



STORIES TO ACTION

Amplifying voices for change

Episode 2: SRHR & Disability

- Kwem:** Welcome back. Today, we're exploring what it's like to navigate your sexual and reproductive health and rights as a person with disability during COVID-19 with guests, from Australia, India, Nicaragua, and Indonesia, your info perspectives from across the globe. How is it like dealing with a lagging Slack during an online doctor's consultation, or keeping your long-distance or long-term relationship going as the world closes down? Also, have you heard of disability joy? Well, we will be exploring more on what that means. Let's dive right in.
- John:** Talking about things that make you uncomfortable and awkward is what we do. We break the ice so that you can freely talk about them. This is Not Your Usual Subjects podcast with your host, Kwem.
- Kwem:** I recently came across the concept of spoon theory, a popular metaphor used in the disability community and folks living with chronic illnesses. Spoon theory was developed by Christine Miserandino as she responded to a friend who'd asked her how it felt to have lupus. Because they were having dinner, Christine grabbed spoons around them to provide a visual representation of units of energy that are a person might have. So one may start off with, say, ten spoons in the morning. And then to shower, to have breakfast, get dressed, then leave for work or school, probably send an email or complete a task or assignment, that's already four, five, six spoons down. And the day is still early and requiring of energy and effort.
- Kwem:** Spoon theory speaks of the finite energy that a person with disability, chronic illness, or a neurodivergent person might have. This is why we will be speaking of disability joy because it is resistance and taking up of space by people with disability in a world system set up to exhaust them. We're also taken through the journey by our guests on what their experience has been as they sought to access services they need, including sexual reproductive health services and information. And we also reflect on how being part of a community as a person with disability is central to experience liberation, joy, intimacy, and friendship. Let's dive right in.
- Is:** Untitled. I used to fill the silence with my voice. Cover emptiness with a shallow cover, hoping it would be convincing enough to stop the darkness from trying any harder. I thought that I could speak so loud, I couldn't think. But what I didn't realize was that if you don't give yourself time to think quietly, your brain would just spit out its thoughts, even louder. The things I would say, I wouldn't want to be credited for, nonsensical, loud, impertinent. Instead of filling the void, they created a new one, one that was more difficult to hide.
- Is:** I was told by a therapist to sit with my discomfort, recognize that the silence wasn't so silent after all that learning to listen to the quiet would not make my existence louder and that even so it wasn't so obtuse to have a loud existence. So I became louder, prouder. The more, I didn't say a word, when I did open my mouth, it was with intention, with jurisdiction over my thoughts.
- Is:** I told people I loved them. I meant it when I thank them for loving me. I spoke softly in the face of angry red-faced men, which made them louder, which made my quiet even more important. I had an unaesthetic thinking face that I would catch in the reflections of phones



or glasses and be inspired to think even harder. I lived loudly by choosing to stay quiet until it was the right moment, until I knew I was doing the right thing, until I knew I was deserving of the loudness. And I opened my mouth.

Kwem: That was Is, our first guest. They are a self-proclaimed writer, speaker, revolutionary, cat lover, and someone with terrible fashion. Is is 18 years old, identifies as a disabled, queer, young trans person living, loving, and working on the stolen Wurundjeri Woiwurrung land in so-called Australia. For Is, all these multiple identities co-exist. They name this as wearing many hearts, all stacked on top of each other and sewn together so they can't be taken apart and worn separately. So how does one navigate the world, communities, and different spaces when wearing many hearts? Is tells us how they've done it, and how they're doing that now with the COVID-19 pandemic?

Is: Well, I think it's really important to acknowledge that the ways in which I've interacted with medical, educational, and kind of employment systems during COVID-19 is pretty unique. So I was in my final year of high school in 2020 when the pandemic began. But I was not in a mainstream school, so I went to an adult education institute, which was very much self-lead, self-motivated, ran more like a TAFE or a uni, oh, it's actually run by a TAFE institute. And so I didn't have a uniform, I wasn't attending close to eight hours of classes a day or anything like that. So that wasn't my experience.

Is: However, obviously, that doesn't mean that because mainstream systems are believed to be more inaccessible, that I was able to access things more, there were still issues as is innate in education. And additionally, I was working a lot last year, all from home, of course, but specifically in an online disability space. So I wasn't necessarily having to interact with the employment system whilst also being in a workplace that didn't necessarily understand my identities. The entire pretense in the community of my colleagues and the young people that I was working with and the people I was sending emails to, all kind of shared my identity or were engaging on the pretense of my disabled identity. So I feel kind of grateful for that.

Is: And then additionally, in terms of the medical system, both being a disabled person and needing regular medical interactions definitely was the case last year, but particularly noting that I spent a decent amount of time in hospital last year. So not just kind of like visiting, but staying there and six weeks, four weeks, eight weeks at a time, or what have you. So wanting to note that that is the framework for what my 2020 looked like, and that's obviously continued into 2021, all of it though, I'm grateful that I'm no longer in education.

Is: And so I think specifically discussing the ways in which they didn't meet my needs, starting with school, I had only three half days of school a week, the rest was kind of self-motivated learning, which I definitely benefited from, but it meant that each class was three and a half hours long, which is incredibly hard to engage in, especially when we're likely to get maybe a five-minute break in three and a half hours.

