Criptiques
Edited by Caitlin Wood

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CONTENTS

Acknowledgements ................................................................. ix

Introduction – Criptiques: A Daring Space ...................... 1

Caitlin Wood

Criplesque .......................................................... 5

Elsa S. Henry

Your Mama Wears Drover Boots ................................. 11

Elizabeth J. (Ibby) Grace
Droolilicious ............................................................. 25
    Leroy Moore

Waiting ................................................................. 29
    Anna Hamilton

Disability in an Ableist World ................................. 37
    Lydia Brown

What Should You Call Me? I Get to Decide: Why I'll
Never Identify with Person-First Language ............. 47
    Emily Ladau

Dreams I'll Never Remember ................................. 57
    William Alton

Palsy Skinny: A Mixed-Up, Muddled Journey into
Size and Disability ................................................. 59
    Cara Liebowitz

Brain Injury, Meet Disability Culture ..................... 67
    Cheryl Green

Going Off the Communication Beaten Path .............. 83
    Eva Sweeney
The Visual and Political Implications of Using Frida Kahlo and her Artwork to Represent Disability .......... 87
    Stefanie Snider

Reflection Toward Practice: Some Questions on Disability Justice ..................................................... 107
    Mia Mingus

The Wholeness Project ........................................... 115
    Nitika Raj

The Erasure of Queer Autistic People ...................... 121
    Alyssa Hillary

Take With Food ....................................................... 147
    Cat Moran

Beauty in Exile ........................................................ 151
    Riva Lehrer

On Surviving “Little 't' Trauma” ................................. 167
    Nina G. Comedian
Preferred Provider ................................................... 177
   Robin M. Tovey

Disability Should Not Equal Poverty ......................... 189
   Danine Spencer

Constant Dissonance: Our Noise is Dangerous ............ 197
   Kay Ulanday Barrett

What Bodies Do: Meditations on Crip Hatred, Elder Hatred, and the Vulnerable Body ............................. 211
   Rachel Cohen-Rottenberg

On Radical Empathy and Schizophrenia ..................... 219
   Ben G.

The Reinvention of Self in the Context of Heteronormativity and Ableism ........................................ 229
   Jen Rinaldi and Samantha Walsh

Krip Power Through It: Disability Scholarship & Activism Helped Me Resign & Rebuild ...................... 245
   Bethany Stevens

Author Resources .................................................... 257
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Crip is my favorite four-letter word. Succinct and blunt, profane to some, crip packs a punch. Crip is unapologetic. Audacious. Noncompliant. Crip takes pleasure in its boldness and utter disinterest in appearing “respectable” to the status quo. It’s a powerful self-descriptor, a cultural signifier, and a challenge to anyone attempting to conceal disability off in the shadows. Crip is anti-assimilationist and
proud of it. Crip is outspoken with no patience for nonsense. Crip is my culture and it’s where I want to be.

Criptiques was inspired by the inherent rebellion found in crip culture. We as disabled people are well acquainted with ableism (and all of the other -isms and phobias that intersect with our varied identities), and many in our community draw on these shared experiences of oppression as fuel for visionary works of creativity. Using song, film, dance, visual arts, fashion and writing, uppity crips are defying mainstream culture’s insistence on our subordination and doing it with style and humor. We don’t shy away from the realities of our nonconformist minds and bodies- we flaunt them. And in this daring space of shameless flaunting we find fellow crips who affirm and reflect our originality and beauty back at us, just as we affirm and reflect back to them. It’s here where internalized ableism begins to crumble. Community blossoms. Our crip bravado reaches out like sun rays and emboldens those who need our swagger the most- those strangers to disability pride. The ones who’ve travelled a long, lonely road and finally discover the joys of chosen family and friends and a rich history they don’t teach in schools. This daring space is important. It’s here where revolution can take place.

The essays in Criptiques are presented in this spirit of revolution. The authors, topics, perspectives and writing styles are highly diverse, just like our community. Though it
was impossible to include every disability issue/experience/viewpoint in one book, the writing here is intended to spark discussion and debate. While Criptiques is innovative and provides a platform for some of the most marginalized voices in our community, it’s just a tiny fraction of the stories we can (and need to) share.

Welcome to Criptiques: a space of shameless flaunting and significant contribution to crip culture by crip culture.
My feet move in their four inch heels, my hips sway to the music, and the lights hit my eyes with a brightness that would usually blind me outright, but in this context I have to focus and bring myself out of the usual cataract-induced fear of bright lights. As my hands move, the audience screams, and my blue feathered fans lift away from my body to reveal the dress I'm wearing - painted to look like a TARDIS.

The audience has no idea that I can't see more than 4 feet away from my face. The audience has no idea that the chair on stage is placed where it is so that I have a marker
for where I can't go past- so I don't fall off the stage. It won't be until curtain call that my secret is revealed, and the audience will notice that for most of my time out and about, I carry a white cane.

For now, they still assume that I am able-bodied and sexy. They assume I'm just a burlesque performer who chooses to wear her glasses. They're wrong.

I am the blind burlesquer, Lydia Ransom.

I've been dancing since before I could remember. My father got an MFA in modern dance at Pratt before I was born. My mother was a go-go dancer in the 1980s. One of my earliest memories is learning how to waltz on my uncle's feet. I have taken ballet and jazz, modern and tap. I've studied social dancing and swing-danced my way through life, learning tricks and flips and trusting my partner to never drop me on the floor.

People seem to think I'm inspiring because I can dance. It is the lightness of my feet which seems to surprise them. The assumption is that as a blind woman I cannot be free in movement. I must be tethered to the earth by my lack of sight, and my lack of hearing.

But I really just want to fly across a dance floor.
I come from a burlesque family. Mom was an instrumental part of the burlesque revival, and I was surrounded during my teenaged years by women who took their bodies and used them as artistic devices. There is nothing they could not express.

I decided to start doing burlesque because it felt like something I ought to understand, as a dancer and as a member of the community. I didn't do it because I wanted to be the only blind burlesque dancer in the world (though I think I might be). I didn't do it to shock, or to stir up controversy. I did it because the art form appeals to me. Because it is in my blood. The reactions are fascinating.

One audience member remarked to their friend that they weren't sure if I knew how sexy I was. They wanted to know whether or not I could tell that I was sexy, and they wanted to know how I knew to be sexy.

You don't have to be able to see to be able to be in your body.

Audiences are always tricky. They often don't recognize the blind woman carrying a suitcase out of the dressing room as a person they saw on stage- apparently they can't connect the dots of the woman with the same face being a woman with a cane.

And then there are my peers in the burlesque world.
Producers suddenly fear I'll hurt myself and decide to pull me from their shows. Others are afraid they are exploiting me or my fellow disabled performers, and showing us as freaks instead of as beautiful women (a concern I actually admire). Their concerns are never about the perceptions the audience may have about me, however. They are concerned that I will not be able to see the edge of the stage and that I will fall off of it- which would certainly be valid, if I didn't have techniques for dealing with that.

I'm not a fragile flower who needs protection from the edge of the stage. My techniques involve requesting specific lighting from the stage, setting props so that I can mark where I am upon the stage, and even calling upon audience interaction techniques to further my safety and their enjoyment at the same time.

Perhaps I have a small amount of self-preservation instinct, but I prefer to think of it as being able to push past my fear of falling, so that I can achieve things I want to. It shouldn't be inspiring that I perform, but it also shouldn't be blocked. I shouldn't have to fight and claw my way onto the stage because people fear for my safety. I've been treading the boards since the tender age of 7. Twenty years of experience on the stage have passed since then- and they still don't think I know how to cross the floor in heels without a minder!

I've been told I'm edgy. I've been told I'm shocking,
which always rings falsely to me since my acts are rarely shocking, or attempting to push the envelope. I have been a naked TARDIS, a stripping librarian, Irene Adler and much more. I have sung jazz standards, and dressed as Jessica Rabbit. None of these things are "edgy" when an able-bodied performer does them.

It is when a disabled woman struts the stage that people are confused.

Being sexual and being disabled are seen as mutually exclusive by so many, we are seen as unable to give consent. Unable to have sex. Literally unable to be sexual. I challenge those assumptions when I take off my clothes, when I revel in the spotlight and drop a glove on the floor. I change those assumptions because I find myself delighting in causing an audience to scream because I dropped an item of clothing- and because I make them do it, if they think too hard about who I am, my audience just might change their minds about me.

So why do I keep doing it? Why do I keep trying to get booked? Why do I keep wanting to push the envelope? Why do I keep trying? I have so many reasons. One of them is that I want people to be able to do this in the future. I want more disabled performers to come out and strut their stuff. Right now we need to pave the way for them.

I also do it because I love it. I love that this is a political
art form, that when I choose to push the buttons really hard, I can do that. I do it because it's fun. I do it because I love to dance.

I do it because it is part of my history, and the expression of my respect for the foremothers of burlesque is to keep doing it, even if it isn't easy.

I do burlesque because it teaches me not to be afraid.
Drover boots are the Australian version of cowboy boots. You don’t have to tie them, which makes them similar to cowboy boots, a boot I also like, but drover boots have an advantage on cowboy boots: their soles are soft rugged rubber, like tires, so if you walk however you walk, people cannot really hear that.

I am using my boots to introduce my particular brand of intersectionality to you because of an insult people used to sling around when I was little that made very little sense. It
was that your Mama wore Army boots. I asked around at that
time about what it meant, and it meant your Mama was a
lezzy. But when I was a kid it was illegal for a lezzy to be in
the Army… And also, Army boots have laces, and who has
the spoons to tie your dang shoes that much each and every
day? Gah.

