

Rampe? Reicht! Season 2, Episode 8: Black Perspectives on Disability, being previously disabled (ft. Christiane Hutson)

SR: I've studied this topic, "scientific podcasting", that's why I'm taking the lead here so dominantly (laughs)

SR: ramp (everyone laughs)

tier: ramp

CH: enough!

tier: 20 minute podcast with

CH: me! Christiane Hutson! (everyone laughs)

SR: yey, we're happy! this is so great! am SchwarzRund

tier: and I am simo\_tier. and we will start immediately with the questions! we got to know you as a scientist affected by social disabilities and wanted to ask: how do you position yourself today?

CH: At the moment, I would position myself as healthy, privileged, abled. Exactly because what I had, what I had, and that mainly led to my positioning myself as a scientist, was a disease, which I've had it since I was 14, but then at some point it became visible and the stress that it caused me, it just led me to really deal with it and also noticed this difference very quickly between: ok, what is actually now, so what "problems" is my body causing me and the much bigger problem with: what problems do the people around me cause me! and yes, then it was just a small step.

SR: That can just change over time, how we are allowed to feel and how terms shape our lives and to this end there is an activist whom we quote here very, very often in the podcast, Kat Blaque, a black trans artist who describes: the terms that used to totally hurt her, meanwhile can no longer cause her any pain, because, through cis passing, she is read everywhere as a woman and is understood as a woman. and yet she emphasizes that this does not change anything in terms of marginalization and oppression and that her resilience is not an allowance to add harm to others because of this, or not to believe them, or even to believe that it is somehow over because of it. and while talking earlier you also spoke about the fact that this risk of individual relief, as I would now summarize, can often be confused with liberation. what is the difference for you?

CH: a few years ago for me it was more like: I have to pry things open, I have to be careful that the space I have doesn't collapse on top of me. and I had, even in workshops like this: "present your problem as a figure!" I always had something I had to press against somehow, or I had the image of "I'm sitting in the car, at a traffic light and want to drive off, I'm in a hurry and then I always want to stop. so the traffic light is red and when it turns green, I always choke up. I have a lot of energy and pressure and can't let it out and now was the moment for me where I just noticed: "Oh, you are healthy, privileged" when I was with the, that's something extra consultation cancer patients get, there I was and my "problem of the week" was that I have so much time! I have the feeling that life is like a red carpet being rolled out in front of me! I don't even see the end and I don't even know what to do now, because the feeling for me was completely, yes, completely new, so I've never had that! I know that in my mid-twenties or something I had a conversation with another disabled activist about what do we think how old we will get and I answered like this: "yes, maybe mid-30s early 40s" or so. but this, so now I'm almost 42 and but with a completely different feeling, because this, this pressure is not there! and the problem with that is that I can now put things on the back burner! So where I used to think: "It is absolutely necessary that I do this right now, even if it sucks!" (laughs) I have something like: "oh, no, hmm hmm, maybe I should think about it again, maybe ..." instead of pushing, pushing, pushing out! of course, I'm a big fan of self-reflections like that, but that works with me anyway. I shouldn't allow myself to deal with it negligently just because I have so much space.

SR: how would you say that your blackness also plays a role in this, so for the people currently listening to the podcast, they don't see us right now, that's why I'm briefly positioning you from the outside (laughs) exactly, and what I mean by that, how that plays in there. Society already has certain ideas about what we as black people are allowed to do, what we are not allowed to do, what we have to do at what speed, or do not have to think about it at all. (laughs) there are lots of ideas

about how we should shape our lives and yes, somehow there is also a shortened life span that is scientifically proven. it comes in on us in several, several directions and I would like to ask you: how do you deal with it, so in your text you wrote that this, I use Sarah Mouwani's term, this "to introduce an analytical separation" between everything is also violent and not necessarily helpful at all and now that you have this what I wouldn't call excess energy, because I think we should all have that, that sounds wonderful (laughs), you have the energy now you would say that you now separate more, so do you see it only as a consequence that "not being socially disabled" or how does being black play a role?

