

# Irina Yakubovskaya

Dec. 4 2020 • 1:09:31

## SUMMARY KEYWORDS

pandemic, people, feel, disability, life, disabled, russia, world, terms, absolutely, difficult, thought, person, job, boston, baffling, point, question, sense, understand

## SPEAKERS

Hannah Soyer, Irina Yakubovskaya

**Hannah Soyer** 00:00

Hi everyone, Today is December 4th 2020. My name is Hannah Soyer and I am going to be talking to Irina Yakubovskaya for the COVID disability archive. These oral histories are being recorded as a way to document the lived experiences of disabled, chronically ill, and neurodivergent individuals during the COVID-19 pandemic across the world. Okay, thank you so much for being here with me Irina. If you could start just by giving your name, age pronouns and where you live.

**Irina Yakubovskaya** 00:42

My name is Irina Yakubovskaya. And I'm 34 years old, my pronouns are she hers, They is also fine. And I live in Watertown, Massachusetts, currently, I reside in Watertown, Massachusetts.

**Hannah Soyer** 01:03

Thank you. And next, how do you identify? So do you identify as disabled, chronically ill, neurodivergent, etc. And then, on top of this, feel free to share any other identifiers that you would like to share as well.

**Irina Yakubovskaya** 01:22

So I don't particularly know, I'm still struggling with sort of putting myself on the spectrum of disability, because I, also I am chronically ill, I have chronic migraines, like super bad, chronic migraines, basically every day, and nobody knows why they happen and all that. But, but that was not, that's not my primary issue or disabling chronic condition, I guess. So I was born with limb differences. And that really affected my life from the very—literally from the very beginning. And then, but the—the thing about it is that it I am able to conceal my limb differences for not as much for as a choice, but just because it's physically, the only way I can like walk in more or less, healthy way, not healthy and silly. But I mean is to, to conceal my differences. Because if I don't like basically, I can't, I can't not wear shoes or some covering on my feet, because that would prevent me from moving basically. Right. So and, and but that puts me in an interesting sort of position where, for an untrained eye or for somebody who doesn't particularly pay attention, I may pass for them as an—as an able bodied person. But I still I am not. And then the other issue, I do have other medical conditions that were—that I was diagnosed

with throughout my life, just a gift that keeps on giving. And I don't know if they sort of put me in a disabled category or chronically ill category but yeah, I don't know. So, sorry, this is a very confusing answer. But that's the question I've been struggling—I'm sure I'm not alone with this, you know, struggling to kind of put myself in a—in a not everyone's in a block. But something like that, right? We're talking about how identify, I for myself, I know I am disabled. I know my experiences have been of a disabled person throughout my life in one way or another. But it doesn't mean that everybody I've ever crossed paths with have felt that they put me in that category.

**Hannah Soyer** 03:55

Okay, thank you. So we're going to go ahead and move into the meat of the interview, um, about your experience with the pandemic. So, when did you first learn about the pandemic? And what was your experience with that? So you know, specifically if you remember where you were, or specific emotions that you had when you first heard about this.

**Irina Yakubovskaya** 04:22

So I was working. Before the pandemic, I had multiple jobs, which was a big mistake. I was very tired. And one of my jobs was, I was working at a coffee shop in Harvard Square. So you know, Harvard is a very highly populated densely populated school, so to speak, and very various people come through and summer in February, I want to say of this year is we started getting the news, you know, in general from the television and whatnot about you know, there's this virus but we had so many tourists come through and In general, you know, living in a city like I live in Boston, essentially. So I commuted through public transit all the time. And gradually, I started seeing more people with more colds and symptoms that were questionable that I got sick. And I didn't know what I had. But it was early on. So I was like, we were still sort of figuring out and not realizing it was very, you know, dangerous. So like, I kept going to work. And I kept commuting, and like coughing and sneezing without having any severe symptoms. And I still don't know, to this day, if I actually had the early stages of COVID, or maybe it was just a cold, you know, because it was February in Boston. But in general, I remember I think the way I learned about the pandemic, really, and it like sunk in, you know, and kind of got to my mind that it was real, was when my jobs, both of them my teaching job, and my coffee shop jobs started closing down. So...and that's the way I reacted to it—was for the coffee shop job, I was really happy it was happening, not the pandemic, but the fact that they were closing, because it was turning out to be a dangerous situation for everybody involved. And then, for the teaching job, I felt I also felt sort of relieved that some kind of action was being taken, you know, to support people, or to prevent people from having to go to work in person, maybe. But I still think that the way that was handled in the US at least, was very chaotic, early on, especially when it was still moving out, right, but because people didn't really know how to proceed, and there was not a very drastic set of actions taken immediately. So there was a difference in responses too. All of that combined made me feel a little bit confused, and lost. And I felt like I had to rely on my own discretion and my own sort of common sense, I guess, right to, to, to make a judgment, whether to go outside or whether to go to work or refuse. So if that, hopefully that answers your question.

**Hannah Soyer** 07:09

Yeah, absolutely. Um, where do you teach?

**Irina Yakubovskaya** 07:13

I taught at Emerson College, which is located directly downtown Boston, like in the epicenter of all the people—extremely busy, very tight quarters, so to speak, like, all the buildings are tall, they're very, like, tiny elevators. Just like also, I had to take the bus and the train there. So all of that, because of the accessibility issue, like for me, like—I don't drive, so I had to rely on public transit. And that was, you know, dangerous. And to be honest, later on, or during the summer, they contacted me, and they said, Would you like to, so it's not funny, but it really kind of is. They were like, many professors will be teaching remotely, because they have their accommodations, but we are asking for, from our adjunct professors, which was me and many, many others to consider coming in to teach half of the classes in person because the way they did the schedule for the fall was like, a combination or something like that. So you would have half of the classes taught online, and then the second half of that particular course, would be taught in person. And so they basically were saying, Hey, would you like to come in, in person, to teach this other half of the class that the actual professors don't want? And I had to say no a bit, which nobody blames me for, because it was basically like, I don't want to put my life in danger by having to take the bus the train, and then walk through the busy town or city or whatever, of course, then just to get to work where it's going to be it I don't even have benefits there. It's like literally, super minimal payment. So it's not worth it in that sense. So yes.