So. I am Gay, and Disabled, and I’m the kind of Out on
both axes (Butch and Autistic) that when I try to come out as
Gay, people say “Thanks for clarifying (smirk)” and when I try
to come out as Autistic people say, “Well now that explains a
LOT,” if they are respectful enough not to say “Duh,” or, a
favorite in the lexicon of strange things people all seem to
want to say, “I know, I’m a professional, remember, and I’ve
been meaning to tell you, aren’t we all just a little autistic?”
People who say that everyone is a little autistic are usually
nice people that I like, but I still think it is a strange thing to
say. If everyone were even a little autistic, fluorescent lights
would never have made it past the first round of quality
control in any nation.

Students don’t say that stuff much; they are most likely
to say, “oh can you help me help my daughter with math?”
(Maybe, and glad to try, because that is a much more
awesome type of question). Surprisingly, it is often my
colleagues saying the more awkward things, which has been
funny. I am an education professor, and some of the really
hilarious assumptions I have heard on the topic of my ability
to be a mother have been out of the mouths of colleagues in special education, especially disability studies. So this is what this chapter is about, as well as about parenting while disabled in general, but also while gay, because, you know, as Popeye says, I Yam What I Yam.

I will tell you some of those things in this chapter but I will also tell you some of the touching and lovely things, because I am the Mama wearing drover boots. I have twin sons going on two years old now, apples of my eyes! And I also have the most wonderful wife anyone could ever ask for. Sometimes, she is the one who points out the wrongness of what people have said to me, because my metaphorical skin has gotten hardened over the years and I shrug, just thinking, “eh, what a tool.” And also I am laughing. But shrugging is not the answer. I have children now and must make a better example in the world. Speaking out is better. Shrugging changes nothing. But I haven’t always known these things.

Speaking out is speaking out even if it is funny, because the spotlight shines on the wrongness all kinds of ways. You may hear some mirth in my voice when I tell you the things, because overall life has been good to me. This is not everyone’s story. This is the story of me, in my drover boots that I don’t have to tie, laughing at manure sometimes, because so many other things are so gorgeous in comparison. But you still see clearly that there is manure. On
my drover boots. That I use for stomping. And then I clean them and move on to another day.

I am the Mama of my babies, and they have a Mummy too, Layenie, who is my beloved other half and whoever wants to have a problem with any of this does so at risk of being directly quoted in some chapter somewhere for the perusal of scholars of human justice. Because having an ignorant problem with other people’s lives is something you should really just do inside your head—or better yet, how about not at all, so you don’t look like a buffoon. Words to the wise.

STOP THE PRESSES! I have to pause this regularly scheduled chapter for a Public Service Announcement. It is time to let everyone know (because of some shameful developments going on in the world of academic feminism and related areas right now) that I am white, and the glorious intersectionality of being a disabled Autistic butch neuroqueer woman who doesn’t pass in any kind of way hasn’t magically stopped me from reaping the unearned benefits of being white in a racialized, unjust society—and people who try and tell you otherwise, well, they are just adding to what I have to clean off my boots. And that ends this Public Service Announcement.

Back to the chapter.
The Labrys -a double-headed ax- was an important symbol for lesbians when I came out. This is a disability book but I have to talk about my subaltern, outsider, othered self intersectionally as what I have come to define as NeuroQueer. Because it’s really hard to tease apart, in many contexts, just what part of my not-quite-right-for-folks self comes from what part of my social wrongness. Disability or orientation? Only the shadow knows for sure. I like being intersectional. It makes me feel like a superhero of potential offensiveness, which is funny because if you met me you would notice I am sort of easygoing and friendly now, unlike the Tasmanian Devil of whateverness I was in my youth. I’m almost, I think I can say this, socially acceptable! Not to everyone, but, you know, to cool people. Still, that’s something deliciously unexpected, something that would shock the socks off baby-me, if I were to go back in time and find out about it.

When I first came out, these Labrys-wearing lesbians notified me that it was not OK to look as butch as I am because that was allegedly emulating the dominant paradigm, which… what? So I found the Queers who thought I looked fine, and learned to fight AIDS with them, which was much more awesome. It was years until I became able to be Autistic in the way I was Queer, like, I’m Here, Get Used To It, And I Will, Too, because all the other Autistics I knew at the time lived in group homes where you had to
have permission to have a lover (this was called “conjugal visits”) or leave (unless you wanted to be considered “AWOL”) and I am not exaggerating. Also, apart from me, my friends with autism and other developmental and intellectual disabilities did not know they had the right to vote. This is real. So I spent a lot of time trying to be in the closet about this giant aspect of myself and do various things to hide what I was really like, because of all this fear of getting my life taken away.

Once in the early ‘90s I even tried to get myself undiagnosed, but they laughed at me. This is the first time I have told people this in print. I am not proud of it, but I think you should know. I, Ib Grace, marched into some medical mental health practitioner’s office in downtown Portland and tried to show off how supposedly non-autistic I had become in all my trying-to-be-in-the-closet glory and get her to take the label off me. And at the time I would have told you I was badass. Yeah. Anyway. Some of the not pretty stuff, some of the prejudice I’m going to tell you about will come from my own dang self. And with that, I’m not laughing as much. But don’t worry. There is beautiful stuff I’ll tell you too. Now I am Autistic and Queer both Loud and Proud. And! I’m a Mama.

*Beautiful Stuff Break: Twin Toddler Boys Giving Each Other The Giggles.*
Now here comes a difficult paragraph. I always wanted children, always loved them, but I “knew” I could never have my own children, from my womb, because I had eugenic assumptions. Yes, I did really write that, and I’ll tell you what I mean. Please think about my lovely boys giggling now first, to counteract the wrongness of what I am saying. I don’t want to trigger anyone, but I have to keep it real out of respect for the reader. My idea was that certain aspects of life had been terribly hard for me in ways I thought I would automatically pass on to any children through my genes. This was an idea I developed sometime early in life, and I am not sure how it flew into my funnel, as the narrator of Thomas the Tank Engine says. This idea was so perniciously and illogically pervasive that it reared up again unexpectedly in a panicky conversation during Layenie’s pregnancy, despite the fact that, clearly, it was technically irrelevant at that time. However, I know that this is what brought it on: what if the kids are broken like me? And this was when I was already doing disability studies. I don’t normally feel broken, so these vestiges are strange and troubling, but I think it is important not to sweep them away and say they were never there.

My boys are compassionate and generous, and they have other people’s backs. Their first clear full sentence, which they picked up together at the same time, was “There ya go,” which they use when handing things to folks. The
daycare teachers recently told us this: it was a new girl’s first day, and her dad’s heart hurt trying to leave because she was crying. He saw our sons had enveloped her in a big hug, patting her, saying “Pat, pat” like in *Pat the Bunny* to let her know everything was going to be OK, and I guess it let him know that too. Yeah, I’m a proud Mama. The boys are very different from each other in some ways, almost night and day in a lot of their individual interests, which is pure joy—and it is also pure joy that they come together as a team in what really matters.

Here’s a day-in-the-life vignette. My hearing is sensitive, which is awesome when it’s awesome, like the music skills, but not when it’s not... like when it’s ouchville. Garbage disposals have historically been on my least wanted list. But my beloved has this thing she does where she sings, “Noise!” in a very lovely lilt ahead of time, to warn me it’s coming, so I can re-set my ears differently to be less-sensitive. Enter the boys. Now, they do it too, chirping along happily several times, with great musicality: “Noise!” And then, even better, they decide to make the noise go away, because they are Champions Of The Universe. “Bye bye Noise! Bye bye Noise!” They lilt, and wave, and voilà! Like magic, the noise is gone. I must confess, all this adorableness that happens around the garbage disposal in my life now is making me kind of like it...

It is not clear to me what it is about my personality
exactly that makes some people think I am less than competent, but sometimes, like I said, I don’t notice. Does the not-noticing itself make me less than competent? Not sure about that, but I will say this: in school, a teacher came up with the idea to call me Space Case Grace, and I took it up proudly, thinking it was a compliment, because I like rockets and stars and planets and things, especially Saturn, because Saturn has cool rings. And I am still trying to forgive Neil de Grasse Tyson for the demotion of Pluto. So I really do notice things, but have different priorities. OK, not incompetent. Presume my competence!

Anyway, in relation to the topic of presuming my incompetence, a colleague, another professor, offered to be my wife’s birthing coach or partner or something, including in the delivery room itself. And I was actually right there for this conversation, but I did not really register the weirdness at the time. It took me some process of listening and thinking to put together that this was one of a string of actions undermining my dignity, but you know, all this took much help and hindsight. And it’s telling what a life lived as your own self can make invisible to you, that others who love you can see clearly. There was a tone I was used to brushing off, ignoring, not engaging with. This acceptance of the unacceptable is a way of being in the world I no longer need, though, and this chapter is part of my shedding of it. I hope it will be of service to any of you who might like to do similar
things yourself.

The experience we had in the hospital is one I wouldn’t trade for anything in the world. It was magical. I am trying to write about it but I find I do not have a good enough command of emotional language to get anywhere near expressing the current of transformative love that carried us around the place. Suffice to say I was able to cope, somehow, with the majestic beauty of miraculous joy, and Layenie was, too. She said to let everyone know that the hospital gave me a New Dad t-shirt that reads: “I Rocked, Now I Roll,” and according to her, I still rock.

