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SEXUALITY SOCIAL JUSTICE

CONTENTS

9. I couldn't see myself, so how could I expect anyone else to do so: Disability, sexuality, and social justice

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Nowadays, when you want someone to come to your social work, psychology, counseling, or education focus class, my name is one of the first ones tossed out, along with Robin Wilson-Beattie, Bethany Stevens, Andrew Gurza, Bianca I. Laureano, Robin Madell, and a few others...but it wasn't always like that.

Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

that had likely been filmed in the 1970s, with a sex surrogate working with a client in an iron lung. Disability was barely touched on, and when it was, the content was so outdated that it made it hard to connect with what disabled sexuality could look like today. Even as someone learning to navigate the world with disabilities and impairments, I could not see myself in the disability conversation here – it created, inadvertently, an othering narrative. Despite navigating daily pain and neurological concerns (as well as not yet diagnosed autism, so trying to perform neurotypicality in an allistic centered world), I fell into the ableist hierarchy of disability – “I wasn’t like THAT, so of course I was not disabled.” This conversation didn’t apply to me, because “at least” I wasn’t trying to navigate my sexuality from an iron lung.

I have been disabled, chronically ill, and neurodivergent my whole life, despite not realizing it most of the time. One of my earliest memories is waking up when I was 3 years old, my body completely covered in hives. After multiple trips to the dermatologist, the solution was just to constantly cover my body in steroid cream, take children’s versions of allergy medications daily, take daily Aveeno baths, and avoid all things with fur, feathers, and pollen. This obviously was not completely feasible (including my family opting not to give up our much beloved cat), but we did the best we could. I first experienced suicidal ideation when I was 10 – I was sent to a child therapist, and I just remember disliking the experience and watching her rotating analog clock tick by so I could leave. Rather than get any benefit, I increased my masking skills, and convinced my parents and teacher that everything was fine, so that after a few months, I didn’t have to go back.

When I was 11, I started having migraines, and most medications were ineffective, so again, we jury rigged a plan that had me avoiding a large swath of food items (challenging, as I was already a vegetarian...in the 90s), staying away from the sun as much as possible (given that it triggered both my hives and my migraines), and just missing school/skating/dance when I had bad ones. At 12, I had my first issues with my knee caps dislocating, resulting in many visits to the emergency room – after seeing six specialists, I was diagnosed with osteoarthritis, and proceeded to wear knee braces, have several years of physical therapy, and five knee surgeries between the ages of 16 and 30. Once I got my period at 14, I would have incredibly painful days that kept me home from school, from my after-school job, and the activities I loved. Sometimes, I would menstruate for several weeks in a row. I was told by medical pro-

Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

I share all of this NOT because I think disabled people need to disclose their experiences and diagnoses to be seen as valid, but because, even with all of these things happening to me before 15, I still, at 20 and in my Master's program, could not see myself as disabled...and neither could any of my health care team. To me, disability was someone using a service animal, an assistive device like a wheelchair (certainly owning my own set of customized and femme-decorated set of crutches didn't count!), or who needed external support on a regular basis. By only seeing a glimpse of disability, disabled experiences were presented as a monolith, one that was to be pitied, and then ignored. If I, someone clearly navigating disability, pain, and illness my whole life, could not see a wider vision of what disability was, and how it applied to sexuality, how could I expect my non-disabled/neurotypical peers and colleagues to do so?

Disability is one of the few identities that one can easily acquire during their life, in a very different way than others. While the language one uses and connection to their race and ethnicity may shift, these shifts usually occur slowly and over time, in conversation, and in community. Similarly, while someone may find their more authentic self-regarding their gender or sexual orientation, or find language that suits them better, that does not occur in a flash, and usually, the shift towards new language and new experiences of oneself come along with one's own consent and agency in the process. Unlike all of these other identities, a disability identity and/or experience can exist from birth. It can also arise at any time; an accident, an illness with long term impact, or mental health concerns can all occur in a blink of an eye. Even more so, disability is EXPECTED with successful aging – if one becomes an older adult, chronic illnesses, mobility issues, vision and hearing issues, etc., are all things that happen to all of us.