Is: And for my neurodivergent and disabled brain that was not accessible at all, and there wasn't necessarily scope to suggest a change in that and that was really hard for me. Additionally, my auditory processing disorder means that I generally really struggle to engage in conversations if I don't have captions and I don't have the capacity to lip read and given online school vibes where everybody has their camera off and will just talk if they have to, but I can't lip-read and certainly the schools didn't have the captions turned on in Zoom.

Is: So there wasn't any way to be able to process any of the information in classes. So even, while I might've been able to attend the class, I maybe captured 30% of what was discussed and shared, which was a huge detriment to my learning and kind of the institution didn't really set up a safe way to request changes to that system in general. And so very much, it was a struggle to even attend a class, let alone, do an assignment, finish my exams, get my finishing certificate, et cetera. So that was really hard.

Is: In medical settings, and notably, hospital as well, with the kind of medicalization and erasure of identity that exists in those spaces, there's kind of in online spaces and physical spaces, the deadnaming and refusal to affirm my queer identity was... it felt like a given, really. And so having that be kind of an expectation that I'd go and get my meds while I was inpatient and I'd have to say my own dead name to get my meds to prove that it was me, that they couldn't ask for any other detail about myself, and that I had to have an incorrect gender identity and name on my wristband and things like that.

Is: That meant that any time I entered the space, I was forced to erase a part of myself, which was particularly emphasized in COVID because those were the only times you were interacting with other people. It wasn't like I had the chance to chat with other patients and gather that connection because we had to just stay in our rooms, which is fine.

Is: But when the only way they know about me is me, deadnaming myself, my dead name being on a whiteboard of like who's quote-unquote, "looking after me" it meant that my identity was not only erased by the professionals, but I didn't have a chance to draw it back in for the people I was interacting with, which made it really hard to kind of battle the already kind of default that I wanted to, which was to recluse and I have really bad agoraphobia. So I wanted to just not interact with people. And when I knew interacting with people would be deadnaming and misgendering, I was like, "Sick. So I'm never going to do that," which obviously wasn't healthy.

Is: And then in online spaces, the same issues at schools being, no captions, kind of pretty poor communication because a lot of medical communication comes via mail. And first of all, that comes to my dead name at my parents' address where I don't live. But also that being unreliable and me needing additional forms of information that I couldn't access because of the pandemic or because of an excuse of the pandemic, which is incredibly hard.

Is: And telehealth is a really important and great thing, but when it doesn't have captions and when it's just by a phone call and I can't lip-read what people are saying, it becomes really, really hard to access. So doing the things that were necessary for my livelihood, my existence, and my functioning, getting my medication, having regular checkups, or what have you, were kind of existing in an inaccessible realm that meant I had to deny my identity, or it would be denied for me anyway, in often kind of quite violent ways, which I'll discuss in a second, was not particularly fun and made that really hard.

Is: But I was really grateful that my workplace was just the best ever last year. I'm somebody who needs kind of lots of different streams of like stimulation to be able to focus on different things and distract my brain from doing its rude brain thing, which was especially needed during the pandemic and is still needed during the pandemic because it is not over. And my workplace is a youth and disability advocacy organization where I am a disabled young person. So I am the entire kind of intention of the organization and getting to work in that space where the majority of my coworkers are also disabled or also young or at the very least care about my



communities, meant that that became my safe space, which I know is something that a lot of people are lucky enough to have.

Is: But yeah, being able to say, "Oh yeah, cool. I'm going to work." Or when I went into hospital, I just sent a message to my manager and I was like, "Is it cool if I continue to work while I'm in hospital?" And they were like, "Yeah. Absolutely. Go for it." And I didn't have to explain myself because the environment I was in was inherently infirming and safe because it was defined by people like me was so fundamental and also something that not a lot of people have access to. So I feel really privileged that, that got to be my situation and also heartbroken that other people didn't get that, what should be the bare minimum. And so I think, yeah, recognizing that different spaces meet or don't meet your needs is a hard thing to come to terms with, but makes a lot of sense.

Is: So as a trans queer lesbian with multiple reproductive health conditions, interacting with sexual health and reproductive services and medical systems is never fun. Often during COVID times or otherwise, I have to choose whether I'm deadnamed or misgendered the whole time, and not seen as who I am, or out myself and that become the entire focus of my treatment and the entire reason I'm at the appointment, my actual health needs be overlooked.

Is: I think it's the same as both direct appointments and services for the health conditions, but also how I'm responding to medications and treatments are inherently going to be different. And then in positions of, "Well, you still want to have kids one day?" or, "Are you sure you couldn't be pregnant?" It's like, "Yes, I am very sure I could not be pregnant." And that inquisition on your decision of what my body is, is then further invalidating the reason I need this support and then makes it not a safe space.

Is: And so I think all of that, even in ordinary times, is incredibly hard. But then when you're online and you're sitting in an awkward Zoom waiting room, there's just less capacity to have that understanding conversation, to have someone see you. And additionally, it is much less safe to disclose any of these things when you are online, it is near impossible because often you'll be on the health platform by the hospital and your name will come up as your dead name. So that's how they've categorized you, and you can't edit that, just as an example.

Is: But then even in the awkward Zoom space being like, "Oh yeah, by the way, I'm trans, by the way, I have other significant disabilities, by the way, this is how this all intersects with me." It's not a nonchalant thing you can bring up with someone who's lagging on Zoom, it's not. And so the issues that exist in the medical system are further exacerbated when it's online because it's not safe to say, "Hey, this makes me uncomfortable," or, "Hey, I need this to change."