CH: Well I think without being black I would have needed a lot longer for myself to understand that people sometimes, so this maliciousness of the isms and that has nothing to do with "it's somehow up to me and I have to change that"! I would never have checked that without being black! So basically the first text that I had about illness that was illuminating for me was from Troy Duster, where he said: "Well, black people," He referred to the United States, "just have a completely different story with the medical system! " It is not an ideal world for them and I will definitely be helped there. where I thought: "yes exactly!" And if I was missing that and ok, what does that mean for the German context! I almost believe this difference in energy levels, which i was only able to perceive now through this change from visibly ill/disabled and then privileged, healthy. I can't do that when it comes to being black. But what I find very cool is for me, I always found it totally ... I'm always completely stunned when you, when I myself in such cool black workshops, or critical witness or about racism where then really people are with whom I get along and when it comes to privileges and "well we just don't notice it" and then there is this by Toni Morrison "what happens with the hand that emits the acid" where I think "uh!" then once I got so excited: "People have to notice that when they act like an ax in the forest!" (laughs) now I'm just thinking a lot, "okay, how do I know that I'm the ax in the forest right now", and that's why I hack on this excess energy because it has now become so clear to me, it's just, I had that my parotid glands were very swollen, so it looked a bit like mumps or "hamster cheeks " it would be ... and then I noticed that I was thinking about should I wear a cutout now, so that I wear something with a v-neck, or that I do my hair so that you can't see it, because there were bruises and so on, so for a long time, or not going out at a certain time , that was a very long series of things where I noticed: "ok, i'm not doing any of that anymore and i don't even have to worry!" so i just go out! exactly, and when i made this list i thought , it got me to this "yeah yeah, stigmatization and what strange things stigmatized people do so that it doesn't attract attention!" and then I thought to myself: "no!" (laughs) "that's not how it is. so i'm not the problem, i'm doing more work so that other people can go through their privileged life without irritation!" and that's the only reason you have so much energy! to be able to spend yourself! and not for I have to do something for others right now so that they don't attack me !

SR: I have to stop at one point because I'm doing that right now (makes a rattling noise). That's a really big topic for me right now: Anzaldúa, a Chicano thinker, i.e. Gloria Anzaldúa, who for me as a black Latinx was incredibly important, all the time on the subject of classism, race, even marginalized blacks, disability, queerness and so on a word introduced that means "la facultad", I don't know if you've heard of it before, and with that she describes the, yes, it is difficult to say in German, the "empowerment", let me say, of marginalized people through the trauma of what they have experienced to have finer feelers. so that you can see better what is in store for you. and what Anzaldúa describes is that this "la facultad" is nothing that we perceive as extra. so i can't tell "that's what simo is really saying now, or that's where my trauma already has "feelers"? but for me it's all the same, so for me the statement has the same sharpness that I only make the distinction because people who don't have "la facultad" like me, see one as true and the other as a presumption. For me that also plays a role in what you just said, how quickly we are denied that we protect ourselves through behavior is marked as "crazy" or as "overly cautious" or, so there could now be different terms, but it is definitely stigmatized somehow in such a way as "but does it really have to be now Christiane?" (laughs) "Is that really important now ? Which excerpt, so isn't that actually victim blaming?" and somehow I find it so exciting that it already has this approach, I think she wrote that 87? I am always angry when there were texts before my birth that describe the things that I now