Yet people fear disability. Disabled experiences are stigmatized from birth; after asking “is it a boy or a girl,” new parents often demand a count of ten fingers/ten toes, as if having a missing digit would be the most horrific thing to experience, and this stigma continues throughout the life course. For many (valid!) reasons, people are reluctant to accept and name their disability experiences and/or identities when applying for jobs, when meeting new potential partners, and even among people they trust and care about. Centuries of ableism have made it so that owning your disabled identity in this world (or supporting that experience of a loved one) can result in so many challenging experiences, including disbelief/questioning of your identity (Eyer, 2020).

Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

(Department of Housing and Urban Development, 2005), removal of children (DeZelar & Lightfoot, 2018), eugenics (Wilson & Pierre, 2016), and even death (Brown, 2012; Erevelles & Minear, 2010), solely because of their disabled experiences. No wonder people are afraid of claiming their identities around disability, chronic illness/chronic pain, Madness, and/or neurodivergence.

When I was about 23, I got a diagnosis of fibromyalgia to explain my ongoing pain and fatigue, and to be honest, it was a such an incredible relief to have someone name what was happening in my body, even if there was no clear treatment. More diagnoses and explanations followed. Over 30 years after that hive-covered memory, an allergist diagnosed me with Mast Cell Activation Syndrome (MCAS), which not only is connected to my hives, but also some of my gastrointestinal issues, and even my migraines. After 17 years of painful and long periods, mitigated only by constantly being on hormonal birth control (which in turn resulted in two large adenomas on my liver), I was granted access to a hysterectomy, in which the surgeon found an incredible amount of endometriosis. Having my uterus and fallopian tubes removed was one of the most affirming and supportive experiences of my medical history, yet was never seen as an option before I started to use chronic pain and disability language for myself to advocate to the medical professional. I went from dreading this aspect of my reproductive system to unfettered joy in having had the agency to remove this piece of my body that caused so much pain.

My osteoarthritis has since been connected to my previously undiagnosed Celiac disease (which I had diagnosed at age 30), with less absorption of calcium as a child due to my gluten intake. My heat sensitivity and dizziness are part of my Postural Orthostatic Tachycardia Syndrome (POTS), which also ties to my migraines and heart rate issues. Turns out that while I have general anxiety disorder, moderate to severe depression, and obsessive-compulsive disorder (OCD), these are incredibly exacerbated by being in autistic burnout. Once I learned about being autistic and switching to having an autistic competent therapist (in fact, one who is autistic herself!), I have been much better able to manage these aspects of my Madness and neurodivergence, to make space for them in my world, and not see them as naturally problematic. Moreso, I've learned to weave these pieces of myself into my relationships (wherein we practice access intimacy for my various access needs), into my sex life (that direct autistic communication just fits so nicely when it comes to asking for what you want

Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

related service as part of play, and I won Mx. Michigan Leather Pride 2022 on a platform of increasing disability access and inclusion).

It took decades for me to not only be believed by medical professionals and have some more clear answers as to what was happening to my bodymind (Price, 2015), but also to start connecting to and identifying with the concept of being disabled. Even the ability to name myself as these things comes in tandem with my privilege as a white person, and a nonbinary person who is read as cisgender. The sheer amount of work I had to do to navigate my own internalized ableism, to recognize that I was just as much disabled as a wheelchair user, as someone who is blind, and also that folks with just one condition or impairment that impacts them are just as disabled as I am.

We often have imposter syndrome around our identities; am I queer enough? Black enough? Trans enough? Disability identity is not immune from this – I speak with people all the time who discuss their anxiety about if their autism diagnosis (self or professionally given) is “real” or if they are somehow manipulating people, and others who navigate chronic pain and chronic illness and do not want to “take” an identity from the “real” disabled people. These fears as to whether we belong are a symptom of oppression, meant to separate our marginalized communities even further. If we cannot find our community, we cannot connect, we cannot learn from our elders, we cannot organize. In the same way that many people of the global majority have to navigate where their identity is situated in relationship to whiteness, and many companies push products (i.e., skin whitening creams, hair straightening, etc.) to “help” people get closer to whiteness, so too are many disabled people asked to perform able-bodiedness, neurotypicality, “normal” mental health, etc., in order to keep/affirm their proximity to being non-disabled.