Is: I even had an experience during COVID, when I was in hospital, and I had a doctor very much just kind of refuse to see me, who I am. When I would ask for support for a number of my disabilities and health conditions, I would get told, "You don't know what you're talking about. You're just a little girl. This is not what you need, you're just a little girl." And it's like, "Fam, I'm not little or a girl, and your explicit decision that I am, really shows me how you value me as a patient, as a client, et cetera, which is to say that you don't." It shouldn't be that way, that that's what we have to expect as queer disabled people entering systems that are supposedly made for us, i.e. medical systems supposedly made for disabled people. And it's frankly not good enough.



Is: Yeah. So I think it's been so bad and so hard for people like me during the pandemic. It's been hard for everyone, I'm not going to deny that, but the particular exacerbated conditions and struggles of people like me, of multiply-marginalized, disabled people not to be understated, and then everyone else's rush to move forward and escape that and escape the things that have been keeping us safe like restrictions and staying home, those sorts of things. Everyone's rush to get out of that is terrifying, and it's really damaging and shows kind of where government priorities are, right? If they're prioritizing an abled person who just wants, "To go back to the pub with my friends," compared to a disabled person who might die if they leave their house kind of thing.

Is: And this would not happen, we would not be in a position where disabled lives are being compromised for the comfort of abled people if there were people like me with lived experience directly in decision-making positions and informing those that had the power to make decisions because, unfortunately, we don't typically have that power. If there were people like us embedded into those systems and the systems were forced to be accountable to us, we wouldn't be in this position, right? And it wouldn't have taken the benefits of remote learning... it wouldn't have taken a pandemic for that to happen because we would have already implemented it because it's necessary.

Is: And so recognizing that because there's no disabled, queer, young, diverse, marginalized representation in these decision-makers, that's why it's so hard for us. It's not like, "Oh, whoops. That sucks for you. What a shame." It's an intentional thing because we're intentionally left out. And so by embedding lived experience, whether it's consultants or, I don't know, just giving us actual decision-making power, electing us, et cetera, if there was that there, then sure, there would still be problematic corruption of values towards us, but it would still have an opportunity for us to be seen and influence decision-making.

Is: And I think just a final point on that is that I think oftentimes people are like, "Oh, well, it's just such a small group of people that feel this way or that are reflected by this." But it's not, the world report say that supposedly 20% of people are disabled. It is significantly higher than that when you understand the social model of disability, like the world disables us. Regardless, that is a fifth of the world, that is not a small amount of people. And so recognizing, and actually seeing us for the group and the people that we are, especially when we're intersectionally identified is so necessary to actually achieving this change, and it's just not something the world is willing to do just yet, which is not good enough.

Kwem: Community is central to people with disability because in community lies the power of shared lived experience. And this is why Revival mag was born. Having community was especially needed during COVID-19, a period of isolation. So what has it been like being together apart with other disabled young people in India who are part of the Revival mag community? I spoke with Nu, who's the founder of Revival mag, and their close friend, Sam, as they shared their experiences. Nu and Sam can I say what a joy it is to have you today, welcome. Let us start by introduction. Nu, would you give us a brief introduction about yourself?

Nu: Hi, I'm Nu. Nu is my chosen name. The name that I have from my birth is Anusha, but I prefer Nu, it's also part of my new identity. I go by they/them pronouns, and I identify as a disabled and queer woman. And I'm the founder of Revival Disability Community, which is an affirmative community of disabled and queer folks in India. So at Revival, lived experiences are everything. They are the crux of all major points, all major structures, and just similar communication. I was a master's student at TISS, Mumbai and



I'm really glad to be in conversation with one of my closest friends, Sam, who was also working with me on the Revival Disability project. I'm very grateful for the friendships that I've made via this community and the disabled joy that we all feel.

Sam: Thanks, Nu. Hi, I'm Sam. I am a lawyer by profession. I work in the domain of corporate law in fact, but I've always sort of been interested in creating more disability affirmative spaces because I've grown up in an area where disability was usually hush-hush, we did not really speak about it. I could never openly speak about my illnesses and that's how Revival became important to me because it became a space where I could come and speak about my disability, my illness, and my experiences were at the center of whatever conversations we had.

Sam: And that's how it is for everyone at Revival. Like Nu mentioned, we focus a lot on lived experience. Sometimes that means sharing things that can be a little embarrassing, like sharing how your disability impacts your day-to-day life, sharing how you have difficulties doing certain things that other people might take for granted. But it's always nice to meet other people who have had similar experiences, similar childhoods, in and out of hospital, similar experiences with doctors. So that's sort of what I work on in Revival, I work a lot in the area of content curation and talking to people determining what all posts we can put up.

Kwem: I love that. Thanks for sharing. So Nu mentioned something, and I'd like to know what that has meant for the both of you, especially during this pandemic period, and that is disability joy. In just two sentences or less or thereabouts, could you share with us what that has meant for you?