have to justify! I wasn't even born then! (laughs) Exactly and this la facultad, do you have the feeling, well i'm just sticking to this term because i push the spanish-speaking agenda massively in all spaces (laughs) this la facultad, do you have the feeling that this is what maybe now becomes even more invisible where you are no longer "visible" as part of a community that has la facultad? CH: I think I have or that's just something that I consider to be so difficult of this thing for myself that sometimes I go crazy with it. I had, for example: I should have gotten some kind of a probing, it has such a technical name, it doesn't matter, a sample of the lungs should be taken and I went there and thought: "Ok, here I come as an empowered black woman, I'm not sick at the moment, nothing can happen to me, he should just take the sample, he won't even make a comment, great!" so i thought it was going to be a male doctor strangely enough! and then I sat there and had to wait and then came a reall nice, I could say really sympathetic, a white female doctor came who was very caring for another patient who was sitting there like "you may come with me now, etc." and I thought: "she is nice, I hope she's my doctor! " and then an old white man came along, no, no ageism, but it was someone who might make me afraid! so just the presence of this person scared me. and i thought to myself this is what i think is so sad about this medical system, the way it tackles, that is to say to time and performance and yes. it would have been great if I could say, "I'm scared of you!" but I didn't dare to do that and I should have said: "As a black woman, I'm afraid of you." yes, but I didn't do it because I thought it wasn't appropriate or something. because after that, so he did everything he had to do and after that I had to stay there for another hour, because of general anesthesia, I didn't notice anything. and when i woke up i had a lock jaw, so that's if it somehow gets through the mouth, it doesn't hurt a lot, but it's super uncomfortable, it also scares you! the jaw! and I had, so out of fear I didn't say beforehand that this could happen, that I could get something like that and it wasn't in those stupid forms where one was asked about everything possible, even about genital piercing was asked! I thought "ey it's about the lungs! what do you want?!" and then later, while they were preparing me for the procedure: "yes, that's because of the x-rays, etc." (frustrated exhalation) so exactly and when I woke up I said: " I have a lock jaw" (speaks like a person with lock jaw) nothing! "yes, go to sleep again" really, middle finger! I can't sleep again now! And all the time that I've been waiting there, they just ignored it again and again and in the end this doctor came along and was totally upset: "you filled in everything in the forms, but not that!" and I thought: "ey, dude" and he got so worked up and I was so glad because suddenly I had a flash of inspiration and said: "please stop yelling at me!" and he was like: "uh, eh, eh" where I then thought: "phew, good!" and then all of a sudden it was "yes okay we can call your dentist, etc." but I thought, well that was also where I discussed it with a friend afterwards, with a white friend who sai: "Well, as a private patient that wouldn't have happened to you." where i thought: "ah, yes" and that's just one point where i'm totally angry that i didn't listen to that, to my feelers and yes. and I now from the outside something like "you exaggerate" that I rarely have, because I think I am very, very choosy who I tell what to. and most of the people know, well they have known me for so long that they know oh yes, this is Chrissi.

SR: yes, that is basically the access to a "healthy" health system, I don't know how I can formulate it better, so a health system that does not make us unnecessarily sick was then made more difficult because you practically did not access your wealth of knowledge were able to access almost unquestioned, which is reality! So even when people say they only believe in statistics and research, that is simply the reality. no matter how we find access to this reality, but that kind of knowledge is only stored in you at the moment. so maybe the optimum for me would not only be that you can tell the doctor that, but that the doctor says "ah, ok i have a black patient, maybe i have to ask again because i know that there is this pressure on patients. maybe we'll talk it through again." so, and I think that's where I always struggle a bit with this black excellence, black leadership, black perfectionism idea, but where the point is that we should, as it were, overcome what oppresses us. I think that's very important, so I think blacks voices are very important and I think disabled voices are very important, but I notice that I am struggling more and more with hearing that in empowerment contexts. that's why i'd like to add a quick quote, because i always find it important to name sources, because most of the thoughts didn't grow on my crap. a black fat queer latinx

tweeted: "friendly reminder that you can't outachieve trauma" [@JulianThePoet] so you can't work it away, you can't be better than that. and I think I would go even further and say there is somehow a form of vulnerability in it. If we say I as an individual can now in "the racism TM," "the classicism" like private patient - health insurance patient, at the moment not overcome by me I behave perfectly with the right sentences, in the right way, so that nothing will happen. I think there is a lot of pressure on individuals. Because at that moment we are just there and have an examination and anesthesia and maybe that is already enough (laughs) to cope with at the moment. That's exactly what I'm thinking about this "outachievement" and I think that was what I told you before wanted to ask, this now that you have more energy because ableism does not take up so much space, do you have the feeling that you are now being more pressured into this image of "non-disabled blackness" achieving, achieving, achieving, overcoming" or is it so far removed from the reality of your life that it doesn't happen?