It is only once we recognize disability/Madness/neurodivergence as part of human diversity, and that the disabled experience is vast, that we can come into our own regarding disability as an identity, rather than simply a medical diagnosis to be “fixed.” That deep seeded fear of identifying with a community we have been taught not only to pity, but also to try and avoid becoming at all costs (“Because if you don’t have your health, you don’t have anything!” and “I’d rather die than be disabled” are commonly used phrases when talking about disabled others) required not only a lot of work on my part, but the generous emotional labor of disability doulas; already disabled folks

won't cover them. What a beautiful way for disabled “elders” (who may or may not be older than the people they are supporting) to offer collective care to newer members of our group.

Let me be clear that I am not saying that disabled, chronically ill, Mad, neurodivergent, etc., people simply need to accept their identity as such, join the disability community, and that they/we will no longer need medical support, nor will they/we struggle in relation to our own experiences of disability, illness, and/or impairment. Certainly not; I would not be alive without the support of pharmaceuticals, therapists (mental health, physical, and occupational), nurses, PAs, DOs, and MDs. Rather, what I am saying is that without connection to other disabled people, and access to learning from the disability community as a whole, it becomes incredibly difficult to situate yourself as a disabled person in an ableist world. Connecting to other disabled people has literally saved my life and countless others; from learning access-need hacks to something as basic as someone else saying “oh yes, me too. I understand that experience,” being in community with other disabled people has made me feel that I am not alone, that there is nothing wrong with me, that I belong here, that I deserve to advocate for my access needs, that I get to take up space, that my pain is real, and so much more.

Yet even as empowered as I feel as a member of this beautiful community, I am still often so challenged by ableism in sexuality and relationships. Questions arise as to when to come out as disabled, as autistic, as chronically ill – do I put it on my dating profile? Wait until the first date? Until we are talking about needs surrounding sex? How can I trust that the person I am sharing these experiences with is willing to do the anti-oppressive work of engaging their own ableism? I think back to Denver in 2012, where there was a queer sexy poetry reading...in a room above a trendy vegan restaurant, up a flight of stairs. When I asked how I could attend, someone offered to carry me up the stairs on her back. I know she likely meant well, but it was so hurtful that this was their solution to a “community-centered” event that clearly was not welcoming to ALL of the queer community. Kink events are often held in old warehouses that may or may not be physically accessible; strip clubs often have strobing lights and loud music. Even when I (rarely) see people like me presented as sexual in the media I consume, it is more the exception than the rule. In fact, as I write this, there is social media drama playing out because Skims, an underwear/bra/shapewear company, in-

Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

sexy is not enough; rather, I must navigate sexuality (already a complex and fraught subject) in an ableist world.

What does this mean for you, our comrade(s) in striving for a more socially just and disability inclusive future in the realm of sexualities? I have thought of some concrete things you can do to make this world a more welcome place for our beautiful and expansive crip sexuality(ies).

Follow disabled creators – on Twitter, Instagram, Patreon, TikTok, wherever you like to get your content. Especially look for folks holding multiply-marginalized identities; oftentimes, disability content and discussions are so white, cisgender, and hetero-centric. If you can pay creators for their labors, send some money their way. This way, you are not relying on just one person, or one snapshot in time, to get awesome and engaging disability content.

Consume media that features disabled folks playing disabled characters, and getting to be in fulfilling emotional and sexual relationships. I am currently obsessed with Quinni on *Heartbreak High* (an autistic lesbian character played by an autistic actress) – it's the first time I ever saw someone on TV portray someone like me when I was in my teens. [*Sins Invalid*](#) is a disability and sexuality performance troop that offers virtual and in person shows, as well as has a wonderful documentary on it. [*Pink and White Productions*](#) is a pornography company owned by a Black queer woman, which frequently features disabled actors, and offers transcripts for their *Crash Pad Series* shoots for accessibility.

