

Rampe? Reicht! Season 02, Episode 01: Who is allowed to call themselves disabled?

SR: (sings) it's autumn

tier: (sings) I have arthritis

SR: (sings) can I say that?

tier: (sings) have no diagnosis

SR: (sings) whether you are entitled to use the word

tier: (sings) "disabled"

SR: (sings) is what both: (sing) this podcast is about today! (both laugh)

SR: rampe?

tier: enough!

SR: 20 minute podcast about

tier: today we're talking about whether a person needs a diagnosis, for example, to be able to call themselves "disabled, sick or crazy"

SR: Exactly! I'm SchwarzRund and currently I'm still writing my novel and my master's thesis.

tier: i'm simo_tier and currently i'm working on a couple of new zines and other projects

SR: nice! yes, this is the second season of rampe? reicht! and I wonder how did tis topic come about?

tier: it's something i think most disabled people, will think to themselves. And we also got some emails between the seasons where people actually asked us that: "If I am like that, can I call myself this or that?"

SR: yes, partly also in brackets, something like "I'm bla, and I think I have this and that, but I don't even know whether I can call myself disabled".

tier: exactly

SR: exactly! that's why we want to talk about it today. i have access to the topic because, for example, my main diagnosis did not exist in the ICD10 until 2022.

tier: (laughs) yes that's really I think like a textbook example which many might have gone through, especially when it comes to rarer things or things that are very difficult to diagnose. or even if one doesn't have access to be diagnosed, for example.

SR: exactly, or if social levels prevent people from being diagnosed.

tier: oh yes.

SR: For example, as a trans person, it is very dangerous to go into medical transition in germany with other diagnosis

tier: oh yes.

SR: yes, because that won't necessarily help you

tier: no, definitely not!

SR: and as a black person there are things that would just never be diagnosed on you.

tier: mhm

SR: exactly, maybe we can split it up in such a way that we first talk about what things are that have made diagnosis difficult for us.

tier: oh yes (laughs)

SR: because i have the feeling that this is often missing in the conversation! when it's said: is it good or bad to diagnose yourself without talking about why do people actually do that?

tier: yes maybe this is really a good starting point. would you like to briefly tell something about you ..?

SR: that's exactly what I mentioned before with the one diagnosis I have, that's CPTSD, or in germany it will be called KPTSD, which I find a bit funny

tier: mhm

SR: exactly: PTSD stands for post-traumatic stress disorder and CPTSD stands for complex post-traumatic stress disorder. and what's important: complex does not mean "worse" or "less severe", people who "only" have PTSD often feel attacked and then think "uh, they want to be extra somehow" (both laugh)

tier: yes, i with PTSD, for example, am very very upset (irony)

SR: the large complex

tier: because mine isn't complex ..

SR: "cool PTSD" (both babble and laugh)

tier: that's irony again!

SR: CPTSD simply means that the experience period was mostly earlier, there is no reality that can be accessed before the trauma and that is almost completely woven into the fabric of one's own identity. So I always say as an example: if you had a car accident at 14 it will probably be PTSD

tier: yes

SR: but if you only get to know it from birth that driving means that someone tries to build accidents to kill you and that becomes your normal relationship with driving and you think that's the way it is, then that's CPTSD. that's very simplified now, but

tier: I think that's a good description. because I've actually thought a lot, so I know that it's complex CPTSD, complex PTS, CPTD ... ok ..

SR: Complex PTSD

tier: you know what I mean and I actually thought for a long time and I forget that sometimes and still think that, but that's my autism again, that it's called childhood PTSD.

SR: yes, one could think that, which I think is mostly the case, but the term is also used, for example, when someone gets married at 18 and is in a cult, for example, and then has been married in it for 30 years, then that too is CPTSD

tier: yes

SR: and I think it's important to remember this group of people.

tier: definitely! yes, that's a good explanation now, because I think many people also think with the childhood trauma PTSD or something

SR: exactly

tier: it's that too, but not only!