Nu: So disability joy is one of the many goals of Revival. We want to spread the idea that disability is not just one dimension, right, like it's been portrayed in movies and media, and that disabled people are just meant to exist, inspire, and more to about... it's like if they can [inaudible] and that's what we want to eliminate. The non-disabled world has in a sense chosen to view all disabled folks as people who need to rise above or overcome their trauma, overcome their disability. You can be successful only once you overcome your disability, once you've, in a sense, achieved able-bodiedness.

Sam: I think it's sort of... there's always this perception right from when we're born, that if our bodies don't look a certain way or don't act a certain way, aren't able to do certain functions, they are somehow less worthy. And we grow up seeing that idea all around us, even if there might be a situation where people are not directly saying that to us, there's still a lot of ableism all around us. There's still a lot of people around us telling us indirectly that we aren't worthy of entering certain spaces. For instance, inaccessible spaces are spaces we can't enter, spaces without ramps, spaces without proper tiles can be really hard for us.

Sam: And we grow up feeling like that might be our fault. We grew up with that idea that, "Hey, something might be wrong with me because the whole world seems to be built for this other person, and I am not that person." So you grew up having this hatred for yourself, your body, for the way it is. And disabled joy is all about trying to overcome that hatred, trying to look at our disabled bodies and say, "Well, this is one thing about me that I have to accept because disabilities don't go away," contrary to the popular representation of disability, where you see people overcome their disabilities, you see them sort of achieve things that are uncomfortable with their disability.

Sam: That doesn't happen in real life. In real life, you're mostly just dragging along with your disability rather than overcoming it.



So disabled joy is about becoming friends with your disabled body, understanding its needs and learning how to listen to it, learning how to sort of perceive it and not look at it as an enemy. I think for me, most of my life, I have looked at the more inconvenient parts of my disability as being enemies, as things that I have to hide from everyone else.

Sam: But disabled joy tells me that maybe I don't have to hide them, maybe I can walk into a room and just tell people that I'm in a lot of pain and I cannot walk and I cannot do this work, and I cannot do certain things because of my disability. And that's nothing to be ashamed of, it's in fact something to take pride in because there are other things I can do. And even if there are other things I can't do, even then, that's nothing to sort of feel ashamed of or feel bad about. It's something that has been a huge part of my life. It will be a huge part of my life.

Sam: And I think disabled joy allows me to be friends and it allows me to develop a relationship with my disability that's not very toxic, where I keep blaming it for everything. I now look at it as something that I have to live with and I will live with, and I will learn in the process. I might have a lot of emotions of frustration, anger, irritation. At the same time, I also have positive emotions sometimes like when I met Nu, when I became a part of this community, those were emotions of fulfillment, emotions of happiness, emotions of feeling connected to someone.

Sam: There's a huge community of disabled folks out there that I am connected to now, who I would have never met if I didn't have a disability. Those are things that I am still happy and thankful for. Of course, that doesn't mean I'm happy and thankful all the time because no one is. I'm still irritated and frustrated and don't like my worry on something else. But it's a process and identifying that it's a process and we're all learning, that's a huge part of disability joy for me.

Kwem: Thank you so much, Sam, that was very, very clear in the sense that disability joy is being in full acceptance of yourself, of your body, and of your disabled body, and to also be in friendship and to be in full understanding that there will be ebbs and flows, and being in acceptance and in love with all of that and all the emotions that come with that.

Kwem: And you've gotten us right into the next place where I wanted us to go, which is, I know that sex and intimacy are a big part of the work that you do within Revival mag. How have you lived out your queer feminist selves, and especially during this period of the pandemic?

Nu: So, especially during this pandemic, we try to hold as many sharing of good as possible, talking about a range of topics, disabled joy, disabled angle... this frustration of not being able to go out during the pandemic, not having access to structures of dating, structures of meeting new people, how this entire system, the non-disabled system has kind of just hidden us away and we've been isolated for so long. And living in new cities, especially for me when I lived in a new city entirely, it was really fulfilling because living alone, believing that I'm independent, again, independence and disability is something which is very complex and layered. It's only understood this way, surface only.

Nu: We'll come to that later. But for me, living in a hostel by myself was the epitome of my freedom, to say. And coming back, in a sense it's very constricting and I often feel shocked, and so does many folks in the community. Where some of us have parents that are homophobic, queerphobic. We can't be ourselves in front of them. Our ableists, we can't be our own disabled selves in front of them. There's something about



walking into a room, not only walking, but walking, wheeling, limping, and hoping, right, because even movement is not linear.

Nu: So with that, I feel like during the pandemic, me forming Revival... I have a physical disability. So whenever I used to walk into a room, I would look at everybody's eyes, if they're staring at me. And I feel like after I have formed this community, even though I've not being able to go out as much due to the pandemic, when I do go out, I've seen a lot of shame has gone away, right, so that is one of the good sides of it. The bad side is staying at home alone because we're susceptible to the pandemic, to COVID as such as a virus because we have a chronic illness.

Nu: And I think we need to start by asking the certain question in our biology textbooks, in all of our textbooks, in our educational curriculum, which bodies are we talking about? When we say abortion should accessible to everyone, who is everyone, right? Are we including all castes, all abilities, all genders, all sexualities, all races? When we say, "What do we mean by accessibility?" Is the abortion clinic... does it have many stairs? Is it not physically accessible? Are the people accessible? So by this, I mean, do they have an accessible mindset? Are they ready to incorporate the disabled perspectives in their minds? Or do they exclude us from their mindset? We don't even come to their mind when they say the word people, right.

