm curious about any other history you have with advocacy around multiple chemical sensitivities. If you can talk about that.

CHIRICUZIO: Yes, I mean I used to run an open mic for nine years, which was a once a month thing. A lot of community gathering there, and so we averaged one hundred to 150 people each time. So I had to let those folks know because as a host and the producer, people want to shake your hand; they want to hug you, and I'd have to be like, you know. Before I just had to, I constantly had to ask people, and make them aware of that and negotiate that. So that came up a lot, there's a lot of interaction around that. I also, in the last couple of years, have had increased number of doctor visits of various sorts that I have to do. And so when I call a new healthcare provider for the first time, I just have a list of questions that (I) go through. Are you queer and trans informed? Are you trauma informed? Do you have a fragrance-free policy? Do you have an understanding of what I'm asking for about that? If not, here's (a) further sublist of questions. Do you use these kinds of products? Do you have plug-ins, etc.? You know, do you have, sturdy chairs without arms? I, as a queer, fat, disabled person with chemical sensitivities and a background of trauma, I need to know that I can come in and be safe. I'm not going to spend my time and energy and spoons (metaphor used by people with a disability or chronic illness to describe the amount of mental and physical energy needed to complete a task) getting to your office and not get what I need. So before I even come in, here's the checklist. And how they respond to that, not only in the answers they give, but how they respond to that fact that I'm asking the questions at all, lets me know if that's a space I can go to. I'm very lucky that I live in a city this large that has that many options that I can do that. That's not true for a lot of people. You know, obviously there's privilege and access that goes along with being able to ask those questions. But at this point, most of my time and energy goes towards working or healthcare for

my own body. So there's not room for me to not do that level of advocacy, which is exhausting quite often, and people feel really challenged, and it definitely brings up stuff and I have a pretty recognizable name, so there's certainly people in the world who have an awareness of who I am and might be annoyed about some things about me, but I'm fine. I will go to a different place if it doesn't work.

[00:43:13]

I'm not trying to, it's not about rabble rousing. It's about education and advocacy. So if they can see that, and treat me with respect and help me get my needs met, great. I'm going to tell everyone about that. And if they can't, I'm going to tell people about that too. You know, because the more awareness there is of those issues, the more that other people will have an awareness that they can advocate for themselves as well. So, I do some instructing. I'm working on a workshop right now about self-advocacy and community care, so how to share resources and advocate for each other and for yourself. I'm putting together some workshop materials and hope to start teaching that in a very specific way, but right now, I'm just (teaching) by example and because it dovetails with the work I'm doing for ORCHWA, I'm able to share that information a lot and model that behavior a lot, which I'm trying to see as a good thing. Most of the time, it is. It's exhausting but it's also important, so.

BLOOM: Right. You know, there's two more major themes that I'd like to get this historical sense of. And they're both related to what you've been talking about so, I'll ask you first about the writing that you do. Can you tell me how and why you started writing?

CHIRICUZIO: Yes, because I am a bookworm. Started reading at a really—probably four—a really young age and saw really quickly that books were not only an escape option, which is something that I needed in some ways, but also a really great way to learn things different from my own lived experience and to have a wider understanding of the world and the people in it. So, the power of words was really appealing to me, and once I discovered poetry, I realized that it was a way to express myself that was really accessible. I think that's one of the beauties of poetry is that anybody could write it—it doesn't have to have the same issues with trying to access it that more formalized writing can have. The things that I write about are my lived experience, right? Because that's what I know. So, as I started writing poetry and sharing it and people would—things would resonate with them that led to conversations, which is encouraging to keep writing. Once I started doing open mic, I was consistently inspired to write because I needed something to share too. And then I'd started working on other types of writing, prose and things like that. I started teaching writing workshops, which really helped illustrate for me the power of being able to share that with other people, inspire that in other people, encourage that in other people. How much you can reach someone with the impact of a poem as opposed to just sharing an anecdote. The impact that words can have in a positive way.

[00:46:44]

And then I actually, there was a local queer paper here called *PQ Monthly*, and they put out a call for a new journalist, which is not anything I'd ever done before, but I love a new challenge—well, period—but when it comes to writing! And I started doing a column for them, like an opinion piece sort of a thing where I would just write an essay about something that I had observed somewhere else, intersecting my lived experience, because that's the most authentic thing I can speak to. But, talking about things like the disconnect of social media as an example, as well as the connection, or what does it mean to be nice in the world but in a way that doesn't challenge things that are problematic, or what is it like to be a grown person having to have housemates because we can't afford our own place anymore, or just topics that were coming up in conversation around me. And observations on that, and hearing back from people that it impacted them, and developed my skill as a writer. It's to the point that now, I mostly focus on things that are about disability and queer community and class and things that don't get talked about as much in the mainstream, and that I have some insights on. So for me it is art, but it's also advocacy and activism. Does it help to get the word out more about these types of things? So I have a piece, and because I have to go (get) involved in healthcare in so many ways personally and have also worked in the field, I have a lot of stories and insights about that as well, so just kind of focusing on outlets that will let me talk about these things that don't get as much coverage. That's the incentive in many ways.

BLOOM: And you've mentioned disability a few times. Is this something that you see as connected to your MCS?