**Hannah Soyer** 08:58

So were you...did you move to teach remotely?

**Irina Yakubovskaya** 09:02

Well, I don't have a job, technically, like, I have one student that I'm helping with, and doing like a directed study, independent study type of thing. But it's practically for free. And I've been unemployed officially since June. So.

**Hannah Soyer** 09:19

Okay, so how has your experience with the pandemic changed since the beginning? So how has it changed over the course of this?

**Irina Yakubovskaya** 09:33

In the beginning, I tried to find some sort of curious or interesting elements of this whole stay at home business, which was exciting for a little bit. Right. I remember having this sort of, wave of you know, all so much of my energy is now available more than usual available to me. Now that I don't have to get up at 4:30am and go to work and work an eight hour shift at a coffee shop? Well destroying my health completely, like I should not have been doing that job, to be honest, it was, was really a bad idea. But um, and then taking a train and going to teach two classes, and then coming home in the evening completely destroyed me. So that lifestyle was not sustainable, even before the pandemic. And when it kind of gradually ended, it was sort of a blessing in disguise in that sense. So I felt in the first several months of the pandemic, I felt like the energy opened up and became more available to me. So I started. And I had been already thinking about switching careers, because academic world is not really something I want to stay in, because also, it doesn't really have any much going on in terms of jobs, as you may know. So I had been already thinking about it. So the pandemic kind of prompted this pause for me, in which I took a second to reflect on what I... what I actually want to do. And if I even deserve

to be doing what I want to do, which is a big question always. And so I started doing more art, I started doing more creative things, I went back to painting more and to do more visual art. And then I focused on, sort of on my own professional development, and I allowed myself to take time and make a website for myself and work on different things and like, just practice things that I feel like I could be good at. And so that took several months, like during the first several months into the summer, I was very, almost not ecstatic, but you know, appreciative, rather, of the good that came out of this. And then, but that was also because I didn't know how long this was going to last. So I felt like, well, if it lasts all the way into winter, then it's terrible. But I kind of felt like maybe it was not going to happen. Well, big mistake. Here we are. And so I think gradually I went through the waves of you know, Oh, I'm so sad. I'm so sad. Because nothing like I can't find a job, nothing's happening. And then my health deteriorated further. In terms of my chronic pain and other issues, like they keep discovering some other medical conditions in me, like I said, the gift that keeps on giving. And so I had to... I had to go to several new doctors to see specialists, which you may imagine became very expensive. And like I said, I'm unemployed. So I basically had to, like, make these choices, you know, gradually, oh, but how do I—do I try and take care of my health as much as I can? Or? Or do I just let it go for now, because they literally don't have the resources to support that. You know, and so that's been quite difficult to choose between, like, what to how to decide. And but now at this point, honestly, I am in this position right now where I have not received my unemployment benefits in six weeks, because there was some kind of mistake on their side. And it's been just on hold. So I'm in a position where I just don't even know, like, what's going to happen next week, you know, I hope I'm not going to be on the street. I think I'm, I can rely on my partner to not let that happen. But it's still... it's becoming more and more nerve wracking to me in terms of, you know, how do I move on? Like, what—What, is he a little bit helpless in that regard, you know, but also to go back to the question of like, how changed? And I—do you realize that? Yes, the pandemic is absolutely terrifying, because it keeps happening. And of course, now I know more people who had the virus, especially overseas, because I'm from Russia, and over there, it's just the end of the world. And that's ...and so it's been very stressful on that side

### Irina Yakubovskaya 13:55

of my life, but I think now I'm just more real I really unrealized thing that I have to prioritize even better, what to take care of in terms of my everyday life. Like, do I take care of trying to eat something, you know, or because I'm so ill, I can't or the other day, actually, that maybe goes into your next question or one of the next questions, but it's an experience I think I should share. I had an appointment that I've been trying to get an appointment with—one with my headache specialists. And they basically are withholding my medication from me and refuse to prescribe it further until they see me in person. And I had to be on the phone with them for hours begging them to not do this. And I said, and I negotiated with them finally to take—to do like an online appointment with me because I said I physically cannot get there. I cannot walk there because it's quite far away. I cannot take the public transit because this is dangerous right now. To say like, what do you want me to do? And they're like, we just need your vitals and I'm like, I'm not gonna risk my life to get you my vitals. That's just not gonna happen. But how are we, you know, so I back to them. And I cried, you know, not intentionally, but I mean. So hopefully that worked out. So they were able to negotiate the online appointment with me, but I had to get my records from another doctor to send to them. So that you know, I mean, so all of that is a lot of management. But it's just so that day, when I found out that they wanted me to come in, in person, I was devastated. I thought, you know, how unfair it is that, that I have to basically beg for basic medical care that I

deserve. And I was terrified about how I was going to survive this week, because usually, when I have very bad headaches, which are happening more often than not nowadays, or in the normal world, I would just go to the ER, which I have done in the past, now, I can't even do that. So I... everyday, you know, I worry that I'm going to have this terrific, terrific headache that was going to just put me on the floor, and I'm going to be unable to do anything about it. And that is scary. So

**Hannah Soyer 16:04**

yeah, that's really scary. And yeah, there's someone that I interviewed two nights ago who was talking about, she called it decision fatigue, and just that, you know, draining the way that not knowing what to do, or trying to make sort of an impossible choice or an impossible decision throughout all of this has been really difficult for her. Yeah, that sounds very similar. Um, okay, so what has your experience been as someone who is disabled and who has these various health issues? What has your experience been as a disabled person and chronically ill person throughout the pandemic? I know you've already touched on this a little bit. But if you feel like expanding on that?