Skip movies like *Me Before You*, where the disabled partner is seen as weighing down the not disabled partner (and casts a non-disabled actor as a wheelchair user), and *Music*, where a verbal allistic (non-autistic) actress plays a non-verbally communicative autistic character. Call out these films, TVs, etc. for their problematic enabling of ableism, and support shows that center disabled voices.

Familiarize yourself with sex toys that are designed for disabled bodies...and those that are not specifically designed for us, but have been adapted for our use. Learn about additional items that may be useful or necessary for disabled folks to use during sex, such as pillows/wedges/ramps, absorbent pads, Hoyer lifts, etc.

and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness; Robert McRuer and Anna Mollow's *Sex and Disability*; Russell Shuttleworth and Linda Mona's *The Routledge Handbook of Disability and Sexuality*; and my recent collection, *Exploring Sexuality and Disability: A Guide for Human Service Professionals*. KinkAcademy.com has a whole section on kink and disability videos that can be super useful, both for disabled individuals and for those who support them.

Create spaces that are accessible. If you're a therapist, assess whether your office has accessible parking/is near accessible transit, if you have accessible and gender inclusive restrooms, if your office is low sensory, if you have different types of seating for different body needs.

If you're a community organizer, make sure to center access needs in your event planning and advertisement.

If you're a sex worker, be explicit that you welcome disabled clients, and consider getting some training to better support them.

If you're an educator, think about how accessible your materials all, from visuals being described, to movies having captions, to being able to engage in multiple different capacities.

Center disabled voices and experiences in your work. Recommend resources by disabled creators, therapists, educators, community members, etc. Pay disabled folks for their labor, whether they are advising you in your practice, helping you with your research, or educating the community.

Advocate, advocate, advocate. Heading to a kink or Leather event? Ask about their accessibility info. Going to a sexuality conference? Inquire as to their masking policy and if they have a virtual option for disabled and immunocompromised folks to be able to attend in our current world of COVID. Be aware of local, state/province, and national policies that may impact the sexuality and overall wellbeing of disabled people, and engage them.

Intersectional awareness! #DisabilitySoWhite was a trending hashtag on Twitter for some time, and it is REAL. Ensure that your disability and accessibility activism recognizes many disabled people are not white, cisgender, heterosexual, spoken English

Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

support those who are given less limelight due to white supremacy and cis het patriarchy.

Whether or not you are yourself disabled, Mad, chronically ill, and/or neurodivergent, we welcome you to your anti-ableist praxis. This may be so new to you or old hat. Either way, *disability justice*, a concept co-created by multiple queer and trans disabled people of the global majority, offers key tenets such as centering the most marginalized, collective action, cross-movement solidarity, and one of my favorite concepts; interdependence (Berne et al., 2018). This notion pushes back against the capitalist and colonial belief in independence being the ultimate goal, and recognizes that we must come together in our shared humanity, support one another, and depend on our community. Disability, and disabled sexuality, is beautiful, and challenging, and it must rely on interdependence, for it is only together that we can create the most just future that we crave.

Solidarity forever.

Reflection Questions:

Take a moment to do a self-inventory. What stories have you been told about disabled, chronically ill, neurodivergent, and/or Mad people? Where did these come from? Which things would you consider affirming? Which would you consider oppressive? How might you have internalized some of these stories? Which of these stories impact how you view disabled sexuality and the experiences disabled people?

What would it look like to embody (or deepen) an anti-ableist lens in your sexuality practice, personally and/or professionally? What actions NOW, NEXT (in the next year) and in the FUTURE (beyond the next year) might you take to work towards this? Where might you find support for this shift? What are the challenges you might experience?

How might you embody a disability justice framework in your sexuality practice? How can you center the leadership of the most marginalized? What would it look like to offer cross movement solidarity in your work? How can you participate in disability cen-

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Previous: Passion Doula

Next: Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor

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Previous: [Passion Doula](#)

Next: [Healing and re-learning sex after sexual assault: Advice from a sex therapist and reluctant survivor](#)

[← Previous: Passion Doula](#)

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