I do, literally. And it came in quite handy when the babies were infants. We had this thing where we knew that it was easier for Layenie to get the guys to eat, and for me to get them to sleep. Being the Human Metronome, it’s easy peasy for me to continue to be rocking like this when I am practically asleep myself. Also, the thing where it is not the easiest for me to be verbally expressive about emotions, called ‘alexithymia,’ does not prevent me from coming up with songs that convey feeling through music whenever I like, and so I can make up soothing or fun tunes for the fellas any time, about anything. Layenie can too, because she is talented. I think the boys might be disappointed when they find out that in real life people don’t break into song about everything at random intervals, but they can always come home, and, for the times they can’t, there’s the world of
Another problem for me in the early life of the boys was that I was afraid to take them anywhere in public without Layenie being there too. This conversation had happened:

Friend: I hope the pregnancy thing works out, because you know, they wouldn’t let you guys adopt, which is so unfair.

Layenie: Really? Even though my visa is perfectly in order? [Layenie is a UK national, a nurse, on a visa for specific workers in shortage fields].

Friend: No, it’s not that, it’s—[starts making totally noticeable head nod eyeball faces towards me that I cannot fail to notice even though I am Space Case Grace].

Layenie: … [face that looks like ‘Wait, what?’]

Friend: [dramatic big stage whisper] Autistic!

So I got this idea that people would notice me with the kids and take them away if they saw me alone with them, because I would be so clearly Autistic and disabled as to be disallowed from adoption. This fed into another secret message I had forgotten about in the back of my own head,
that I would really be unable to be a good parent because of who I am, not just my genetic profile replicating. I don't believe these things when I think it through.

But the fears feel real when you are having them.

I used to dream of having a way to get kids without having ruined their genes, back when I thought I had ruinatious genes. There was a hospital nearby and I heard people used to leave babies there, just leave them, and I thought, well, what if I went over there one day with a friend who happened to be going to the hospital, and they were giving the babies away, you know, like they do with puppies, and they saw me, and they magically saw the way it is inside my heart, and they would say, here, have a baby, and love the baby, because the baby deserves to be really loved. Because another part of me always knew I would be good at loving that baby, because I am good at loving. If there is one thing I am better at doing than any other thing in the world, it is loving, and loving so that the people I love are able to notice that they are loved, because I love big and warm and in a way that is both soft and strong at the same time. Layenie affirmed this for me when I was afraid, and our boys confirm it for me every day now by being well adjusted, flourishing little Captains of Laughing.

It is with this knowledge that I proceeded to become a
Mama, in full faith that the other voices were not telling the truth: even the other voices that were my own. And now the other voices have diminished and I wake them only in memory to put them in the story here, because I know I’m not the only person who has known such things, and it’s a lot easier to clean the muck off your boots if you know what’s there and where it is.

I know I’m good now, and born to the role, because when there is a Roughhouse Catastrophe, and the tiny John Deere gets its axle all bent, Mama can fix it.
I released a single titled Drooolilicious from my CD The Black Kipple Delivers Krip Love. It was put out for download on Valentine’s Day 2013, with music production on Drooolilicious by Rob 'Da Noize Temple.

If you Google the term Drooolilicious, you will find it linked to food and sexuality from the mainstream’s standards of pretty, e.g., a white, able-bodied, skinny woman or muscle-bound white male. However, if you break down the term, you will see that the term and its reality are shunned by society.
As an adult with Cerebral Palsy that sometimes drools, I have witnessed popular reactions to my drooling in my daily life and seen common drooling images online. Drooling is automatically put in categories of (excuse my language), “homeless, crazy, useless, gross, poor,” and such. If you search for *drooling* in Google images you get babies, people that are drunk or sleeping, animals, and zombies. One Facebook meme that came up in the results was an image of a young, white woman posing sexy with the statement, “Drooling is only ok if you're retarded. Or really, really hot.”

Many people with disabilities including myself were told as children over and over to catch our drool and even went to therapy to try to “fix” it. We were told that our drooling was/is not acceptable, that we might not find love because of it and that it might bring harm to us if we drool on the wrong person at the wrong time.

In today’s society with the disability rights movement, more disabled activists, poets, writers, cultural workers and scholars are taking our identity that comes with our politics and displaying it on the page, stage, in the studio, on the big screen and more importantly, in our daily lives, thus passing it down to the next generation. There have been many poets, artists and cultural workers in all communities that have flipped what the mainstream has thought of as negative, gross, and ugly into political and personal pride and acceptance. I’m not the first and won’t be the last to take a
part of myself- in this case Drool/ing- and flip it by using a cultural vehicle, poetry and song, switching what people are used to seeing as a negative and giving it a new window.

**Droolilicious**

I’ve got my own language
Speaking slow fat tongue
Scares knocking knees
On billboards displaying body image

Cerebral Palsy, was schooled to catch my drool
Now I’m a man changing the rules
Found someone who thinks it’s sexy
Now I’m naming it

Droolilicious
Baby, come here & give me kisses
Straight from my lips into your mouth
Goddamn I’m making disability hot & famous

Cerebral Palsy, was schooled to catch my drool
Now I’m a man changing the rules
Found someone who thinks it’s sexy
Now I’m naming it

What a relief it is
My drool is now Droolilicious
Close your eyes imagine this
Rolling down my chin onto your body
Drip drip Drop drop Fizz fizz

Got the real krip walk
Slur speech when I talk
Yeah got it all and she is drunk
No sipping just chugging down my droolilicious

Cerebral Palsy, was schooled to catch my drool
Now I’m a man changing the rules
Found someone who thinks it’s sexy
Now I’m naming it

Droolilicious
It’s delicious
Many couldn’t held it
Found the one
Who wants to bathe in it?

Droolilicious
Droolilicious
Droolilicious
WAITING

ANNA HAMILTON

I am grinding my teeth. I know instinctively that I shouldn’t— it makes my jaw hurt and can often lead to a loathsome headache, but right now I have no other outlet.

I sit hunched over in an uncomfortable plastic chair. I’m dressed in old jeans and a sweatshirt that could use a washing, scanning the room like a hungry, angry buzzard on the lookout for a freshly dead creature upon which to feast. I am just that grizzled, as I have been for the three months I’ve been waiting for this appointment.

I started experiencing overwhelming fatigue and joint
pain five months prior out of nowhere, and when I reached two months of feeling like I’d been hit by an SUV from the time I woke up in the morning until I went to bed every night, I went to my GP and asked if she could figure out what was wrong. Since a 20-year old presenting with unexplained pain and fatigue was out of her wheelhouse clinically, I was referred to a neurologist. Of course, he had a three-month waiting list.

The overarching issue - as has been driven into my skull over and over again as I search for a treatment for whatever it is I have - is that as a culture, we expect doctors and medical science as a whole to be our saviors. We expect them to automatically know what’s wrong with us, and to make it go away. We expect them to make sense of maladies that often do not make sense, and quickly. No one has told me that figuring out an illness can be a long and complicated process. So I expect that someone- at the very least an expert such as this doctor I am about to see- will have at least some answers as to why I’ve been feeling like death-warmed-over for the past five months. The only thing I can do at this moment, however, is focus on how much I dislike this waiting room.

The room is nearly colorless and flooded with fluorescent light. The light makes the carpet the color of vomit, and the cheap, plastered walls like rapidly expiring cottage cheese. Magazines are scattered on plywood tables:
Parents, Child, AARP, Yacht Digest Monthly. None of these apply to my immediate situation and to take a cursory browse through any of them would make me even more impatient and angry. I would gladly kill for a copy of U.S. News and World Report right now- anything that could take my mind off of my pain for even a minute would be a blessing.

I gingerly remove my iPod from my backpack, snap the headphones over my ears, then press play. The opening notes of Tori Amos’ “Happy Phantom” fill my ears, and for a brief moment, I am pleased.

The song’s bizarre imagery of Tori running naked and chasing strict nuns around is quickly interrupted however, as the office’s phone roars to life. The middle-aged blonde receptionist with a hideous floral shirt and long red fingernails picks up the phone. In a voice louder than I had anticipated, she chirps, “Clinic, this is Anna, how may I help you?” Not only does this woman share my name, she has a voice like Marcia Brady on steroids with a megaphone. I know that no matter how loudly I turn my music up, I will not be able to avoid hearing her. Sighing slightly, I dump my iPod back into the dismal abyss of my backpack.

After sitting hunched in my chair for what seems like an eternity, another blonde woman emerges from the mysterious door leading to the back that has until now remained closed. She holds a clipboard in one hand, a pen
in the other.

“Ms. Hamilton?” she says.

I nod briefly, smile politely, and get up, shuffling out of the waiting room. The doctor, a short, stocky man with thinning black hair and no-rim eyeglasses sweeps into the office that I have been shown to, all business. He eyes me carefully before sticking out his hand.

“Hello, I’m Dr. West.”

“Hi,” I say quietly.

He peers down at my gigantic file, readjusting his glasses with an aging, veiny hand. I assume that my primary care providers must have faxed him a complete set of my medical records, although I suspect that a “complete set” may actually require a sturdy hand truck and a cardboard box to cart around.

“So, what seems to be the problem?” he says, looking at my file.

“I’ve been having really bad joint pain for a couple of months, and I’m tired all of the time. My energy level is really low, and it’s difficult for me to get out of bed some days. I just feel kind of...dead.”

He nods, still staring at my chart. He does not make any eye contact. “Anything else I should know?”

“Well, uh, I’m a vegetarian and I usually eat pretty healthy foods, I was born prematurely and have a mild case of Cerebral Palsy—the actual term for it is Left Hemiplegia. If
you need any records on that or anything, I can call my former physical therapist and she’ll fax them to you—“

“None of that matters. You can stop.”