**Irina Yakubovskaya 17:07**

you know, weirdly enough, I feel like, I'm going to shift to a more positive year, I guess, maybe if I can, I don't even know if I can. But I think interestingly enough, I feel like this time has allowed me to come to terms with my disabled identity. Because I've been thinking about how throughout my life, I've had multiple careers, or career directions, and education, all that. So I've tried so many different things, professionally, and also moved. So from so far away, I changed my life so many times, and drastically, you know, started over. So I feel like, throughout all these changes in my life, the only part of my identity that has been constant has been my disability. And I finally... I'm 34. So it took me a while, but I'm finally—I feel like I'm really starting to embrace it. And I have been paying more attention, not just superficially before real to the disability discourse that goes on on social media in different channels, different groups, and I've been trying to participate, but not you know, too much, or to the extent that I'm comfortable basically. In other words, even a year ago, I don't think I would have reached out to you or report or responded to the, you know, the Twitter I think it was right, the question that was sent out, in just because I didn't feel like it was my place, or I didn't feel like I had a place in the community. And it's me, it's me, it's not the community, you know, and again, I'm sure that many people struggle with similar thoughts. But to me now, I still feel like I have obviously a lot to learn, a lot to embrace, a lot to negotiate sort of within myself. But the other element of that—my, my positionality as an immigrant, in this country, in the US has made it more difficult for me to openly claim disabled identity. Because it really scares me, especially with the still current administration, right? It really scares me to speak out because legally on paper, I'm not... I don't have a disability on paper, like I don't collect disability benefits for example, right? And that's because even when I still lived in Russia, which I did for 23 years of my life over there, everything is so corrupt—to get disability benefits my mother had to beg them every year to renew them and do some humiliating things. She never told me what but she said she stopped doing that because she just couldn't anymore. Just because the system is designed against people, period, right? So when I moved here I never even gave it a thought and then as a... as an immigrant, it's very, it's a very tricky sort of place to be in because you as a person who can conceal, so to speak, right or pass as able bodied as myself? Majority of the time, on paper? I don't—I feel like I have the privilege of not disclosing on paper when it comes to immigration papers or what have you, right, like applying for, for a green card and all that stuff, because especially now they have the public

charge rule, which is a total, just a travesty. It's terrible. Right. And so you always, even though you, I feel like in this country, we're somewhat people are in general, somewhat more protected by the law is hopefully, right. But at least there's a hope of that. I still feel like, I don't want to be in a situation where I give any, I give the wrong people, whoever is doing people who are going to govern any reason to claim some sort of non-existent. I don't know. jeopardizing element. I don't know, I don't have to explain this. Anyway, that was a very convoluted way of explaining that, up until very recently, actually, until the election, to be honest with you, like the day of the election, or, you know, the week of when it was pretty much clear that things went somewhat well, I felt like such a huge weight just dropped from my shoulders. Because I felt like, maybe there is hope for me that I can be more outspoken about who I am without constantly being terrified that I'm going to get a letter or something, you know, anyway, does that make sense?

**Hannah Soyer** 21:36

It does. Yeah, it does. What is the public charge rule?

**Irina Yakubovskaya** 21:42

it's a fun one. No. So the way I understand it—I'm not a legal expert of any kind—but the way I understand it is, especially this administration kind of changed a lot of immigration rules. And it became, at some point, part of the immigration process. You have to declare whether you think you will, at any point, become a public charge to this country. And I think it was literally like finalized and solidified somewhere, maybe like a year ago or two, I can't remember. But I felt, even though I already had my conditional green card, which is a green card you get if you get married, or through family. And then if they verify that your marriage is real, which, again, is another whole other process. But I remember going to the interview with my spouse, they interviewed separately, and they asked me a question, like, do you foresee yourself being a public charge? And I said, No, because I honestly don't. But it's, you know, I mean, I kept thinking, I don't ... they don't read me as a disabled or chronically ill person in this moment. And that is a privilege that I have, in this particular moment, because they don't question or don't jeopardize that, you know, my existence in that sense. Does that make sense? So I think, so I think for me, right? Like, I don't, I still don't know how that's going to affect me if I ever, you know, if my health deteriorates, if even further in the future, or should I say when it does, because, you know, not getting younger? It goes the other way. But I think, yeah, I'm just trying not to think about it as much anymore. But it used to really freak me out. Just because I, being from a paranoid country with well, the government is out to get you all the time. Right. I always felt like, oh, I need to be worrying... worrying about this. And none of the people I know, like people who – none of the people who are American, and who are able bodied, none of them understand what I mean. To be honest, they kind of don't quite, you know, don't quite get it. So.

**Hannah Soyer** 23:56

Yeah. So just to clarify, so I make sure I understand. Yes, public charge means like, if if you end up needing, like, assistance, health benefits from the government?

**Irina Yakubovskaya** 24:13

I think yes. But also, the way I understand it goes to basically say, in this particular case, like if you think you will be claiming disability benefits in the future, because at this point, this particular

administration framed it in a way that applies even to like food stamps, right, and stuff like that. So—but again, I don't know, I'm not a legal expert, but just the thought of it makes me terrified.

**Hannah Soyer** 24:38

absolutely, yeah. So it sounds like there's, um, it sounds like you've had this you know, you've caught you've, you've been able to come to terms with this specific part of your identity. And yeah, there's been always this like, background fear of one pointing out what Identity wouldn't mean, yeah, yeah. Okay. So how has your disability impacted how you have dealt with a pandemic?