SR: not only, exactly and why this self-diagnosis is so important to me, is that with CPTSD it is simply quite dangerous to do some treatments that are exactly right for PTSD or depression.

tier: mhm

SR: so the typical example is, for example, eye movement deconstruction re ... progr..blb. EMDR eye movement desensitization and reprocessing and with EMDR it is so that you are put into a kind of hypnotic state by a monotonous noise, something like "tick-tack" or that the therapist taps on both of you cheekbones and thereby you slip off intentionally in order to be able to deal with the trauma on another level. it is a very very successful form of therapy, but with CPTSD not so good because everything that is monotonous, for example clocks ticking, and so on and so on, doesn't take me on a meta-level, but literally brings me back to the traumatic situation.

tier: oh, ok.

SR: as I always describe it, the difference is: if you've driven a car before and you've had a car accident , you can think about, "but I used to drive 20 times and nobody tried to kill me "

tier: yes

SR:" that was good ", so you can slowly learn with this strategy that it becomes almost overwritten with new experiences, but also with old memories.

tier: ok!

SR: but that doesn't exist for me, that means: the only thing you overwrite are the old memories about the current trauma and everything is getting thicker and more terrible and (laughs)

tier: oh god, not good!

SR: not good, exactly, and that's just the way it is with a lot of things, that's why this diagnosis is so important and is now finally going into the ICD-10, into this diagnosis catalogue, but that's why almost inevitably all of people with CPTSD are not officially diagnosed because it's not possible!

tier: which doesn't mean that these people don't have the diagnosis! they do! and maybe this is really a very good example for "what is considered official? what is there, what is not?" so that's a very structural level, but even if we then look into the smaller, into the personal level, for example,

diagnoses that are known, so of course autism comes to mind for me as a thing that is very common, but because it is very difficult for a lot of people to get a diagnosis, firstly because it is really difficult. period. in germany. but because it is often not seen that autism is a spectrum and manifests itself very differently in different people

SR: and the gender bias, right?

tier: that's exactly what I wanted to come to now, that when in women and girls, autism often manifests itself differently on the spectrum and is therefore often not diagnosed and yes, because many people who experience sexism and other forms of oppression are also much better at adapting and therefore autism isn't often visible from the outside but very often from the inside, so I know that with me and with many other people who just experience different forms of oppression that at first people simply think "I am somehow like so and i don't understand it." and then you meet people and they say "ah, i'm like that as well" and you keep on learning. and is like "ok, probably i am this now", but then the question is mainly in adult age: does one need a diagnosis at all? I know autistic people who don't have a diagnosis, they don't have the feeling that they need it, which I find completely legitimate. I got a diagnosis, but only for bureaucratic reasons, namely to increase my GDB [grad der behinderung], degree of disability.

SR: yes and I think if you mean that it is difficult to get such a diagnosis in germany, there is also this thing that it usually takes a moment to develop the realization, so "now XY is a barrier for me in everyday life" and if you have something it is not that you, before you know your diagnosis, constantly think "damn it! autism again" but the world is just complicated or, or, or

tier: yes exactly

SR: yes and otherwise it is just , yes, we have already addressed a few levels. so who has access to the medical system? finding a neurologist is much more difficult than finding a psychotherapist sometimes

tier: yes, exactly!

SR: why go through the diagnosis first before I actually get help? because neurology doesn't necessarily help you actively, but maybe they give you medication and both: the diagnosis! (laughs)

SR: but if you say "actually I want to finish my education and can't cope with the depression" you might rather go to a day clinic than getting a diagnosis first. there are so many reasons why it is simply practical to have a rough idea of what you have before getting a diagnosis and also to know the bias, especially when we are dealing with fibromy..hmm

tier: fibromyalgia?