Nu: How do we navigate and find love during a pandemic when we are disabled? How do we navigate systems of virtual meeting when we have a speech disability, or when we are deaf, or when we are blind, right? How do we have access to an entirely new online world that we carve out for ourselves? How do we maintain disability affirmative? How do we make online spaces sex-positive, not only sex-positive, but disabled sex-positive?

Kwem: Thank you so much for that, Nu. Sam, is there something that Nu has touched on that you'd like to share a bit more about, or that has had resonance with you and as relates to sex and intimacy, especially during the pandemic, as well as before, is there something that you'd like to share with us?

Sam: Yes, actually, I mean, Nu has sort of covered how we've been trying to create more spaces for disabled folks, which are also queer-affirmative and disability-affirmative. But there still exists so much discrimination in these places that still exists in traditional spaces, particularly, because before the pandemic, most of our access would depend on traditional spaces. We did not have spaces of our own that we had created. This is a space that we've created only during the pandemic. So before that, there's always been a huge, huge accessibility issue in any space that relates to dating or sex or intimacy. All of these spaces have been sort of policed by able-bodied folks, and they've been built with able-bodied folks in mind moreso.

Sam: To give you a simple example of this, most dating apps, for instance, are all apps which, naturally, are not really built with accessibility in mind. We do not have image descriptions on the apps. You do not have the ability to hear your messages. On some of the apps, you can not even send audio messages to another person. Although of course there might be safety and security reasons for that, there is still no thought that goes into these apps when it comes to accessibility.

Sam: And the main reason for that, I think, is that, of course, most disabled folks and most folks who live with chronic illnesses are considered to be folks who would not be as interested in sex or intimacy or dating for that matter. They are considered to be... we're put into this category where we aren't really considered to be sexual beings or beings with desires of any kind.



Our desire is supposed to be one-fold, which is to get better or to sort of all work on our disability magically. There's never a desire for friendship that we speak about. There's never a desire for intimacy that we speak about, a desire for casual relationships, even, that we speak about.

Sam: And that's really, really untrue because I remember spending most of my life waiting for a friend who would understand my disability, more than even waiting for a significant other or partner. I waited for a friend who would be capable of understanding that my disability had ups and downs. So someone I could go to and just say, "Hey, that doctor is such an ableist," and they'd completely understand what I was talking about. They are someone who I could just go to and say that, "Hey, this place is so inaccessible, it's such a huge pain," and they'd know what I was talking about.

Sam: So I think that feeling of community is something that's always been missing. Even at the grassroots level, even at the level of friendship, you do not easily have people that you can build community with because there is no access because disabled folks don't meet and don't speak about things. Particularly in India, there's not a lot of culture of having support groups for disabled folks where we can just come and talk to each other. While there are support groups that exist at the parent level, at the level of the disabled person itself, there's no sort of support or community that's built.

Sam: So I think that's also really important when we talk about sex and intimacy, while it is important to talk about the desire for a partner, the desire to have a significant other, and how that's something that disabled folks also aspire to do, we also need to talk about how there's also a desire for platonic intimacy. There's a desire to just have friends who understand you. There's a desire to have spaces which understand you and spaces which are angry about the same things that you're angry about. And I mean, while Revival is a space like this, that's a space that we build on our own after 21, 22 years of living, but we've been disabled all our lives. And while we've been disabled all our lives, we've never had community all our lives.

Sam: So it's important for disabled children to also have access to each other, to also have the ability to speak to each other, to also have ability to build communities of support right at the beginning, not when they are already suffering, not when they already had lived so many years without that support. I mean, I think my life would have been a whole lot different if I knew that other people went through the same thing I did, if I knew that other people also experienced pain on a day-to-day basis. And I could learn probably better vocabulary to communicate about my pain when I decided to date someone, when I decided to get into a relationship with someone, I never learned those things because I never had experience of talking about these things at all.

Kwem: Yeah. As community being very central to living your full disabled self. And I think Nu really touched on that when they were speaking about how they do feel empowered since the founding of Revival mag, for just being able to find that community with other people with relatable experiences. Thank you so much Sam and Nu for sharing with us your multi-dimensional universe and the revival that has been going on in your lives, and that continues to. We are really deeply grateful that we've been able to share with us and our listeners today.

Kwem: From India, we're shifting over to Nicaragua to hear more from two young people on how they've been navigating life and love during COVID-19. Let's start by hearing from Chris.



Chrissh: Greetings. My name is [Aneska] Rodriguez, but I like to be called Chris. I am a non-binary being, I am 21 years old and I am a visually impaired person. In 2020, I thought I already had everything I could wish for at the time, a job, university, a partner. But the arrival of COVID in Nicaragua changed everything. In my house, they decided to do a quarantine that extended to three, if not four quarantines long. And at this point, I could no longer continue my studies. I lost my job, and because of this and other factors, I also lost the partner I had at the time.

Chrissh: I fell into a state of depression, disinterest, a terrible state of anxiety, and I really lost the will to live and the will to do many things since I had always been very active person. I liked going out, playing sports, going for walks, going out to spend time with my friends or my family. And the truth is that I love to feel the wind stroke my face and ruffle my hair, and I felt that I wasn't going to feel that again. And if it was going to happen, I didn't know when or how or where.