“But—”

“What I can tell you so far is that your symptoms aren’t consistent with a textbook definition of any type of rheumatological issue. They just aren’t consistent. I can’t give you a diagnosis at this time.”

This is the guy I have been waiting a full three months to see. By this time, I have had multiple blood and urine tests, many speculations by different doctors, and more accidental “sick days” off from school than I can keep track of. Plus there’s the pain and fatigue- all day, every day. I have been waiting, rather impatiently, for answers, and now that they are supposed to be here, they are not. I want to scream at him: I cannot continue to live like this. I’m not a fucking case study in a med school textbook. I’m in pain.

I don’t yell at him. If there’s one thing that a lifetime of dealing with weird health problems (including Cerebral Palsy, life-threatening allergic reactions, and depression) has taught me, it’s that I have to be polite and patient to get anywhere with medical professionals.


“I’m going to start you on some steroids. These may
make you feel better, or they may make you feel worse.”

“Okay.”

Since I’ve been on steroids for my anaphylactic allergic reactions before, and have been surprised every time at how they completely drain my energy and tiny reserve of zest for life, this does not sound like a promising treatment plan.

The doctor leaves, and another nurse leads me to a tiny, closet-like room with barely enough space for a scale, a cabinet, and a blood pressure machine attached to the wall. I sit down in the room’s only chair, staring at the door as the nurse takes a needle from the cabinet’s top drawer and unsheathes it. She grins at me, slightly frizzy hair forming a halo around her wide face.

“I’m just going to make a little bubble under your skin,” she says. I automatically offer my right forearm. The needle goes in. The nurse’s expression changes.

“Oh, you know, I forgot to put the fluid in! Silly me,” she says, and giggles a bit. This does not strike me as especially amusing, considering that I could have had a heart attack due to such an error.

“That’s okay,” I bleat automatically. The needle is filled with the requisite fluid. I offer my forearm again, like the next cow at the slaughterhouse who moseys up the conveyor, unaware of the gruesome fates of those who went before her.

The needle slides in again. The fluid-skin bubble forms.
The nurse smiles apologetically. I begin to sob.

The doctor pops out of the corner, sticking his head into the doorframe. “Is everything okay?” he asks in a monotone.

“Oh, she’s fine. She’s just scared of needles,” the nurse says, with more pep than is necessary. The doctor utters a short grunt and continues down the hall. I shake my head as the nurse looks at me sympathetically. “He’s very good at what he does,” she intones.

I don’t want to hear any more from her. If this “expert” can’t figure out why my body has turned against me, who will? Five months of feeling completely deflated has been enough, and at times felt like more than I could handle. I realize that finding out what is wrong with me will be a long and arduous process, but from my vantage point here in the doctor’s office, crouched and upset, it looks like this will go on forever.
Disability as a constructed concept is not a commonly understood or propagated idea in the mainstream of an ableist society. The average non-disabled person, and frequently even disabled people who’ve had limited or no exposure to disability rights theory or disability culture, does not understand disability beyond something that happens to other people, thereby rendering them tragic objects of pity, scorn, and charity. The general understanding of disability among those whose professions and research lie in the long-
established fields of health sciences, rehabilitation sciences, special education, and abnormal psychology is one of a highly and often exclusively medicalized model that understands disability as a pathology in need of treatment, remediation, rehabilitation, and mitigation.

For theorists in the emerging interdisciplinary field of disability studies who are increasingly disabled themselves, there are two foundational understandings of disability—essentialism posits that disability is inherent to the person, whether innate or acquired, while constructivism posits that disability is a social construct and exists only because of sociological, cultural, or political factors. Those who understand disability as a medicalized phenomenon through the lens of an exclusively biological or psychological model of disability are essentialists. Those who insist that there is no such thing as disability or that everyone is disabled in some way are frequently constructivists.

But it cannot be denied that disabled people of any particular disability or condition do have inherent differences from nondisabled people or people with different disabilities. The Autistic brain is different from the non-Autistic brain; those who are Deaf or Blind perceive the world in different ways than those who are hearing or seeing; those who use wheelchairs move differently than those who have no need to use wheelchairs. These differences are real, and the differences are certainly not social constructs. Thus,
constructivism does not adequately address the lived and inherent neurological, mental, emotional, and or physical differences that disabled people of any particular group have from those outside that group.

Yet essentialism discounts the roles that lived experiences, attitudinal biases and prejudices, policy and systemic barriers to access, societal ableism, constructs and representation of disability, and hate crimes play in the lives and shared experiences of disabled people across all sectors of society. Essentialism does not address the systemic denial of equal access and opportunity for disabled people in education, housing, community and social life, healthcare, employment, and policymaking. And it certainly fails to consider the consequences of rhetorical and discursive constructions of disability and the disabled experience.

Disability is far more complex and nuanced than either pure essentialism or pure constructivism are capable of adequately conveying. The experience of disability, of being disabled, arises when a person whose neurological, mental, emotional, and or physical differences are atypical and divergent enough from the neurologies and physicalities of the majority so that this person is forced to exist and live in a society and world not constructed to incorporate natural supports and full inclusion and access for people like this person. That is, the experience of disability and being
disabled is the result of the interaction of a person’s inherent differences with a society and its attitudes and policies.

On the Massachusetts island of Martha’s Vineyard, it used to be that a significant percentage of the island’s population were deaf until the mid-twentieth century.[i] As a result, nearly all residents learned Sign language from an early age, whether they were Deaf or hearing, and easily switched between signing and speaking without much effort or thought regardless of who was present in the conversation. Today, there are no longer any Deaf people born into the signing tradition living on Martha’s Vineyard, yet elderly hearing islanders continued to communicate in Sign language as late as the 1980’s.[ii]

In communities where everyone or nearly everyone shares the same sensory, physical, cognitive, or emotional experiences, such differences that might in mainstream society be considered to be deficits or disability are not, in fact, disabling at all. While divergent and diverse neurologies and physicalities exist in nature and in isolation of cultural, sociological, historical, and political context, disability does not exist in the absence of a society’s rhetorical and discursive constructions of it that create attitudinal, systemic, and institutionalized barriers to access for those whose neurological and physical variances are atypical.

In order to fully understand disability and the disabled experience, and in order to effectively and meaningfully
advocate for attitudinal and systems changes that will lead to
equal access and opportunity in a more just and equitable
world for disabled people, it is imperative to both examine
and challenge the common rhetorical and discursive
constructions that posit disabled people as the Other and
disability as a pathology, while at the same time suggesting a
radically different construction and understanding of disability
and the disabled experience as natural and normal parts of
the human experience.

Disability has historically been understood in the
paradigm of a strange and alien other, as evidenced by the
sterilization and eugenics movements targeting the disabled
for fear that we might bear disabled children and perpetuate
disability. Even today, disabled people who wish to kill
themselves are more frequently praised as brave and
courageous, and offered the option of euthanasia, while non-
disabled people who express the same suicidal ideations are
referred to anti-suicide counseling and support.

The lives and humanity of disabled people are routinely
questioned not merely by the supposedly objective and well-
meaning professionals hailed by the public as experts on
disability, but also by the mainstream media. Disabled
people face prejudices and attitudinal barriers such as the
presumption of incompetence, infantilization,
dehumanization, the belief that disabled people are
incapable of being sexual beings, paternalism, and the
prevailing assumptions that our lives are tragic and that it should be normal for a disabled person to seek to be cured of disability. We are frequently assumed incapable of having opinions or directing our own lives, treated as children even when we are adults, denied access to basic healthcare or education, deprived of accessible or meaningful sex education or even the opportunity to form romantic relationships, treated as though our opinions and ideas have no value, and discussed as though we are not present and cannot be.

Our experiences and lives are usually described through a paradigm of grief, pity, shame, scorn, tragedy, and fear. Our non-disabled parents are taught to mourn their disabled children’s existences and to wish for their children to be cured. Our neighbors are taught to pity us, and our families are taught to be ashamed of us. Youth who believe that their intentions are good are taught that our lives are inherently tragic and that they should be afraid that more children will be born disabled if they do not contribute money to charities working frantically to eradicate disability. If media portrayals and representations of disabled people are to be believed, we are incapable of living full, rich, and meaningful lives, and we remain perpetual children regardless of biological age. Society teaches the non-disabled to fear and pity us, and it teaches us to be ashamed of and hate ourselves.

The concept of disability pride, which has existed for
decades in an organized fashion, is revolutionary in its biting
response to the paternalism and discursive constructions of
disability popular in our society. The idea that people with
deformities, people with visible physical disabilities, and
people with neurological or mental disabilities are capable
not merely of accepting themselves but of publicly
proclaiming their pride in being disabled is anathema to a
society in which deviation and divergence from neurological
and physical typicality is labeled pathology and defect. Yet it
is a necessary idea, because we who are disabled must
continue to reassert our necessary presence in shattering
old rhetorical and discursive constructions of disability while
creating and perpetuating new ones.

Without significant changes in societal and individual
attitudinal barriers to access, there will be no meaningful
systems change, no changes to policies and institutions that
create further barriers to equal access and opportunity and
full and equal participation in all facets and aspects of life.
Few outside the disability community ever consider the
consequences of their perceptions and limited understanding
of disability, and many whose views are shaped by unsound
and dangerous ideas continue to perpetuate ableism without
ever having their privilege challenged and examined.
Disability exists because we are largely complacent in
allowing ourselves and our society to perpetuate a world
where disabled people are marginalized and oppressed by
attitudinal and systemic barriers to access.