CH: I believe the latter, that is because I am very, sounds strange now, but I live very withdrawn, so I rarely do anything in community contexts and what is also related to that, so that this is the process of one for me "Black awareness" and awareness as a disabled person, yes, that it ran very close together and then I also had black community experiences and white disabled communities, I thought "yes, ok" (laughs) I didn't even want to go! So it was just ruled out at the moment, because I think what I think about the, or where I've moved in a lot, in the us-american context, disability justice, and the people, so what they say I thin is cool, because there's a lot going on, so everyone benefits when we and the others say their needs, it then works out better for everyone! and I think that's very cool and that's also something that I sometimes lack in the "classic" understanding of being black, this "yes it's ok" and also needs, so not so "I have a requirement" but: "hey I need that, otherwise it won't work for me."

SR: maybe even a "I have a need to make it nice for me!" (laughs)

tier: people are talking more and more about so-called "micro aggressions". Already in your text on multidimensionally vulnerable you dared to shift from the question of how exactly privileged people are motivated for their actions to a radical focus on the marginalized person. The question now would be: can you perhaps use an example or picture to make it clear again what marginalization structures do with us?

CH: yes, I think that's what I said at the beginning when I said it feels like i'm holding room, like the walls are collapsing. So I believe, and that I feel that way. and I have to keep it all going and I'm so busy with it that I don't even think about asking "why is it all collapsing?" So it is this and constantly questioning myself and taking it less seriously than the opposite person. so as less important. So basically this service thing that I had at the beginning, where I have to do something for others, take up more space and I don't have enough time to think about what I actually want to do for myself? So yes, I think that's what makes up a large part of these marginalization structures for me. So otherwise, when I imagine the prick, it's as if I'm lying under a sewing machine and the needle just sticks down and I usually have the feeling, especially if you think about the marginalizations separately from each other, I have, or a person has the feeling: "yes i turn a little to the side and then the needle goes past it and now i make myself very small and it goes past me" and with pricking, so i don't know that .. i went with my children to the museum or we had to prick, it was like pricking at such a piece of felt so that it would then become a shape and I thought to myself: "Yes, that's exactly what happens!" just wildly punching with the needle, then you have the stereotype what you want, the structure and I think the nasty thing about it is to be believed over and over again "well ok, I don't always notice the needles, it's because there is space so that I can meander around it or in between. and that is not the case! and even if I am not hit directly, so to speak, the ground below me trembles because someone was hit a millimeter further away.

SR: yes full, I can imagine that very well and that also takes out a bit of this difference from "I the privileged person - you the non-privileged person, I only listen to you have to act" so all this binary that we always bring into it but ultimately it just shakes the whole thing, the whole piece of textile (laughs) everything is moved by it and the only question is whether we are now lying under the sewing machine and if we have a disability that is what I think super good picture, because a large

part of the people in their lives will experience social disabilities in one way or another and because this "yes-no-picture" doesn't work as well as it does with being black, for example. do you have a text or a video, a scientist, a person, something where you say: "be sure to check them out, I think they're great?"

CH: Leah Lakshmi Piepzna-Samarasinha, she is great, everything about her is great! (laughs)

SR: Thank you very much for being with us, it's a huge honor! and we hug you firmly through zoom! (everyone laughs) Thank you very much for listening, watching, reading. that was rampe? reicht! with Christiane Hutson!

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