SR: exactly! or autism and so on. Depression, being bipolar is incredibly difficult as a black person or brown person to be diagnosed with, because things are racialized and so on and so on

tier: oh yes

SR: yes, so let's start with the topic why do people actually do that and that's not so unbelievably different to how everyone else ticks, it's always a situation-related thing! if you have a cold you can say: "I have a cold, I have a cough."

tier: exactly, why is the self-diagnosis ok, but not with a perhaps more complex psychological things or other matters? so that's where I think we should talk about the community aspect: what does that mean? does community, or to i.e. to participate in groups, to find exchange, because many disabled, chronically ill people, neurodivergent people and so on, often the only access we have to our "diagnoses" is medical and that is usually not very supportive! you go to the doctor once or every few years or months and then you sit alone with it and I think exchange is incredibly important with these things too.

SR: I think what bothers me about it is this picture of "copy paste", so there is, in the end a lot of it is always based on an idea of exclusivity, right? so if we look at the black movement: this thing of "we are now doing black politics and only black people are allowed to this meeting because we want to force a black policy." so in relation to being black it makes sense, because that is a category that has been assigned to us. and when we say "ok, you assign us to be less worthy, us as a group of black people, although we come from different countries and so on, we then take your categorization to differentiate ourselves."

tier: yes

SR: because we don't say "we are really the same", it was never the idea that we as black people really are the same, but we say "in this one point, in this artificial categorization against being white, we experience the same thing!" and now white disability activists suddenly say "only the right kind of disabled people are allowed to participate!" and refer themselves implicitly to the black movement. And that, well that would lead a bit too far now, but in the queer scene it is exactly that which leads to a crass transmisogyny, this decategorization of being a woman, always with this implicit reference to black groups, to asian groups, that have organized themselves this way, which doesn't work at all for disability! and I think with disabilities it gets really, really, really, really difficult and dangerous, because first of all: these are just as artificial categories, but they are still being artificially drawn all the time.

tier: yes yes yes!

SR: they are constantly being rewritten, for example right now I am someone with PTSD and in 2022 what is already in my neurologist's book will be rewritten as CPTSD.

tier: yes

SR: well, it shows how ..

tier: .. artificial

SR: how wobbly the limit is and someone we have already recommended to you several times, Jessica, makes it clear that denying people to be their illness or disability is much more violent for the community than three people who might say they have DID, but in reality they have some other personality disorder or something. i'm not saying that it's not painful in the moment, i totally get that! but it's not the same as a white person who tries to become a black professor (laugh)

tier: ai, yes, no! (laughs)

SR: it's put in the same way! and i think that is what is actually the discourse behind this criticism of self-diagnoses from a disabled perspective.

tier: definitely! so i'm very pro self-diagnosis and I think that should be handled in the same way as other categories that might be similar, such as sexual or gender identity, because that's also something.. like i'm autistic and that won't change, it's a part of me and i didn't choose it for myself and that's so .. it is what it is and that's why i would never deny someone else who says "this is now my reality and that is how it is." how do we want to control that? do we want to say at some meeting for disabled people everyone should bring their diagnoses, right? so it's just absurd!

SR: yes, so it is clear how it is then used again, the person who is too feminine to be autistic, the person who is too black to be bipolar, then we already notice which tools we are using: that is the old damn tools, the rusty ones lying in the corner. and i think another aspect that comes with it is, now we have talked about it, why do disabled communities criticize that? but what do you think, why do the state or society or something like that criticize self-diagnoses?

tier: that's a good question! the first thing that comes to mind is probably because the more we deal with who we are, with whom we want to work, and so on, the more we can emancipate ourselves and join forces in order to have more strength! so, like now, a lot of movements can be created.

SR: the veteran movement comes to mind!

tier: yes, very good! because the more we will open, connect, work together, and the more we are in numbers, the more strength we have, and power we have to maybe change structures and society.

SR: and I think maybe, I can think of two more aspects, I don't know if that goes a little too far, but one thing would be: it's mostly about these in-between people, i.e. people who get their job done, make money, but might have something like schizophrenia for example. if they now start to participate in society then it is not just anyone, these are the people who work enough in capitalism to give money to the movement, to give us structure. this means: those who are of no use in capitalism, if they organize themselves well then .. [sarcasm] that's just the way it is

tier: yes.