We need the concept of universal design to move from small academic circles and pilot programs in public schools to a foundational principle of all aspects of life, culture, and society. We need to incorporate the language of the Developmental Disabilities Act, which describes disability as a natural part of the human experience, into our fundamental attitudes and everyday practices. We need to stop using language that marginalizes and oppresses and begin to craft rhetorical and discursive constructions of disability that recognize our innate ability to lead full, rich, and meaningful lives as disabled people across the lifespan. We need to stop medicalizing and pathologizing every characteristic belonging to disabled people, and begin to address the problems and deficits in our society and its institutions and policies rather than looking to problem-find in the disabled person. We need to stop presuming incompetence and dehumanizing disabled people, and begin to presume competence and recognizing the innate humanity and equal quality of life of all human beings.

We need to build a world in which all supports are natural supports provided unquestioningly, without the feeling of legal or contractual obligation, but because of a sense of human dignity and decency, and where those supports are not viewed as accommodations for a standard system but natural and normal facets of a universally
designed system. We need to educate young students, young researchers, young clinicians, young educators, and young service providers about the diverse and rich history of disability cultures and communities in the context of a disability rights activist movement and a disability studies interdisciplinary scholarship, and we need to encourage and support young disabled people to empower themselves and their peers to demand equal access and opportunity and full and equal participation and inclusion. We need to educate our children and youth about disability as diversity, and we need to incorporate our history into mainstream history.

Ultimately, we need to challenge the constructions and institutions that continue to perpetuate ableism across all facets of society, and we need to promote this radical notion that disability is natural and normal—not something to be feared or pitied, but something to be welcomed and proudly proclaimed.

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From what I can recall, I wasn't even introduced to the person-first language (PFL) movement until I was mid-way through my undergraduate career. I was born with a disability. I called myself a disabled person without a second thought. I spent my entire life seeing no reason to take
offense when others called me a disabled person. So you can imagine my discomfort as I sat in a lecture and heard a professor - a nondisabled professor - essentially proclaim that the way I have identified myself for two decades is flat out wrong.

A good friend of mine shared with me a rather frustrating encounter with the concept of PFL. As a wheelchair user, he, like me, has never hesitated to refer to himself as a disabled person. When a class he took as part of his major required him to demonstrate mastery of person first language, he went along with it for the sake of his grade. To measure the class's understanding of PFL the professor gave an exam. My friend did not receive a perfect score because he incorrectly translated an offending phrase to PFL. What I find most distressing about this incident is that my friend's nondisabled professor presumed to have the authority to grade disability identity as if it is set in stone like the days of the week or the months of the year, thereby asserting some kind of control over how my disabled friend identifies himself.

Herein lies one of the major paradoxes of PFL: the assumption that it is acceptable to dictate how disabled people should be identified while claiming it is meant to show regard and respect for us. All too often, nondisabled people presume to have the authority to tell disabled people how we should identify ourselves, and I for one, have grown weary of it. The intention of being respectful is honorable, but using
PFL also shows a complete disregard for people who proudly count disability as a key part of their identity. Though PFL is supposed to be about putting the person first, it puts the feelings of so many disabled people second by denying us the opportunity to be our own person and embrace our disability. In fact, I believe the mentality that it’s offensive to put the word “disabled” before the word “person” perpetuates the exact stereotypical mindset that PFL purports to overcome. That is, associating a person with his/her disability signifies that the person is somehow less-than, so to account for that, disability must be sidestepped, hidden, or pushed aside.

Though I do not feel I should be obligated to use PFL, I can somewhat understand the original idea behind it. I realize that nondisabled people assume showing disabled people that you are somehow looking past their disability is supposed to demonstrate respect. It’s supposed to show that you perceive a disabled person as a person, first – as a whole being. This frustrates me, because my disability is very much a part of what makes me human and what makes me whole. It gives me a sense of pride; I want it to be noticed and acknowledged. Not to do so is to deny an integral facet of who I am.

I must make a confession, though, and it’s one I’ve heard from countless disabled people: my relationship with disability as part of my identity has been and always will be a
complex personal battle. When I was younger, I used to devote my efforts to denying that my disability was part of me in much the same way PFL does. I mean, I couldn’t literally hide it, because I’m physically disabled and have always used various highly visible mobility aids. But I embraced my disability only when it was convenient for me and then spent the rest of the time trying to dissociate from it enough to be perceived as “normal.” In other words, I had it in me to be proud of my disability, and at times I definitely was, but I usually wanted to hide from my disability as an identifier, to be known as Emily, without being identified by visible signs of my disability. Looking back on it, I’m not even quite sure what I thought I was accomplishing or who I was kidding.

I suppose I was kidding myself. I thought if I only acknowledged my disability when I wanted to, it would somehow disappear from me the rest of the time. I was trying to be a person with a disability instead of a disabled person. Everything hung on the word “with.” If I could treat my disability like something I kept in my back pocket, I thought I could be in control of when I wanted to take it out and put it on. This caused ridiculous inner turmoil on top of typical teenage angst, much of which could have been avoided, had anyone tried to give me the message that I didn’t always need to try so hard to assimilate in the able-bodied world. Instead, I believe I was a victim of the
mainstream's ableist mentality.

After attending a pre-school for disabled kids, my parents chose to place me in a mainstream elementary school. I was surrounded by nondisabled kids and I knew I wasn’t ever going to be 100% like them. So I worked incredibly hard to be Emily – with a disability, because I wanted to keep up with everyone else. I spent nearly my entire public school career fighting against any and all circumstances that called extra attention to my disability. I wasn’t embarrassed to be disabled, but I certainly wasn’t fully embracing it either. Able-bodied kids playing kickball on two legs just didn’t create the kind of environment where I could let my disability identity develop and thrive. I couldn’t put this huge aspect of my identity first.

Now, I’m not saying I would have preferred to live a sheltered life where I was only exposed to other disabled people. But being fully mainstreamed did take a toll on me in ways that I’m embarrassed to admit. When I would find myself in a situation where I was near another disabled person in a public place, I would become uncomfortable or uneasy, worried that the presence of that person called way too much extra attention to my own disability. I was a contradiction on wheels; I wanted to advocate for inclusion and access and equal rights and I wanted get far away from disability so people would forget why I was doing it. I assumed equality came with conforming to mainstream
As I’ve grown, I’ve been struggling my way through these horribly inaccurate misconceptions I had about what it meant to include disability as a key part of my identity. My perspective is still a work in progress, but I no longer push my disability aside the way advocates for PFL tend to do. I’ve come to embrace it in ways that sometimes transcend explanation. It just is. I’m disabled as much as I’m a brown-eyed, brown-haired, glasses-wearing female. But this self-respect and self-understanding needs room to breathe and change and constantly evolve, and societal and attitudinal barriers don’t always give my identity this kind of space. Internalizing and maintaining my emotionally hard-won transition from being a person with a disability to accepting my identity as a disabled person is difficult when I constantly encounter people who claim to be advocating for “people like me” while simultaneously telling me that I’m advocating incorrectly due to my linguistic choices. I’m tired of being told that I’m defining my existence wrong.

And yet, this has occurred on numerous occasions.

I once shared a piece of my writing on stigmatization of disabled people within everyday language with someone who has worked for years as a disability rights advocate (but is not disabled), and the feedback I got was “This is great, but you should use PFL.” Why “should” I use it? Because it’s politically correct? Because it’s the cool thing to do and all
the major disability “rights” organizations are doing it? I’m the one who’s disabled, and it’s my right to choose how I identify myself. While you can bet I'll be the first person to tell you that I am so much more than just a woman in a wheelchair, there’s a difference between not wanting to be seen only for my disability and consciously choosing to identify as a disabled person. While I’m truly grateful when people demonstrate that they see me for all that I am – and not just for the wheelchair I sit in – my disability is still a part of me. It doesn’t go away because a person tries to make it go away with their language, and nor would I want it to.

By making the conscious choice to call me a “person with a disability,” or by telling me I “should” be using PFL, I feel that you are subconsciously buying into society’s idea that disability is something that must not be acknowledged as part of a person. And furthermore, you can use PFL all you want, but if you call me "a person who suffers from a disability" or "a person who is confined to a wheelchair," you're putting the person first, technically speaking, but you're still using words that impose negative social perceptions on my disability. This happens all the time, and makes no sense, because if someone does use PFL, they should at the very least use it well. I'd rather be called "a person who uses a wheelchair" (although I'm partial to "wheelchair user") than be referred to as "a person who is wheelchair-bound" or "confined to a wheelchair." And I'd
rather be called "a person with a disability" than "a person who is suffering from a disability." Simply referring to me as "disabled" need not evoke the same negative connotations as words like "suffering" or "bound" or "confined." Being "bound" and "confined" to a life of "suffering" is not part of my identity, but being disabled is. Thus, I’d prefer moving away from PFL altogether, since it generally doesn’t even properly serve its intended purpose.

No matter how much I advocate against PFL, I am aware that I cannot claim that my beliefs on the matter are the same as they are for all disabled people. Disability as an identity is a highly personal and subjective issue, and I understand struggling against it firsthand. That being said, PFL is by no means the only appropriate method of addressing disability. Using it seems to give many nondisabled people a feel-good pass, allowing them to conform to the politically correct thing to do. Then they can pat themselves on the back for being so thoughtful and/or linguistically progressive. But going out of your way to say “person with a disability” instead of “disabled person” is not the kind of action society needs to be taking to produce real positive change in access and acceptance. After all, you wouldn’t go out of your way to call me a person who is Jewish or a person who is white, right? I simply am these things: a Jewish person, a white person, a disabled person. My identity is complex and ever changing, and it is infringing
upon my rights to place how I see myself in your hands. I am proud to count disabled in the long list of things that make up who I am, and I never want my disability to be secondary to the rest of my identity.