**Irina Yakubovskaya** 25:10

Well, I mentioned already, I am unable to get places, like doctors offices and such. So when choosing a medical specialist, I always make sure that it's walkable, like, reasonably within like a mile or something, which is pretty hard to do. Because I really don't go outside at all. And I have, I definitely when I do go outside, for whatever reason, for longer than 20 minutes or something, for a really large distance, I really feel like there's... I feel in my body, you know, it feels like it hurts more, and all these different areas, which are, yeah, problematic, but also. So in that sense, it impacted my ability, my ability to access certain places, it impacted in terms of my, you know, mental health, I'm sure everybody can relate to that. I used to, whenever I felt blue or something—back in the day, when we could travel to a city that you live in, I would just, you know, take a train or a bus and go hang out in Boston, sit on a bench or something. I can no longer do that. And that has been a very tough, you know, tough experience for me, mentally, in terms of my headache, chronic pain thing. It's been really bizarre, because it... just like I said, it's completely unknown, the origin is unknown. And maybe it's alien, I'm not sure. That would explain so much. But it's been really difficult to sort of, because when it, when it gets very bad, and they have it almost every day, it's very much debilitating. I can't, I can't stand, I can't think, sometimes I get very nauseous. It's like the worst migraine symptoms all at once. And it's like, 110%, it's pretty bad. And I get, it affects my ability to apply for jobs, it affects my ability to, to do what I'm trying to do. Like I'm taking online classes, to learn graphic design, and to learn online marketing and some kind of applicable skills because I have a master's degree and I have a PhD, but it's not helping me right now. You know. So doing that kind of work, or even, I've done a lot of like service writing, like I've volunteered for the website where I write and, or I did this book review recently. And it's like, it takes a lot of effort for me to even look at the screen like when when I have a headache, let alone edit the text, right. So it impacted my ability to produce a coherent work period. It even affected my ability to produce art. Because I'm an artist, like it's my hobby. I do have an Etsy shop, but it's not my primary income. And in fact, you know, I do sell my paintings, but they're not—I'm not saying I'm a professional artist, but I've made, I've tried making paintings when I had headaches and I had to throw them away because it just, it just felt like I was twisting my my soul into something that came out of you know, tremendous pain. So it affected my... a lot of my experiences in all directions. The other thing is, oh, well, what did else did you say? My memories funny. I forgot I'm sorry. It'll come back to me.

**Hannah Soyer** 28:47

Oops I muted myself. Yeah. Um, yeah, I should have said this at the beginning. But you know, you can like not look at the—not look at the screen if that's better for you. Okay, you are okay.

**Irina Yakubovskaya** 29:01

I love your your pigtail. Those are adorable.

**Hannah Soyer** 29:05

Thank you! Um, so, yes. And also, I want to make sure I would love to get a link to your Etsy shop. That's cool.

**Hannah Soyer** 29:13

Thank you.

29:14

Yeah,

**Hannah Soyer** 29:14

I'll send to you. Yeah. Um, okay, so. So you mentioned that, you know, before all this started, you were able to, for example, like take public transit to Boston, downtown Boston, do these different things. So I just want to make sure I fully understand. So before the pandemic hit, you were able to get outside of your apartment more, right? Yes.

**Irina Yakubovskaya** 29:46

Okay. I also had to do that because my work was at Harvard Square. And it's like, there's a bus that goes from my house to Harvard Square, and then a train that I took from Harvard Square to Boston. And yeah, but that was like the last year or so. And before that I was at Tufts getting my PhD, which is in Medford. I don't know if you're familiar with this area, it doesn't matter. But it's basically all of that is pretty close by like a couple of miles away. But because of Boston's terrible public transit, it takes like an hour and a half to go five miles on a bus or whatever. But I used to do a lot more when I was still in graduate school. I used to do, like, I didn't have a lot of friends, or any really meaningful community of any kind. So I would just go hang out in Boston, even before I worked in Boston.

**Hannah Soyer** 30:34

Okay. Okay, so, um, what have your relationships with people been like throughout this? And have they changed in any ways?

**Irina Yakubovskaya** 30:48

People? What are those? I don't really have a lot of friends. Period. Before the pandemic, I was trying really hard, too hard to bond with my coffee shop crew. And despite the fact that we had like, 10 plus year difference, and all of them, most of them were, you know, much younger, and just really different mindset. And I tried to fit in so hard, it was pathetic. But there was a lot of, you know, social pressure that I kind of inflicted upon myself. I have kind of lost touch with most people from grad school, because my graduate school was not a pleasant experience in any way, big surprise. And I basically stayed in touch with one particular friend who's also an immigrant. And we've been, you know, texting more and phone calls, or Zoom calling, whatever, I have had multiple hangout sessions with my best friends from Colorado where I used to live. And we've done that—we had like a group text going since the pandemic started. So that's been very supportive. Sometimes it's just good to vent, or, you know, to send funny pictures to a group of friends who, you know, love you, no matter what. And I also, maybe

this is too personal, but you know, okay, there's no such thing I, I think my relationship with my spouse has improved, it was never bad in the first place. But prior to the pandemic, we were both extremely busy. And we would both come home—him, he would come home from his work, and I would call them from my works. And we would be just so completely exhausted. And just like, didn't have any time or energy to pay attention to anything, each other, we would hang out with a cat, obviously, the cat is very important. I would show the cat that she's sleeping somewhere, and I don't want to wake up the beast. But since the pandemic, we really bonded even more, me and my spouse, and we—it allowed us to have, you know, more profound conversations, sort of, to become more supportive of each other, in whatever shape or form. And I don't know, I think it even made our marriage stronger. Which is such a weird thing to say, I'm not really a monogamy, supportive person, or whatever. Like, it's not really sort of my mindset at all. But in general, I feel like Yeah, before the pandemic, my but my personal sort of played my, the way I felt like I was being part of a marriage just felt really chaotic, and is it as if I didn't process it well enough when it happened or something to me. And then now I feel like we've had a different type of because we got together when we were in graduate school, and everything was just a mess. And then, since the pandemic, we were able to kind of zoom in into our own relationship and find the spot where we feel both like we don't want to hang out with anybody, and we can't, so that's a good thing. And I do appreciate it that that I was able to open up more and be more authentic with my partner in regards to how I'm feeling like physically and emotionally and to be honest, this person, my spouse was the first person who even suggested that I incorporate my disability, my disabled identity into my life more because he always, you know, said he encouraged me to even present at a conference, specifically with a do a presentation focusing on disability and on my experience as a disabled person, so that that's been even better since the pandemic.