SR: but when suddenly the "in-betweens", who aren't really "in-between", join in. and the other thing that comes to mind is always this idea of obtaining benefits by fraud.

tier: yes it is important that you mention that!

SR: and I think that's my absolute favorite counter-argument, which I can't say exactly who originally said it: even if! for example we just had this example that a teacher showed you the school before your first day of school.

tier: yes!

SR: and that made it easier for you to be prepared for the new situation.

tier: exactly exactly!

SR: That would be cool for all children!

tier: that was really great!

SR: That would be absolutely a totally good thing, regardless of autism!

tier: so why is that seen as fraud?

SR: exactly

tier: and not just a barrier that is being dismantled that would actually benefit everyone?

SR: exactly! yes i think these are points that play a role with self-diagnosis. so if you're getting upset about it a lot about it or think "wow, all the people who always say they have OCD!" that annoys me too, I have obsessive thoughts, so a sub-category of OCD. maybe you just roll your eyes, but shut up! because in the end it hurts more to being denied to belong to the community. you can tell, I almost don't want to say it: to keep the community "disabled enough", to keep it "pure", it always sounds fucking disgusting!

tier: uh, yes, really! and maybe when people use a word because of ableism, I think there are people who actually have OCD and say "I have OCD", that doesn't necessarily mean, that is not necessarily the same. and if you are just talk for a few more sentences with such a person, I think it becomes clear very quickly! so I think the limit there is also very easy to break.

SR: Exactly! I think there is ultimately no clear limit and it's what is so extremely difficult for us as a society to accept. exactly, we wanted to chat about that with you today to give you a first insight and hopefully bring that into your communities too

tier: yes! so let's start with the second season! a little soft start, or not so soft? I don't know, but it's nice to be back! in case you are wondering about our little song at the beginning: we are recording this now in autumn. we always like to take a lot of time but ..

SR: if the arthritis-police is listening and saying "wait a minute now!"

tier: then you can call me and I'll tell you what doctors have said about this matter to me so far and then... yes! (laughs)

SR: Exactly, that was our idea for today's podcast! many thanks to everyone who wrote us e-mails and shared this uncertainty with us

tier: definitely!

SR: and call yourselves whatever gives you access to things, because capitalism should never withhold these things from anyone at all!

tier: yes exactly! many thanks to everyone who supported us financially via our paypal account and patreon where we can be found everywhere as a rampereicht, or on rampereicht@gmail.com, which is our e-mail address

SR: and you can also send us questions there! we would be very happy if you all have questions about disabilities and mental illness and mental divergences, just go ahead and dare to ask! it doesn't have to be perfectly worded, you can write anonymously, you can write "please read it out exactly like that" or "for heaven's sake, don't read it out like that" (both laugh) we'd be really happy! if writing is not for you then just record a short spoken message and attach it to the e-mail, that's no problem at all, then we'll just listen to it.

tier: the next episode will be available in two weeks, as usual. as I said, we look forward to being back! you can still find out everything on youtube,

SR: instagram, twitter ..

tier: everywhere as rampereicht

SR: uh, and you can also follow us via stitcher, via spotify, or simply via podcast, no, just add it to the feed via rampereicht.de if you are a rss feed user. yes, and that was the first episode. we have a recommendation for you: in keeping with the topic of self-diagnosis, we don't want to link intense

content-related input, which tells you yes or no, but want to recommend Casa Kua!

tier: a new resource that will hopefully help a lot, and we are very happy about it! it's is a trans inter queer community and health center, which is mainly organized by the BIPOCs and is already open. and there are a lot of great offers and ..

SR: courses and everything is ..

tier: recources!

SR: it's in the former schokoladenfabrik in berlin and just check the website casa-kua.com we are:

tier: disabled

SR: crazy

tier: self-diagnosed with different things

SR: queer

tier: trans

SR: black

tier: tired

SR: and this podcast

tier: is it as well!