It is my hope that disability identity can be a source of pride to many, and that we can celebrate disability as a culture rather than as something secondary, something to be dangled cautiously at arm's length. Ultimately, I believe that the PFL should not be promoted under the assumption that you’re doing a favor to the feelings of disabled people/people with disabilities. Rather, we should move towards acceptance and understanding of disability as just one of myriad identifiers in our culturally rich and complex world.

I am not less of a person because I’m disabled. “Disabled” is not a derogatory word, and I do not take offense when I am referred to as such. It's more important to me that you don’t go out of your way to try to be overly sensitive and politically correct- that shows me that my disability is not an issue that you feel must be tip-toed around. I want my disability to be accepted just as any other part of me. And that is why I confidently call myself a disabled person. It is simply another part of my identity, both because I take pride in it and because I accept it as a part of me, whether you do or not.
I wake from dreams and stand in the window staring at the hills with the trees standing black against the black sky.
I wake from the dreams I cannot remember and stare at the trees and wonder if there are people living in the houses nestled there sleeping through their own dreams they cannot remember.
Staff comes to the door and asks me if I’m doing okay.
I cannot sleep, I say.
Come to the nurses’ station, they say.
We walk through the hall, and they give me pills and I sit in the hallway waiting for the pills to come on.

The pills wash over me.
The pills wash over me and the walls start to bend and bubble.
I close my eyes and Staff walks with me to my room.
I lie down and the dreams come on again before I’m even asleep again and the window looking out over the hills with the trees black against the black sky seem to open and I wonder if the people living there are thinking of me dreaming my dreams I’ll never remember.
I used to take pride in being palsy-skinny. For the uninitiated, palsy-skinny is the type of skinny that many people with cerebral palsy (CP) experience. According to the National Institute of Neurological Disorders and Stroke, we burn energy at a rate of 3 to 5 times faster than the average person does. Our muscles are constantly spasming, and that
uses up a lot of energy, thus burning a lot of calories.

I was always palsy-skinny from a very young age. I nearly fell off the percentile charts at points, and doctors were actually concerned about the small size of my head. My friends used to tease me by telling me I had a bony butt. Later, I listened to people bemoan their tendency to gain weight and I would smugly inform them that I could eat whatever I wanted and not get fat. It was a party fact, a badge of honor. To me, skinny was good. It was something that I had that most people did not.

College came and while others gained the freshman 15, I didn’t. I reveled in my seeming immunity to that dreaded college curse. Never mind that I was in the midst of an emotional breakdown which eventually led to an anxiety disorder diagnosis. Never mind that the very thought of eating food in the dining hall would send me into nauseous panic. Never mind that my social life, or what was left of it, was suffering badly. Or that I would go to the gym and do the treadmill purely out of boredom, because I needed something to get my mind off the fact that I was miserable. I was still skinny, and skinny was still good.

As my mobility and abilities began to change, the warnings loomed above me like a hovering raincloud. *You have to be careful about your weight*, I was told ominously – by my parents, by doctors, by people who had no idea what it felt like to be me. *The more weight you gain, the harder it
will be for you to move. You don’t want to lose your ability to walk. This was always presented as the worst-case scenario, an outcome intended to scare someone into losing weight. I internalized these warnings and began to obsess. Always having an avid sweet-tooth, I tried to limit myself to one sweet thing a day. It didn’t pan out as well as I hoped. Food – particularly dessert – was how I coped with life. I would try to justify it, telling myself I “deserved” a treat. Then I would feel guilty for my choices. I would berate myself for taking my scooter to the dining hall instead of walking there with my crutches. But some days the idea of walking was just too much to bear and the sides of my brain would go back and forth endlessly arguing with each other.

Around the same time, I met one of my best friends. Staci is fat and has several disabilities and chronic illnesses that are not readily apparent, one of which directly correlates to weight gain. Through her, I experienced the realities of fatphobia and sizeism. I began to critically examine the messages that society sends to us about weight and size. But being rationally aware of the issues didn’t make things any easier. The whispers continued in my brain, telling me how fat I was, how much fatter I would become if I didn’t lay off the food, if I didn’t walk more, if, if, if. I banished the thoughts as best I could and attempted to look at the issue from a detached, social justice viewpoint.

Things came to a head in what was supposed to be the
second semester of my junior year. My field experience rushed over me like a tidal wave and nearly drowned me. I wasn’t getting nearly enough sleep, and my meals were more often than not microwaveable Chef Boyardee raviolis—something I could make easily without having to coordinate my uncooperative hands. I was uncomfortably conscious of how messily I eat—a product of impaired coordination—and was sometimes embarrassed eating alongside my colleagues during lunch.

A series of discriminatory acts against me by professors and other authority figures led to my graduating a year early without the teaching certification I had expected to be leaving with. Shaken and traumatized, I returned home to find that seemingly without my knowledge, my body had morphed into a figure I hardly recognized. My pants no longer fit, my formerly small boobs were bursting out of my bra, and I had exactly zero shorts to wear for the summer. I looked at my thighs, now streaked with stretch marks from the rapid weight gain. My body had rebelled and was no longer in my control.

I complained to my friends that I had gotten fat at college. They didn’t see me that way. Some of them told me that the only reason I felt fat was because I had previously been skinny, like a toothpick. They were probably right. All of a sudden it was like the rug was pulled out from under me, the tables were turned, and I had become one of Those People
who had to worry about their weight. It was a new experience for me.

I know many other people with CP who are “palsy-skinny” and take pride in it, just like I used to do. Some have told me they use it as a sort of defense against ableist families—something to celebrate about their bodies when they are being told that their bodies are wrong in every other way. It’s that type of oppression that’s the most insidious and hard to combat. It combines internalized oppression (absorbing things your oppressors say about you and thinking along those lines yourself, even if those things may cause harm to you) with horizontal oppression (being prejudiced against another minority group to feel better about yourself) to create a type of super-oppression – one that never goes away. It’s one thing to battle oppression from the outside, but what do you do when the ideas that are attacking you are your own?

As with all forms of oppression, sizeism doesn't exist in a vacuum. It interacts with and impacts other forms of oppression, including ableism. For those of us with disabilities where extra weight can make moving around that much harder, the threat of losing what mobility we have can loom over our heads. Ableism tells us that we must walk and become as “independent” as possible; sizeism blackmails us into making sure we stay that way. They both reinforce the man-made idea of an ideal body, one that everyone should aspire to have. Both feed into the capitalist idea that we must
pull ourselves up by our own bootstraps, that we must fend for ourselves, that we must not be a burden on anyone else. The two work in tandem with sexism as well – a female body should be Barbie doll skinny, sleek and sophisticated, and anything else is just gross.

Our culture's standard definition of beautiful depends on preconceived notions about how the perfect body should be, notions that rely on various forms of oppression to legitimize them. A model body should ideally be white or white-passing, slim and nondisabled. Is it any wonder we don’t see fat, visibly disabled people of color posing on the covers of fashion magazines?

When I gained weight I felt displaced because I no longer fit that acceptable standard. I had come to rely on my thin physique more than I knew. If I couldn’t be an ideal woman in the eyes of society, I could come damn close. I thought I had long ago accepted my body and myself for what – and who – it was, but it turns out I had merely grown complacent in having a specific type of disabled body. Now it was time to adjust to a whole new type of body. After 21 years, I could no longer lay claim to the title of “palsy-skinny.” My get out of jail free card – the one that let me be halfway tolerated by society because at least I wasn’t fat – had been revoked.

As a disabled person, accepting your body doesn’t just mean accepting your disabilities and the limits they place on you as a human being. Accepting your body means finding
your own groove, whether it’s fat or thin, disabled or not. It’s about self-care- taking care of yourself, at any size, at any level of ability. Though fat activists and others have long discussed the idea of Health at Every Size (HAES) I believe a more important, accurate concept would be Self-Care at Every Size. That doesn’t necessarily mean doing things that are obviously harmful to your body just because it makes you happy; it means taking care of your body and mind equally, and not sacrificing your mind for the sake of your body. It means shedding the preconceptions that society has saddled you with and deciding if independently of anyone else, you are comfortable in your own skin.
Where are the people with brain injuries who love crip culture as much as I do? I've chatted briefly with the only three I've heard of to date: Disability Studies scholar Mark Sherry and Krip-Hop Nation artists Lady MJ Warrior and T. Alicka Hickman. To be fair, these three people do not all use the term “crip” to describe themselves. I am using it here as shorthand to describe an edgy activist segment of the disability community. These activists have reclaimed a negative word--crippled--and embraced it as an identity
marker of pride and solidarity. If anyone else with a brain injury is out there loving crip culture (whether or not you like, or feel included by that label), please let me know.

I often ponder why my brain injury community does not spend much time in crip culture. In fact, many people with acquired disabilities have not heard of disability culture, pride, justice or identity, or that individuals and groups have been working for years to go beyond basic human and civil rights. However, that is just the start of why folks with brain injury rarely participate in the larger disability culture. It is partly a matter of competing cultural values.