**Hannah Soyer** 34:54

Wow, yeah, that's really great. Um, so have you had to...have you had to like, distance yourself from people at all? Due to perhaps like, how different people are approaching the pandemic? Or would you say that that hasn't really changed?

**Irina Yakubovskaya** 35:24

Yes and no. So on one hand, in a physical space, the only people we are ever in proximity to are people who live in the same house, they have a different apartment, but in the same house, so they spend time in the basement quite a lot. And I spend time in the basement when I paint. So that's been in, we're not friends with them, I'll just leave it at that. And it's been a bit frustrating to, you know, have to wear a mask to go to my home basement, I got a face shield, just in case, like I want to make, like, I want to, like sanitize everything on my side of the basement, like, just in case, you know, so I basically have to take that I don't have to, but I choose to take those steps, you know, just to make sure that there is no more risk than necessary. So that physical distancing has been sort of annoying, but I'd rather do it than not, you know. And then to basically wear the mask at any point where I'm outside of my door, like whether it's on my porch or something like just I don't want to risk anybody's safety. And emotionally and socially I've been, like I said, I'm from Russia, originally. And I don't particularly talk to many people there anymore. I talked to my family there. But it's been difficult to see so many people over there, over the course of several months now, just completely disregard all the precautions and post these Instagram pictures as if nothing's happening. And then it was the funniest and the saddest, but also the funniest thing in a way of one one girl was telling me, we like talk all the time, or often

about art and making Arboretum and she was telling me how she didn't really respect any of the precautions and I was like, but this silly and she and she was like, well, everybody in my family had it. And most of my friends have it. So whatever. I'm like, Are you kidding? And then she got it? And she was like, oh, yeah, now I have it. And I'm like, and nobody in the doesn't bother anybody. Like are you just felt okay with it. And many people I know, have knowingly bro, broken protocol of it of all kinds, and basically disregarded all the precautions then got sick, are still sick. And they're kind of like, well, it is what it is. So that's been a bit difficult for me to process just because I just don't understand it. It's people I love and care about, you know, it's not some strangers that I could just yell at, you know, on Twitter or something. Now that I do that, I don't even do that. But it's just been baffling. That's the word. Because I did not understand, I just—I cannot understand. And so I guess in that sense, my distancing from them has been, you know, I had to make a choice, do I support them? Because I don't want them to like die? Or do I just ignore it? Because it's, they kind of brought it on themselves. You know what I mean? It's one thing when you get sick accidentally or something, but it's another thing when you've purposefully go out that way it masks and say the virus is not real, or whatever. And it's like, oh, anyway, so that's been difficult to reconcile. And in terms of proximity, or frequency of communication, I've been really, really communicating a lot with my parents with my mother who is in the United States, but she is like, on the phone with Russia 24/7 Essentially, so she's physically here, but I don't know where she's somewhere in between probably mentally. And, and her husband of my stepfather. So they live in California right now. And they've been going through, he's also disabled. And they've been going through a lot of, you know, issues of their own, like losing jobs and trying to survive and being afraid because they're obviously my parents, so they're older, right? So they're definitely a more of a risk group. And supporting them has been a struggle because at this point, I had to really learn, relearn how to indicate my boundaries, because at this point the whole world to some degree needs support right and we can't—there's so much we can do even to the people for the people will love the most. So at some point, I just I just had to tell them you know, I love you guys, but if you call me to vent about how you can find a job, I will support you by I can't listen to all the time because I'm literally in the same spot and I cannot do anything because I'm gonna send you money because I literally have no money like, I can't I don't have the reason Sources now emotionally, but otherwise, you know, to provide to you. And let's just make sure that we don't freak each other out for no reason. Because this is another time, you know?

**Hannah Soyer** 40:13

Yeah, so I'm assuming you still have family in Russia?

**Irina Yakubovskaya** 40:19

Yeah, my mom is here. And like I said, she mentally is there. And her husband is also Russian also is here, and then everybody else is there. Okay, well, my grandparents, my biological father, who I could care less for, but you know, he, I guess exists. And my, all my, my, my uncle, my cousins. My mom has been trying to, to make me talk to them more. And I'm like, again, I can't like I don't. They're not my children. I don't, you know, I'm not gonna force and that's, it doesn't just apply to children in general. Like, I don't feel like I'm obligated to talk to somebody who doesn't talk to me, you know? Does that make sense?

**Hannah Soyer** 41:05

Yeah, absolutely. Um, so, from your perspective, do you feel like those people are people that, you know, in Russia? I mean, I guess I guess what I'm trying to ask is, the, the way that people are approaching the pandemic? And I don't mean, you know, I'm like a governmental level, but just, yeah, you know, everyday people. How do you feel like there's a difference in those who, you know, in Russia versus people, you know, here? Or does it you know, about the same?

**Irina Yakubovskaya 41:44**

Um, I don't know, personally, anybody here who is actively breaking protocol and quarantine roles, I am happy to say, I'm not familiar with those individuals in person. I know they exist. I see them on the streets whenever I'm outside. But I don't know who they are. And I don't want to know who they are. And therefore I don't want to know their reasoning. Right. For for the people in Russia that I'm familiar with. I know that my grandparents are barricaded in the house. And we've been begging them not to leave, and they've been fine with it. But I think they are the only two people I know, who are Russian, who are in Russia, and who don't give up on the whole situation. Everybody else, my 96 year old grandmother, the other one, like I have to set one and a half sets of grandparents. She on the phone was telling me how she doesn't care because she's got immunity for the virus. She's 96. So that was like, I give up I can't, I just can't. And so, you know, and then that's an extreme example, right? She's old, who knows what's going on in her head, right. So, but, um, but the other people like younger people my age and older, younger, I just, it's baffling. They, they just don't, they don't care. I like I said, you know, I tried explaining being like, hey, you know, when you don't wear a mask doesn't harm, just you harms everybody else, who you're not, you may not even know you go on a train, you cough on somebody, and then they're gone the next day, and you will never know. And they just don't they don't hear it. I don't know how to explain it's just a complete. It's not like an active, you know, subversion of the rules as it is here or appears to be most of the time. It's more of just a complete oblivion. People are oblivious. And then I, the other part of it is that I keep seeing on the social media, you know, all these people who post like news about some famous people dying in Russia, famous actors famous theatre I, because I come from a theatre background. And so a lot of my connections, or at least social media connections are Russian theater artists, because I just can't help I can't bring myself to deleting them all. I probably will. But it's the post about all these cars, the Russian great artists dying in their old and it's like, they don't say why they die or how they die. But I'm pretty sure most of the time because of the frequency of how it's happening now. I'm pretty sure most of them die probably from COVID Because I know that the hospitals in Russia are completely full. There's absolutely they're in my hometown, which is not Moscow. It's a smaller town, but, it's completely...there are no medications anywhere. You can't even find the budget call it the the thing you put on the finger to measure your oxygen level.