Chrissh: After a couple of months of being uninterested in my life, I decided to give myself the opportunity to meet a girl through social media. We started writing to each other, sending audios, making phone calls until everything became beautiful and an atmosphere of trust that I found incredible because neither online nor physically had I ever felt this kind of connection with anyone else. Generating this trust and this connection in all aspects, we decided to give each other a chance. And right now we've been together for a year and almost five months.

Chrissh: Living the love across borders has been quite a different experience, something I admit I was never prepared for and I wasn't looking for. But it is one of the most beautiful and meaningful things that has ever happened to me, hearing her when she smiles, when she says she loves me, when she says she wants to meet me, those are incomparable things. They're moments, sensations that I will keep forever. With her, I've been learning that kilometers don't matter when there's a union between souls, between hearts, when you're really willing to do everything in your power to make a person happy and to make them feel alive again so that they can explore again, want to fly again, as they did before, only now with a companion. A companion that although she will not tie you down, she will never let go of you throughout the journey and will never have the intention of hurting you.

Chrissh: I learned to merge my life with hers, eating meals together, listening to movies on apps, sharing our day-to-day, sharing photos, audios, videos of what we were doing. These are things I have never thought of doing that I sometimes even thought were crazy, but I realized that it's cute and that it's really very meaningful. With her, I've learned to take on new challenges, make new decisions and not be afraid of my negative emotions. I can't say that I've eliminated all of them, but the only thing I can say is that I regret absolutely nothing, having started a long-distance relationship because being so far away, because being so many miles away from me, it has been able to fill me more and has been able to make me much happier than anyone who has been by my side here in Nicaragua.

Chrissh: My partner is from Mexico, and we hope that when COVID passes, we will be able to see each other or meet in person because virtually we've been building a relationship of respect, a relationship of trust, a relationship of much love and understanding. Just as I included in my life, a beautiful relationship, it's important to keep in mind that society needs to include in every possible way. That inclusion is a word that goes beyond mobile devices, computers, or a document where the word is written. Inclusion is that despite all the barriers that may exist, whether of infrastructure, of communication, economy, time, space, it is knowing that as a person who



includes you will be ready, and that as an institution that includes, you will be ready to take action when this happens. So that all people you say you include can have a dignified development full of support so that together we can overcome all obstacles that come our way.

Chrissh: For example, a university that claims to include, should pay a little more attention to how working remotely in virtual spaces affect someone who's had an excellent grade point average all their life while receiving in-person classes. They should notice a difference, know that something is happening, and see how to work together with the student to improve this so that virtuality is not another inconvenience when it comes to wanting to perform, to want to be professional, and to want to have better opportunities in life.

Chrissh: Likewise, a company that claims to be inclusive when talking about work to go virtual, must find a way to really take into account all of its staff, or as many as its economy allows, but without putting the person with the disability first on the cutoff list. Another example of a truly inclusive university is that they take time to make their platform friendly to all people, that people with visual impairment can use it without assistance, that people with cognitive or psychological disabilities can understand it, that there's a section that includes sign language so that people with hearing disabilities can really understand what is going on. And so that all people with or without disabilities can learn together what true inclusion is, what it really means to work hand-in-hand to create a better future for this society.

Chrissh: That we be inclusive professionals and leave aside the bad competition that we've been taught since we entered preschool. Instead of passing over the opportunities of others, let us see how to take the rights of all people to new heights and that no one, absolutely no one is left behind. The day that all human beings learn that our rights end where the rights of others begin and that it is also our job to ensure that the rights of everyone are fulfilled, that day is when the world will change for the better because by respecting the rights and inclusion of human beings, we will be able to respect the rights of nature, which needs us so much.

Chrissh: I imagine my future will be very beautiful. I hope to finish the two degrees I am currently enrolled in, communication and law, and to be able to fight for the opportunities and the rights of the most vulnerable people of intersecting identities, to continue to be a feminist and an advocate for the LGBTQI+ community, to be able to keep my relationships beautiful and stable, being able to do something [inaudible]. I imagine myself having formed my own home, having children without submitting to the rules of heteronormativity. And I imagine myself being free and happy without becoming a selfish person whose freedom comes at the price and suffering or discomfort of others. I imagine myself defending my rights and those of the people I care about.

Chrissh: If everything goes well and my personal finances allow it, I hope to give opportunities to many women in the LGBTQ+ community and people with disabilities so that they can have dignified jobs. And I really hope to be very happy. I know that happiness is relative, but I'm sure that all the actions that I plan to do, that I am fighting to accomplish are going to lead me to a path where I can be happy because many people I care about will be able to be happy with the actions that I achieve. It was a real pleasure to have shared with you. Let's remember that inclusion is in all senses and that all people have the right to get ahead, to love each other. We have the right to pleasure and the right to true inclusion, and it applies in all, absolutely all senses of everyday life. Best regards, Chris.