I was a regular attendee at brain injury support groups for quite some time after my traumatic brain injury. I could not often put out my call for other brain injury crips (BICs) since a support group is for social and emotional support, sharing resources and venting. It is not the place to bring up academic terms like "internalized oppression" and "identity markers." So I tried to observe what defines a brain injury culture and what values it might hold that are different from crip culture's. As those values came to the fore, I began to understand the divide. Here are three major values of brain injury culture that stand in stark contrast with a contemporary, critical disability culture.

1. People with disabilities don't accept us (because we get better, and they don't)!
2. I'm not disabled! I'm differently-abled! I'm alternatively-abled!

3. Just think positive, and you can overcome all adversity!

I heard these tropes repeated and applauded in various forms both in and out of support groups. I responded to them in silence, worrying that voicing concern might indicate betrayal to my community’s narrative. Protesting a trope is often viewed as threateningly rebellious. The rare times I attempted to question those who said these things, I was met with defensiveness, over-compensatory apologies or blank stares. So I knocked it off. I sought a cross-disability social group in which I could consider these issues in a critical way. I present my responses to these cliches here to address what maybe lies beneath the surface.

1. They don't accept us (because we get better, and they don't)!

People with brain injury are introduced to their disability status in doctors' and rehabilitation clinicians' offices. In those contexts, disability means "impairment" and does not carry with it the rich, cultural aspects of a disability identity. I think speech therapists should hand us two welcome packets. One is for Patients, which teaches you how to set
and meet achievable goals so you can relearn how to act like everyone else. The second, for People, introduces you to stereotypes, discrimination, civil rights, and justice in case you don't fully recover and need to know about these things. Or in case you would like to join the movement regardless of your patient or impairment status.

Many people have a reduction in impairment over time or learn ways to compensate for brain injury impairments. But to say that we are excluded because "we're not disabled enough to be in the club" takes a passive stance on this disconnect among communities. Brain injury is hard to understand as a disability. It does not easily fit into commonly understood physical or sensory impairment categories most activists embody but lies somewhere along continua within both. People with brain injuries were not included in early civil rights work and the building of disability culture. Unfortunately, the "not disabled enough" stance nowadays reinforces the disability hierarchy—where some impairments are valued more highly than others—to which dominant culture subscribes. The larger disability justice movement today challenges this hierarchy to work toward a more inclusive society. The brain injury community does not know this challenge to the socially constructed hierarchy exists. Plenty of people with other disabilities will and do accept us as we are. It feels like the easy way out to blame the broader disability community for not wanting to include
us, as the movement is not actually keeping score of how crippy individuals are.

I think that on our end, we do spend a lot of time socializing only with others with brain injury. In our medical model-oriented society, we come to internalize the belief that no one on the outside can relate. So we stick with our impairment group. While a brain injury support group may have certain accommodations needs that a group for leg amputees may not, perhaps we sometimes put too much emphasis on sticking with sameness. We need to share ideas and resources with others with similar needs, impairments and struggles. Yet we contribute to our own isolation when we do not also mix with folks with other types of disabilities. It would be hard for those groups to accept us: they do not know we are even here when we are only meeting with ourselves.

As someone whose communication and emotional regulation skills have been altered, I know how difficult it can be for others to accept or, as some unfortunately put it, "deal" with us. Some people’s impairment increases the chances of violent outbursts, and we are known to blame you for our own confusion. It is hard to know how to respond to that quirk many of us have of speaking non-stop for twenty minutes and getting angry when someone else wants a turn. Even I do not always know what to do when my or someone’s impairment is annoying or leads to inconvenience
for others. I do know, however, that a response based in compassion and patience is essential.

Given some of the odd communication many of us exhibit, it is helpful to recognize that part of tacit brain injury culture is to expect to give and hear about gruesome injury details and explain your impairments the first time you meet someone. As a group, we do not expect privacy and have a difficult time relating to the privacy many folks with other impairments need. This is a genuine cultural barrier that must be acknowledged so people with brain injury are not offended when someone refuses to answer whether they are disabled and in what way. Likewise, folks with other disabilities need to recognize our cultural norm to ask about your impairments. Of course you do not have to answer. Just understand that we are intending to get to know you, not objectify you. That may help ease the burden of that question. After all, we are trained to believe that only others with brain injury can understand us. So we are testing the waters, however uncritically.

2. I’m not disabled! I’m differently-abled! I’m alternatively-abled!

In fact, many rehabilitation clinicians tell us these things. What’s odd is that they are unable to bill insurance and could lose their licenses for treating people who are different rather
than disabled. They also tell us how great we are doing on a regular basis. At a time when close contacts openly show us their grief over losing the person they once knew, compliments are a breath of fresh air. It’s no wonder we like to believe what the clinicians say when it’s so positive. Often, many of us feel a huge disconnect with clinicians who set us up with activities and homework that don't feel appropriate or geared toward our own recovery goals. Some of them baby-talk at us as well. So compliments of some types are needed. Otherwise, many of us are living under a cloud of self-doubt, self-pity, and resentment for a familiar life stolen without warning and replaced with worksheets.

The most beloved narrative of brain injury is of tragedy, grief and loss of identity. One reason clinicians encourage us to focus on our gains is to help us get away from that narrative. Each gain in clinic in attention, memory, and organizational skills for them signals less disability- as if it were that linear and a universal desire for all people with brain injury. Media reinforces this, claiming the stories most appealing to the masses are those of someone overcoming great tragedy and learning to achieve despite their challenges and deficits, rather than with their changes. The larger, general discourse on disability is of pity, shame, inferiority, inspiration, and ending and preventing medical conditions through genetic testing, selective abortion or assisted suicide. It is no wonder people with brain injury-
related impairments might prefer to say they are not disabled. This is the message of negativity with which we are most familiar. As long as we are separate from a critical community (see #1 above), we do not realize we are shaming ourselves and others by saying we are not disabled if the reason for that denial is that we despise the notion of disability. It is a complicated denial in which people acknowledge an impairment and its consequences but defend themselves against a label they interpret as derogatory so as not to be associated with those deemed inferior.

Regardless of impairment type and level, many people accept that their identity now includes "brain-injured," "having a brain injury," or "disabled to some degree," though they may not associate brain injury with disability. For instance, someone can identify as having physical but not cognitive impairments even though they will describe difficulties with memory, attention and communication, which is perfectly acceptable from an identity politics stance. Often a key to acceptance is not to dwell on loss or a good-old-days-biased view of ourselves as having been perfect pre-injury. I know many people who are pleased that the injury caused inevitable life changes that led them to become better people, more enlightened, and more in touch with their gifts and strengths. It is not very common, though, to assign positive attributes to the injury symptoms and impairments
themselves because those are seen as negative, as deficits we are supposed to be correcting in rehabilitation.

I would like to challenge those who feel strong and enlightened but eschew any disability identity to broaden their definitions of what it truly can mean to embody a disability identity. And to recognize that disabled does not mean "less than." It means oppressed and shamed because of having an impairment. There is a subset of people who are unaware that “strong and enlightened” versus “disabled” is a false dichotomy. Thus, they cling to a negative image of a disability label. Those engaged with crip culture recognize the oppression inherent in equating disability with weakness and brokenness. Using patronizing language such as "alternatively-abled!" or "handicapable!" makes it clear that you are not one of "those" people who is weak and broken. But why mention your abilities at all unless you are aware you have acquired some level of disability or impairment? I would like to see those who do not want a disability identity say, "I'm not disabled" and end the sentence there. Others can say, "I'm disabled." And we can appreciate how brain injury affects us differently, how we can each respond to it differently, and that regardless, we can be proud. Infantilizing vernacular does not help us gain respect primarily because when nondisabled people say we are "differently-abled" they specifically mean they see us as "disabled" but prefer to not use that word.
3. Just think positive, and you can overcome all adversity!

Oh, the balm of positive thinking. The folks with brain injury with a positive, forward-looking attitude are likely to enjoy their lives. Some will even encourage others to think positive too. After all, it worked for them! I have yet to speak to someone with a brain injury with a hugely positive attitude who feels social privilege and access to resources played a significant role in their recovery. I have spoken to many people who also deny the role that injury severity might play in recovery over time. The narrative is their positivity directly led to their recovery and restoration of a satisfying, engaging life. But quality of life is not tied linearly to impairment level. Some of the least impaired are the most troubled by it and unsatisfied for many reasons. Recovery does not only refer to how many neurons stitched themselves back together and gave you your thinking skills back. It can refer to all aspects of life and living, from the biological to the social, economic and political.

Looking at the most glaringly positive thinkers I know, I asked myself what they have in common: They are white, middle-class women in long-term relationships who survived life-threatening injury. Many people I know who don’t fit into this quintuple whammy focus enormous time and energy on
positivity. Yet in conversation, they speak of life in more nuanced terms and are less likely to proselytize that their attitude is the main thing that healed them. In fact, some long to have a more positive outlook but cannot due to organic mental health struggles from the brain injury and/or the harsh reality of living in impoverished, isolated, unsatisfying situations.

My issue is not with positive thinking. Ok, that is part of my issue. The way in which positive thinking in the brain injury community alienates it from the crip community is less in the statement "think positive to get better!" and more in its corollary, "if you're not better, it's your fault for not thinking more positive!" Setting complete recovery and full health as the universal ideal is exclusionary enough. Adding blame to the mix makes it unbearable for many, myself included. When people with brain injury wax philosophical about how much it helps to look on the bright side and believe we have the power to heal ourselves completely, they absolutely mean well. But preaching positivity silences very real, ongoing stories of pain and oppression and gives us a seemingly easy out from taking responsibility for social inequities in our community. Those inequities are felt quite strongly in the lack of coordinated care for brain injury in medicine and rehab as well as a paucity of resources and access to social, vocational, and health supports after rehab ends or is cut short. I feel ashamed when people in my
community advise one another to wash our hands of those who are “too negative.” They posit you cannot maintain your optimal health and brain function if you are surrounded by sick or sad people. But don't sick or sad people have the right to a supportive community as well? Don't brain-injured folks who get sick or sad have a right to be respected and offered support amongst each other?