**Hannah Soyer 44:53**

Oh, yeah. Pulse-ox

**Irina Yakubovskaya 44:55**

Yeah, that thing. They can't even find that, nothing is available. They're the doctors just don't come to you, if you call 911, or whatever, they just don't show up. It's literally like, it's just, there's nothing people can do. So people just kind of forget about it and give up and walk around and post beautiful pictures with their children, but no masks in the vicinity. And I and— I wonder, yeah.

**Hannah Soyer** 45:21

Yeah, that makes a lot of sense.

**Irina Yakubovskaya** 45:23

But just to add to that, so just before I forget to stress, the most stressful part about this whole, like, how it's how it's treated in Russia right now, and how difficult and different it is that travel is becoming just basically a death sentence. Basically, not for me personally, I wouldn't, I don't have the resources to go anywhere right now. Right. I haven't been to Russia in 11 years, almost. I moved here to go to graduate school. And there's that. So before the pandemic, I had hopes to maybe save up at least some money to go there. Because it's like a big deal, not being to your hometown. Nothing your family in 10 years. But now I know, it will probably, I don't know when it's going to happen, both because of the pandemic, but also because of how it limited my ability to work and find work really, in a sustainable kind of way. But in terms of travel, my mom is somebody who really needs to go and support her parents, because they're very old, and they need assistance, you know. And she, we talk about it almost every day, she is in the situation where she can't, she can't go because it's dangerous. She knows if she goes she's gonna probably pick up the virus on the way that's a long trip, you know, from California to Russia, it's like halfway across the world. And she knows she's probably gonna bring the virus there, and then she's gonna have to quarantine herself, hopefully recover. Even if she doesn't become sick, she's still going to be a risk factor, you know. So it's like this, this, and I'm sure hundreds of millions of people around the world are in the same position where you've been separated from your family already, for whatever reason, but now it's even more just terrifying everyday. What to do if something happens that you know?

**Hannah Soyer** 47:11

Yeah, absolutely. Yeah, I think that that is such a difficult place to be in it sort of feels like, again, that idea of like, you know, what is the right choice here? Trying to figure that out? Absolutely. Okay, so has your current living situation been impacted at all by the pandemic?

**Irina Yakubovskaya** 47:39

So I'm smiling. I don't even know why I got a laugh. Well, yes. And now. So yes, I'm fortunate that I still have a roof over my head. I am, it is unfortunate that I'm still unable to find a job. And at this point, because of the unemployment benefits that stopped coming from, for this stupid mistake thing. It's basically I really hope that something will figure itself out somehow, within the next two months, at least, at the most. Because I don't, my spouse does not have the resources to pay our tremendous rent. Boston, obviously. And just support us throughout because that was not, there's just not doable. The other issue is because we're at home all the time, while I am, he goes to work, but his office is empty. So it's fine for now. But again, like he'll probably come back to work from home because we anticipate further lockdowns. We have these neighbors who have two children, and they have, you know, just basically loud all the time for one reason or another. So that's been an issue. More so recently, then, or during the pandemic than before the pandemic, they were already allowed before the pandemic, but at least we went outside and we were elsewhere during the day, he only had to deal with it in the evening or something. Now, it's just all so like, I don't, it's been really difficult to, to do anything really. We've lost countless hours of sleep because of this. And they just refused to. They basically went and knocked on their door to say to turn the music down. And they yelled at us and said they will call the police on us.

Like, whatever, it's fine. So and we're even looking for a place to relocate even temporarily just like you know, because so that my husband could afford to support us. But moving right now is also sort of this. How do you how do you even move in the pandemic, can ask for like for help from anybody. Like I can't lift many things like how how is this going to work? It's just not going to work. So parts is going to have to figure it out, I guess but in that sense has been impacted in terms of the Yeah, but I am I am fortunate and thankful that I still have a place to live. It could have been better. And I hope it gets better. Yeah, but I think in terms of the kind of circumstances around all of that, I think, for me individually, if and hopefully when I find some kind of job, hopefully it will create a sort of a better resource for me to just feel like I don't have to look for a solution all the time, you know?

**Hannah Soyer** 50:32

Yeah, just like a more, more of a sense of security, I'm sure.

**Irina Yakubovskaya** 50:37

Yeah, or some sort of stability of using temporary. So.

**Hannah Soyer** 50:40

Absolutely. Okay, so do you feel like your relationships with different institutions have changed throughout all of this? So, for example, health care, government, the media, etc?