- Kwem: We also spoke to 24-year-old Anielka, an activist that's been working in the area of sexuality and disability since 2018. I asked Anielka how navigating the long-term and long-distance relationship is like during COVID-19.
- Anielka: Entering a pandemic in a long-distance relationship, which we have been in for five years was very difficult because we already had plans for that time to meet and to celebrate our anniversary and spend it together. And suddenly they come to say, "No, there's a pandemic, you can't, you have to stay at home because your health depends on it." Well, obviously we had to abide by the decision. Although in my country there was no biosecurity restriction, like in the rest of the countries. We did it voluntarily and it changed the relationship dynamics a lot.
- Anielka: For example, it is true that we had already been messaging each other for five years, but now there was an uncertainty of, "Okay, we're going to continue messaging, but when are we actually going to be able to meet again?" Individually, we were both used to going out a lot and interacting a lot with people because we're both athletes and we move around a lot and we go to train to the university. So suddenly being cooped in our houses, for me, it led to a lot of depression, and for him too. We stayed awake a lot, sometimes we slept only during the day. We had no control of our schedules. We had no control of life in general. I mean, basic tasks became a little complicated for us, even at university, not because we were not familiar with online platforms, but because suddenly everything was part of virtuality from an exam to a conversation.
- Anielka: And then switching overnight to knowing, for example, in our sex life, that we were not going to meet, that we were not going to have physical contact also implied making many changes in the dynamics of our relationship. So yes, it was very complicated, But, well, let's just say that there was a lot of understanding, a lot of help between the two of us. That was the most important thing. I think that if we had not understood each other's situation, no, it would have been very difficult. We would have not have been able to overcome it and it would probably be over.
- Kwem: During my first chat with Anielka, we were discussing sexual and reproductive health and rights, when they said something that struck me, "We are not children." I asked them to elaborate a bit more on this.
- Anielka: Well, yes, we are not children, as I said. But as people with disabilities were often categorized as children, we are infantilized, we are overprotected. And that causes a lot of harm to people with disabilities because we're vulnerable because anyone can attack us, can abuse us sexually, psychologically, and in physical ways. They can hit us and touch us in areas such as the vulva, the breasts, the penis because many people with disabilities do not know the names of these genitals. And that is very, very, very bad because knowing information is power. And if we know about our body and what it implies, the respect that we should have for it and that the rest of the people should have for us, then that will generate that we can be attentive to any aggression.
- Anielka: But well, we're not allowed to do so on so many occasions, so it's difficult. And often it's not only because of family but also because the information available on the internet, which is now the only medium for many of us to investigate is not always reliable information. There is a lot of charlatanism, and because we don't have the information from a reliable source, such as our family should be, we are involved in many cases of rape, abuse, mistreatment, so many things. And many times they're normalized because it's believed that this is what one has to live and it's not like that.



Anielka: So what information do I want there to be? Well, I want there to be relevant information. I want people with, and without disabilities to know about sexuality, I want us to stop treating it as a taboo, as something that does not exist and that only exists in intimacy because no, sexuality does not only imply sexual intercourse, it involves many things. From the moment you relate to someone, in the way that you begin to explore the world, you are already exercising your sexuality. So it's important to know many concepts that if they were held in a general and open way and talked about calmly, I think that many things would be avoided.

Kwem: Lastly, I asked Anielka what they're excited to see in the future.

Anielka: For the future? That there should be accessible information for everyone without excluding any sector of people. And what information did I have before? I was fortunate to be part of a project on sexuality and disabilities, where I was part of a group that validated a guide specifically for people with disabilities, where these issues are discussed. So that was the major aspect, I already had some knowledge before but it was very basic. This aspect of the guide, this work, this project allowed me to know many more things, to learn more concepts, and above all it made me understand that, as I said, sexuality goes beyond sexual intercourse, which is what is generally believed.

Anielka: So thanks to that, I've been able to educate myself and also educate my family, and thank God they have also let themselves, and I hope that I can continue to support other people in this way. Being very honest about the future, what excites me the most is that I don't know what is going to happen. That is what excites me the most because I think that many good things can happen and it allows me to hope that maybe there will be accessible information for everyone, that sex will stop being a taboo. And that it will be something that we will be able to talk about in a free and responsible way with real information and not with false information. And that would avoid many things.

Anielka: So I would love for that to happen for there to be information, as I said, that is real, that is accessible, that is for everyone, where we can say, "I'm a lesbian and I'm happy," without people judging you. Or say, "I'm a person with a disability and I have a partner," without someone saying, "Oh, poor thing. They're going to leave you." I don't know. Things like that. I would love for that to happen. For people to stop judging you, for discrimination to stop. But those are my dreams for the future, and I hope they'll come true.

Kwem: Our last guests today are two young people from Indonesia, from East Nusa Tenggara to be precise, Ice and Geby. So Geby is a 20-year-old activist and graduate interested in social science, loves to read, and in future plans to become an entrepreneur. Ice is three years younger, and a high school student who loves to cook, is keen on learning English and plans to become a nun in future. With translation support from Paulan, the communication officer at No Leprosy Remains Indonesia, a major change-maker in the fight against leprosy, we hear on how Ice and Geby are navigating the ongoing pandemic as persons with disability.

Kwem: According to the 2019 national social and economic survey data, Indonesia is home to about 25.6 million people with disabilities. That's about 10% of the population. And yet 40% of people with disabilities did not access adequate life-saving information about COVID-19 and its prevention. This is following an online survey conducted by the Indonesia Disability Network in April 2020 involving 16,000 plus respondents with disabilities from 32 provinces. So I asked Geby and Ice what the experience of COVID-19 has been, how it's impacted the relationships, intimacy, pleasure, and access to sexual reproductive health and rights and services?