CHIRICUZIO: I feel that it's part of, the idea of disability is that you—it's a tricky word but it's what we have to work with at the moment—is that there's a compromise of some sort in the ability of your body to do things that you want to do, or that you need to do, to get through the world. So chemical sensitivity falls right into that for me. It is something that hampers my ability to move through the world and get my needs met and get what I need because of the impact it has on my health. So for me, that to be someone that, because my disabilities include chemical sensitivity, include chronic pain, include immune disorder, include, you know, these are all things that are part of the disability that I work with. I don't know if everybody considers multiple chemical sensitivity to be a disability piece, but I don't know how it wouldn't fall within that realm. I consider a fragrance-free policy to be part of making your space accessible. If somebody says, their building is ADA (American with Disabilities Act), but they still use chemicals, I say that they're not ADA. That's the challenge that I have brought to more than a few places. It's great that you have a ramp and an accessible bathroom, absolutely those are important. But is it also a gender-neutral bathroom and are you cleaning it without chemical scents, because if not, you're only doing part of the job that you need to do.

[00:50:45]

BLOOM: Have you sought healthcare for multiple chemical sensitivities?

CHIRICUZIO: Do you mean am I seeing doctors and things?

BLOOM: Yeah.

CHIRICUZIO: I mean as far as I know, and as far as anyone has told me, I'm not sure there's anything anybody can do about those pieces. The food allergy, which overlaps with the chemical sensitivity, because there's an airborne element to it as well, cigarettes, onions and garlic in the air, scents, all of those are things that impact me and are overlapping, and the only thing that any medical provider has ever done around that for me is to give me an inhaler. So, if there are actually treatments out there for it, I would be interested, but I haven't. I mean, it seems, and I don't know everything, but it seems like given my focus, and given the amount of research and work that I do, I haven't run across anything that's like, "And here's a way that you cannot be made sick by chemicals in the room with you." You know, if you know of anything I would love to know—

BLOOM: —I don't know of anything, no.

CHIRICUZIO: —to look into. But I would really love to, I'm not surprised that you don't, and I would be very suspicious of something that was being counted as a cure for something like that, because the cure is to stop poisoning ourselves. That's like somebody saying their product is unscented because they found a chemical that masks the scent of the other chemicals. (added clarification by Chirucuzio: That's like someone saying their product is unscented because they added a chemical that masks the scent of the other chemicals.) That's not really a solution. I think that the only real solutions are being able to have more control over our environments, and being able to have a wider public education and awareness about how problematic all these heavily chemical products are for everybody's health.

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BLOOM: And I think that leads into the sort of wrap-up that I'd like to do, which is, if you're thinking about what's going to happen in the future, what would you like to see happen around multiple chemical sensitivities, say in the next fifty years.

CHIRICUZIO: I would love it if all of the products that currently contain chemicals were taken off the market or modified so they no longer contain chemicals. That would be one giant step

which of course, I know involves capitalism and all the reasons that's unlikely, unless we really shift our thinking about priorities. Because there's a lot of money invested in chemicals, and there's a lot of money invested in signature scents, and perfumes, and products that smell like X, Y, and Z. Like, the amount of, thought and cultural shift (added clarification from Chirucizio: shifts in our thinking, and cultural shifts) that would have to take place for that to happen is enormous. But, you know, global warming and everything else, we really have to change our thinking about lots of things if we're going to survive ourselves. So in my dream world, it would look like no chemical fragrances in anything anymore because they are unnecessary and they are harmful. It would look like putting our energy in resources to researching things that we did before all of that. Because, the high level of chemicals in our products is relatively new. This is not something, you know... people have cleaned their houses and their bodies for thousands of years without any of these things. We have the information, the resources exist to do that again. We just have to be willing to make that shift.

So I would like to see a shift in awareness and education around that, that leads to us collectively deciding to do better by ourselves. In the meantime, I would love to see chemical sensitivity be part of the criteria for a building or organization to be able to have ADA status. I would like to see fragrance-free policies as a general practice in any place that people need to gather on a day-to-day basis. And I would like to see more sensitivity and awareness around the impact it has on people and some willingness on the general population's part to make adjustments, even if they feel inconvenienced. Understanding, of course, that the pieces of class and culture that impact that—it's not a simple thing, it's pretty loaded. Everybody's relationship with scent is pretty intimate, so it's not an easy ask. And I don't think it should be a cavalier one-size-fits-all sort of solution, but we do need to start making a shift, because people with chemical sensitivity are going to become the rule instead of the exception that it seems like we are now.

[00:56:19]

BLOOM: Great, well thanks, that's given me so much to think about. And, I wonder, as we're just completing the interview, is there anything else that you want to talk about that you haven't had the chance to talk about yet?

CHIRICUZIO: I don't think so. I feel like we covered a lot of ground there. In the moment, I can't think of anything, but this was pretty, you had some very good questions, and I feel like we covered a lot of ground with that. It's much more likely I would think of something later today or tomorrow after I've had a chance to mull over everything we've talked about. And you might as well, I do welcome follow up questions if you have any, after the fact.

BLOOM: Wonderful. Great!



[00:57:08] (End of April 19, 2019 interview.)