**Irina Yakubovskaya** 50:55

Um, yes. First, I think the media in the past four years, or five, even right, because of the political situation has been the constant source of anger and frustration, the media in the world. In now, if you like, throughout the pandemic, I have used my skills that I have, from my research background, and just, you know, educational background and socio political background, I use my skills to filter out certain attitudes and informations because I think it can be very overwhelming to just absorb everything. I'm a bit of an empath, unfortunately, for everybody. And so it's been, I've been practicing, or I've been kind of building the filter system, that doesn't let all of it in immediately, because that's too much. And, you know, because sometimes I just can't filter things out. And then it just, it affects me physically, it's so overwhelming. So in that sense, my relationship to the media has been more moderated or in the past several months or so. So I appreciate that I took a time or took time to, to filter or to monitor my consumption of media, just because I can't do it all at once. I can't. And then the government, you know, as I mentioned before, my positionality, as an immigrant is very peculiar in that sense. So I don't particularly have a direct relationship with the government in it, outside of them giving me or me applying for paperwork than approving paperwork or not. I mean, obviously, it's changed, I've never thought that I would be on unemployment, because I always had some kind of job going, because I had to as an immigrant, just as a student, especially before it became a permanent resident, I had to be a full time student, otherwise it would be deported. So I always had to maintain some kind of all of that was, you know, and I was I didn't have any resources. So I had to have a job within the university. So it's legal, but so I can support myself. So, but long story short, I never thought I would be on unemployment just because I never really thought about it. And so I am glad I had this option. I'm glad I was legally allowed to, you know, apply for unemployment and get it. I mean, except for the past month and a half when they just kind of stopped randomly. So there's that. But in terms of the medical institutions, I with, with the additional number of medical conditions that people keep discovering in me,

I think I have an account with every hospital in Boston at this point, which is saying a lot because there are many hospitals in here. So that's been interesting. I think. I think I, I've all you know, is any person with chronic illness or any disabled person, we know how, and also not men, we know how tremendously difficult it can be to advocate for ourselves in the medical environment. I have been so exhausted by just like the ignorance and the I've been told so many times, oh, no, you just have panic attacks. You're an emotional person. And I'm like, I'm shaking in them anyway. It's, it's a neurological disease, like, what do you want from it? You know, so all of that. I've had all that happen many times. And I do think that I have learned that persistence cannot be substituted by anything else. And I have to be persistent, unfortunately, as well. As annoying as it is, I have to keep advocating for myself. Like no one else is going to call the doctor and say that I refuse to come in in person because it's dangerous for me, or physically cannot Right. Like I have to do that work and it's exhausting, emotionally and otherwise. But I have to do it. The interesting thing about it is that I think I have like, I have embraced my right to choose who takes care of me if that makes any sense, which is a huge privilege, sort of, I

**Irina Yakubovskaya 55:18**

guess, right. But what I'm saying is, in the past, I would just go to whoever was available medic, medical doctor or a mental health specialist, but I never was able to find the match, you know, it's so important to find a doctor who would, who can understand you and actually take care of you. And I think I finally started relying less on random coincidences in that sense and more on my agency in choosing who is my caregiver. And I think that's been helpful. Like, I finally found a therapist that I actually enjoy working with, and who actually is helping me, and it's been many years, you know, of just random or whatever. And now, I made an effort and made a rubric, what has to happen in order for this person to work, and so it works out. The other thing is, yeah, I don't know, I think, institutions in general, my huge beef is with higher education institutions, because I have received that I have worked in higher education for 10 years, basically. And just looking at the fire dumpster fire, that is the higher education right now. It is baffling to me how underappreciated people are in higher education. So basically, what I'm saying is my relationship to the higher education institutions, has been really tainted, to the point of absolutely no return, if that makes any sense.

**Hannah Soyer 56:43**

Yeah. And do you feel that has been specifically impacted by perhaps their response to the pandemic?  
Yeah,

**Irina Yakubovskaya 56:51**

yes. Specifically how, you know, I'm not really judging much that for the first several months of the pandemic, because everybody was kind of confused, and to know that we're doing but moving forward with this particular semester, I'm just very disappointed in first of all, in schools opening at all, even for hybrid learning, like, that's just not, I honestly thought, you know, why can't everybody just take a semester off? Can we just pause this, like, but unfortunately, I understand the systemic issues within it, how everything is so tied up with the money that goes into the education from essentially non sustainable model. It's like, you can't rely on tuition money to maintain your workers, like just not that's wrong, you know, but anyway, I know, there's all different conversation. But basically, all these systemic systemic issues just became so apparent. And it also became very obvious which institutions

were willing to jeopardize the lives and safety of their staff, and faculty and students, just so they could make basic amount of money. And I think, yeah, I just, I just don't think it's worth it. My other issue is with the institutions of Performing Arts, specifically say theatre and film, because I have always been very upset at all of that for their hypocritical approach to diversity and inclusion. And now, you know, many was, specifically when it comes to training programs of like performing arts and practices of Performing Arts. I've been very baffled by the response of people who got very confused. How do we teach acting online? Oh, what a challenge. And I was saying from the very beginning, do you understand that opening up your space to be more accessible virtually becomes makes it more accessible to people who historically have never been in an acting class because you don't even know that you discriminate against them? Us? Right from from, like Headstart and all of that, at some point, I kind of like gave up because I don't really, I don't feel I don't have a position in my current institution, or anywhere else really to, to, to say it loudly enough for the people in the back, you know, to actually hear me, but that that whole frustration has been it's been ongoing in my life, but especially now it's intensified because this is such an opportunity to open up your education to people who have been descend from disenfranchised for centuries, and many people just don't take it and keep maintaining their alias practices. And it's just, all very angry about that.

**Hannah Soyer** 59:34

Yeah, that that makes a lot of sense. So, what has been the hardest part about living throughout this? And there can be certainly more than one answer to this as well.