- Ice & Geby (Tra...: During the pandemic, I once shared my feelings and thoughts to my close friends, not about a boyfriend because I haven't got any. I've always missed my close friends, their presence and togetherness because they always give much attention to me, encourage me, and motivate me. Moreover, we always share experience together on everything. So when to release my longings, I call them or communicate through cellphone or Facebook because it is not expensive, and I use a free mode. And I loved it because I can communicate with low budget and no additional costs.
- Ice & Geby (Tra...: I have seen changes. For example, in my family, we used to eat together and closely at dining table, but after the pandemic, we cannot do it again due to physical distancing instruction, even though we are at home. Related to my friends, I still contact them, but I cannot meet physically very often. We meet each other by phone, video call, or WhatsApp. I feel sad about it, why are there so many rules for us just to meet each other? I usually share my feelings with my friends instead of my parents because I feel comfortable talking to them.
- Ice & Geby (Tra...: Talking about my relationship with my boyfriend, in the pandemic, it still runs as usual. But the difference is that before pandemic, if you wanted to meet each other, we didn't have to wear masks, not to take physical distance, nor wash hands. But now because of the restrictions, if we want to go out and meet, we have to follow the health protocol like wearing masks and physical distance, and we need to do preparation. If we have cold or cough, we cannot meet because we are afraid to transmit the coronavirus. So when we cannot meet, we usually chat through WhatsApp by phone or video call.
- Kwem: Himpunan Wanita Disabilities Indonesia, an organization for women with disabilities, researched the needs of women with disabilities during COVID-19 and found that 80% of respondents were facing abuse, with 40% indicating this abuse was happening daily. Needless to say, responses such as lockdown measures has had an impact on these numbers. I asked Geby and Ice how as young Indonesian people with disabilities, the local COVID-19 measures has impacted them and others around them with disabilities, and what has been coming up for them as challenges and opportunities?
- Ice & Geby (Tra...: The COVID 19 measures can help protect and prevent us from getting infected by COVID-19. And I see there are opportunities for us to follow the health protocols well. For me, COVID-19 measures are not so burdensome to me and to my friends with disabilities. Instead, they are good to practice. We are so grateful with the government's health protocols, such as wearing masks, washing hands, avoiding crowds, and staying at home. With the measures, I can also encourage my friends to follow the COVID-19 protocols.
- Ice & Geby (Tra...: With the national COVID-19 measures, I can also use the opportunities to share my experience as a person with disabilities due to leprosy through KBR radio channels program on progressive view toward inclusion, in Live YouTube and online Zoom.
- Ice & Geby (Tra...: I think there is one measure, namely obligation to wearing mask. Surgical masks cost very expensive, and we can use it only once after several hours.
- Ice & Geby (Tra...: I know this one good opportunity. We have a good habit of washing hands. It is good to practice it, not only in the pandemic.
- Kwem: Geby and Ice elaborated on how they're still able to find ways to access sexual reproductive health and services and comprehensive sexuality education despite the COVID-19 pandemic.



- Ice & Geby (Tra...: I have received a lot of experience and new knowledge. I have participated in several events, such as a webinar on community practice in communication, reproductive health education for children and parents, standing program in emergency situation, and the 2021 Indonesian Youth Summit on youth of various identities for inclusive Indonesia, and webinar on dissemination of COVID-19 impact study on people with disabilities in Indonesia. Another change that I experienced is my participation as a child champion in the My Body Is Mine project [inaudible] and FRIDA Foundation as a child with disability due to leprosy. And I also learned about sexual reproductive health.
- Ice & Geby (Tra...: During the pandemic I visited health clinics in my village. I was treated warmly by health staff. Health service does not differentiate between those with disability and those with non-disabilities.
- Kwem: And so what do Ice and Geby hope for young people with disabilities and their sexual and reproductive health and rights in Indonesia during and beyond the pandemic?
- Ice & Geby (Tra...: We badly need sexual reproductive health services and new modern facilities. Also, we need initiatives and supports that can broaden our perspective. I hope that my friends with disability and I can get sexual reproductive health services equally as stated in the Convention of the Rights of the Child.
- Ice & Geby (Tra...: I hope my friends with disability and I can still have access to sexual reproductive health services, and I hope the pandemic will be gone.
- Kwem: So that's all we have for you today. I hope you enjoyed listening in to today's conversation and you'll carry the different reflections with you. Join us next time, we'll be talking about self-managed abortion. Until then, take care.
- Kwem: The support of Not Your Usual Subjects podcast comes from staff and volunteers at Stories To Action who are conjuring alongside young people situated across borders all around the world. Together we envision a world where every young person's voice is heard on their sexual health and reproductive rights, even in times of public health emergencies like COVID-19.
- Kwem: We would like to honor, thank, and acknowledge all our contributors and guests for sharing their Stories To Action. Share-Net International Netherlands, who we are so deeply grateful for funding and resourcing this podcast reminds us of the role that philanthropy in working with youth in the diversity should and can play in raising collective consciousness.
- Kwem: Please head on over to share-netinternational.org to find your regional hub. Please commune with us on social media to find out about our next episode and share your feedback, thoughts and reflections with us, this is on Facebook, Twitter, Instagram, LinkedIn, @StoriestoAction. Links are available in the show notes at the podcasting platform of your choice that you listen to us from. Please share this episode with someone or someone you know should have a listen.
- Kwem: (silence).