**Irina Yakubovskaya** 59:53

I'm not having or I think the hardest part has been really realizing that ... realizing how little resources I actually have in my life, compared to what I thought I did. And that I'm not just referring to money, but or material sort of resources, but also opportunities that I don't know, throughout the pandemic, I just kept thinking about how the guiding sort of motivation of my professional life and personal life to some degree, right has been throughout my life has been my desire to be professional in the performing arts, whether performer or director or any sort of, you know, creative basically, I've always wanted to be a creative, and I have been a creative person and a creative professional. But unfortunately, I realized, especially throughout this pandemic, that even in this country, which is comparatively somewhat better in that regard to other places, like I'm from, right, it's still too many doors are closed to me, because it's such a complex system of networking and opportunity. So many opportunities come from connections. And if you do not have certain connections, you don't have certain doors opening to you or even, you don't even know where the doors are. So basically, that's been a revelation that finally hit me, it's been kind of growing in my mind, you know, in the past several years, but I finally think I think came to the realization that it's very, it's very difficult to get in the room where it happens. Some pun intended, but you know, I mean,

**Hannah Soyer** 1:01:48

and I think, yeah, me. Yeah, go ahead. Sorry.

**Irina Yakubovskaya** 1:01:52

No, it's okay. I was just Yeah, I don't, I think that's been basically the hardest part to just realize that my resources that are available to me, and again, I don't just mean the money are less of the resources.

And I had thought, you know, the feeling of the promised land not really being promising has been detrimental, maybe. But I think the I'm going to say, there has been a positive sort of upside to that, is that is this pandemic really taught me to appreciate small moments, it kind of, it's sort of de-escalated my ambition, if that makes any sense. In a way that I realized that none of my ambitions has... have ever been really mind they've been imposed by society or some expectation of somebody else. I finally, I think I'm coming to the realization that it's okay not to have ambitions, professionally or otherwise. And it's okay not to be guided by these, you know, flashing lights of, I'm not even gonna say fame or whatever. But like, the cool stuff, or whatever shape or form, you know, or going viral or whatever, you know, I mean, like, it's, it's okay, just to be a person. And it's, it's, it's great to be a person and it would be great if the society saw us as people, but you know, one can hope. I think, also the other positive, I think, thing is that I've been making efforts to learn more about disability community and how to communicate better within the community. In particular, like, for example, with my art, I started writing image descriptions for every hour that I post. And that's been absolutely terrifying, because my art is very abstract. So for like doing that is like, it's very difficult, you know, but I know I want to do it, because I want to be as helpful as possible and as accessible as possible, what in whatever I do. So that's been like an interesting, challenging kind of way. But not definitely not the hardest part. But maybe the best part? I don't know.

**Hannah Soyer 1:04:09**

Yeah, that goes into my last question, which is really, have there been any silver lining? Which, you know, you've already answered in some ways, but if you feel like you want to expand upon that at all, are you scared doesn't need to?

**Irina Yakubovskaya 1:04:25**

Yeah, I just want to say that, you know, deep down I know that the silver... the main silver lining is, as somebody like myself, who has had multiple near death experiences throughout her life, starting with the very beginning. I've had multiple moments in my life where I was forced to by the circumstances to stop and reflect on what the hell I'm doing. Like, and I've had many regrets. And I've made efforts at some point in my life to turn my life around to make it better, but at some point I didn't. But even though it was the moment of you know, I could have died quite easily. But here I am. So why right? Now, I think it's another one of those moments, it's less momenti. And more prolonged, right, because of the time that we're in. But I am trying to find the positives in terms of just learning, I guess more about myself and how I operate in the world. And what, what is it I think I became more unapologetic, or like, I've always been unapologetic, but now I feel like I don't filter that out anymore as much. Because even like to get bring you back to the thing, the realistic things like applying for jobs and stuff like that, like, I don't, I don't want I mark, I do the check mark. Now that I'm, you know, in the questionnaire that they have, are you disabled? Or have you ever had it? Spit? I check? Yes. Now, because why do I have to, I want to, I don't want to hide it, you know, I mean, like, if it matters to them, they're going to ask, and I'm going to expand on that. But like, it's, it's, it's okay. Like, basically, what I'm saying is, I think I'm finally realizing that it's okay to be me. Both physically, literally, figuratively, or, you know, also in terms of My presence in the world, and it's okay to find a balance between who I really am, and kind of let my actual drives through, you know, and not let the noise of the world shape who I am. Because I don't want that anymore.

**Hannah Soyer** 1:06:31

Yeah, that's, um, that's really great. And remember, even though it's like a really terrible situation, that's really great that yeah, that you've been able to sort of embrace those different parts of yourself more? Absolutely. Okay, well, that's all I have, do you have anything that you would like to add?

**Irina Yakubovskaya** 1:06:55

I would like to add one thing is that I am truly and tremendously thankful for the opportunity to talk to you and to share my experiences. I have never been a part of any community for real, because all the communities I've been trying to be part of were kind of resistant to my presence, or were undermining my existence even because of how able, yes, they are, and all that, but I think it's been such a humbling experience to be witnessing the desert disability community discourse going on, but also being knowing that I am part of it. And, and it's okay to be a part of this community with even if I don't, you know, vocalize it or explicitly share every time, Jeremy, what I'm saying is, I don't want I don't I he like, I don't feel like I'd have to have, you know, in my social media bio, or something that I am disabled or identify as disabled, necessarily to know that I'm part of this community, or vice versa, right. Like, I don't, I don't owe it to the world to explain myself. And I know that my community is accepting of me. And I appreciate it.

**Hannah Soyer** 1:08:11

Yeah. Thank you. It's, it's so great to have you. And yeah, I just think that, you know, the stories and experiences are so important to record and to document. And I think that yeah, I think that disability is such a it's such a changing category to you know, so there's a lot of, I feel like gray area, it's not really a black or white thing. And so, yeah, I'm really glad that this has been, you know, a good opportunity for you or an experience for you. And, yeah, I hope that you are able to continue to find. Yeah, just to feel more welcome in the disability community. Absolutely.

**Irina Yakubovskaya** 1:09:05

Thank you. I also just feels so surreal for me to be on this side of the interview, because I have interviewed hundreds of people over the course of my life for as a journalist for for my dissertation for my research, and it's just I keep wanting to ask you questions. Well, because I want to ask you questions, but also Lake and it's just so unusual. So thank you.

**Hannah Soyer** 1:09:25

Yeah, absolutely. I'm gonna go ahead and stop recording