If we hold a more balanced view of the role of positive thinking, we have a great point of connection with the disability community, especially with those who have experienced disability their whole lives. Using "if I can do it, so can you" is a carrot for some, but not everyone. What's more, those of us who have access to resources, assets, and community must be careful when preaching a positive attitude to those who don’t have the privileges we may have.

I think more people with brain injury can become BICs (Brain Injury Crips), though I imagine tales of overcoming tragedy and disability will never fully leave our table. After all, many in my community have returned from the brink of death or death itself. With changes in perception, interpretation, thinking, communicating, behaving, moving, sleeping (really, everything) that cannot be seen or felt by others, a need to describe and justify these things does not necessarily have to leave our conversations. Perhaps, however, these stories can play a different, more unifying role. To become a BIC might require the following shifts:
● accept that our injury and impairment stories are not the only, or most important things about ourselves and telling them can overshadow other parts of our personalities and experiences
● realize that we can be working toward justice as well as basic rights
● advocate for and with other marginalized and oppressed groups
● engage in cultural activities such as storytelling, music, visual arts, media, dance, acting and blogging
● understand brushes with death may give powerful insights, but that we are not automatically more enlightened than others recognize that identifying as superior to those without brain injury hurts our attempts to reintegrate into society and be seen as leading “normal” lives
● develop a positive connotation to the word "disability" rather than fight the word and use it only when convenient, such as when applying for a reduced-fare bus pass.

I hope that by developing more BICs, we can come together to challenge the narrative that overcoming disability and being inspirational are our main achievements in life post-injury. This will be hard because so many people with and without disabilities outside crip culture really love the idea of disability as overcoming tragedy. It is a value with an important historical context. How could we have fought for
and achieved landmark legislation like the ADA, IDEA, Rehabilitation Act, accessible public transportation, and cultural shifts like having special education classes held on the main floor, not the basement, without people rising up to show how hard they were working to overcome obstacles and barriers? We couldn't have.

We needed our disabled predecessors to prove they were whole, competent humans who deserved the rights that belong to nondisabled citizens. They did that by making themselves public and the realities of their impairments and obstacles known. What most of our society remembers of these fights, though, is the physical impairments they could see. With so much focus on impairments, we as a society have come to believe that the only obstacles worth mentioning are personal and internal. In fact, what disability rights groups were fighting for was to eliminate external obstacles, whether environmental, structural or attitudinal. The current disability justice line looks at intersections of oppressions: micro-aggressions and subtle or covert forms of ableism, and a whole reframing. Disability is a natural occurrence not defined by lacking, deficiency, or reference to "able-bodied" as the norm and the ideal. This argues for us as full, complete humans who deserve the rights that belong to nondisabled citizens.

So come on, my friends with brain injuries. There is a beautiful, enriching culture out there for us to join. I
understand from my own first-hand experience how so many obstacles after a brain injury genuinely are internal. I still believe that while we are working on those obstacles (or not, as each person chooses), we can also work on external barriers to our inclusion in a compassionate society.
My preferred communication system is a laminate piece of paper with the alphabet on it. In this world full of computerized communication devices, I purposely chose and continue to use my low-tech communication board. I have tried one of the high-tech communication devices (AAC) but ultimately stuck with my board.

I taught myself to read at 22 months old so written
language became how I communicated. My dad made my first letterboard when I was 3 years old. That letterboard got me all the way through elementary and middle school.

The summer before 9th grade, however, my dad decided I needed to learn a high-tech AAC device - an electronic device that speaks what I type. I was starting a new school and he felt I needed a way to initiate conversation and not have to wait for people to come over to me. I was against the device, but when he said he'd pay me, I agreed (a good way to motivate any teenager). I became proficient at it but when my dad packed it for the first day of school I spelled on my letterboard, "I'm never using that again."

I still use a variation on my original letter board. People often chastise me for not using a high-tech AAC, saying I'm not independent since I rely on someone else to read the board. However, I strongly prefer my letter board to any electronic device because it's so interactive and quick. Rather than wait for me to type an answer, the person I'm talking to reads what I'm saying and thus remains engaged in the conversation. I always have an assistant with me who can explain how my board works and it only takes a few minutes to learn. People are very willing to try my board even if they're nervous.

Illiteracy is very prevalent among people with disabilities. If a person can't read or spell, they get thrown a picture-based AAC device. The problem is that able bodied people
program X number of sayings into the devices and since the people with disabilities can’t spell, they’re stuck with only X number of expressions. This severely limits what they can say, and what they can participate in.

My board makes difficult conversations easier. When I was twelve years old I had a secret. I felt I couldn’t tell anyone but I really needed to. So one of my closest friends and I had a chat. Using my letter board, I was able to come out as a lesbian. As hard as it was to spell out, I knew my friend was with me all the way. I know if I had had to make her wait while I typed it out on an AAC device, it would have been excruciating. With my board she could ask me questions and I could immediately respond. There is a certain intimacy with my board. I felt she was listening to every word I spelled.

One might think an AAC device would make a job interview easier, but personally I still prefer my board. Last year when I had to fill out paperwork and meet my new boss, my assistant just set up my board and voiced what I was spelling. I was able to answer and ask questions and my new boss felt at ease because he could communicate with me. I think the lag time with AAC devices would have made the conversation awkward. However, I fully respect whatever communication systems people choose to use, if all options are presented. I think speech therapists should discuss the full range of AAC devices, from low-tech to high-tech and
discuss pros and cons of each. People with disabilities should choose what feels right to them not what “experts” push on them.

Choosing my board over a high-tech device was a hard decision especially with so much pressure to use something electronic. I’m glad I’m very stubborn and stuck to what I wanted. My board is the door to communication and opportunities for me.
In May 2013, I attended a lecture at a local university on the history of disability public policy, and as many programs are wont to do to advertise themselves, a small brochure was placed on every seat in the room listing all of the disability-related programming for the month. The program series of four events was called “Representing Disability:
Disability Studies and the Humanities.” The brochure caught my eye not simply because I was interested in learning about the planned events, but because the front cover of the brochure was illustrated with a cropped image of a Frida Kahlo painting. As an art historian by training, and a visually-oriented person by nature, I was immediately drawn to the image on the brochure. While I knew the lecture I was there to see probably wouldn’t be addressing Frida Kahlo or her paintings, I was curious to see what event in the series would be discussing Kahlo’s work. I read through the brochure once, twice, and then again, just to clarify what I found about Kahlo in it: nothing. While they each sounded interesting in their own right, none of the four events in the “Representing Disability” series included a discussion of Kahlo’s work or any related topic, such as Mexican or Latin American visual art, feminist artists of the twentieth century, or paintings made by artists with disabilities. Currently, Kahlo is one of the most well-known Mexican or even Latin American artists in the U.S., and as such, her paintings, especially her self-portraits, are fairly easily recognizable to the U.S. public. Yet why was a painting by Kahlo used as the visual representation of the “Representing Disability” program when neither Kahlo nor her work was being addressed?

And so began a quest to find an answer and to examine the larger implications of how Frida Kahlo as an artist, as a
disabled woman, and as a woman of color is visually represented within the realm of Disability Studies. The painting that was used on the cover of the “Representing Disability” brochure was one of the last self-portraits that Kahlo painted a few years before she died: *Self-Portrait with Portrait of Doctor Farill* from 1951. In this painting Kahlo pictured herself in an interior room with wooden floors and light yellow walls with a large blue stripe along the bottom of the walls. Kahlo painted herself sitting in a wheelchair while wearing a long gathered black skirt and an over-sized white shirt that is decorated in the center of her chest, just below the v-neck collar, with two blue tassels. Kahlo’s body and face are shown in a three-quarters pose and in her right hand she holds a group of paintbrushes whose tips drip a few drops of blood onto her smock shirt; in her left hand she holds a painter’s palette, resting on her lap, which is covered in an anatomically-correct human heart that approximates the shape of the palette. Next to Kahlo, on her left side, stands a wooden easel holding a stretched-canvas painting of a realistic portrait of the face and upper chest of a balding man in a suit and tie, Dr. Farill. There is no other furniture or people in the room and the central representations in this painting are clearly Kahlo, as a painter in a wheelchair, and Dr. Farill, as a painting in a painting.

*Self-Portrait with Portrait of Doctor Farill* was used in 1997 as the cover image of a foundational Disability Studies
book: Rosemarie Garland-Thomson’s *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. It appears that this is why Kahlo’s painting was chosen to adorn the cover of the “Representing Disability” program; or at least, this is my best guess as to why this particular painting was selected to “represent disability” in this caseⁱ. Certainly the organizers of the program series could have chosen Kahlo’s painting because it literally does visually represent disability in terms of showing an artist “at work” using a wheelchair; but the fact that it had been used to represent disability on a well-respected Disability Studies book fifteen years prior to this event series makes it the likely origin for “Representing Disability.” Unfortunately, this does not provide a particularly good reason why the Kahlo Self-
*Portrait* was used on the brochure; just because the painting had been used on a Disability Studies book does not make it an ideal candidate to do the work required of a visual image to symbolize disability despite, or perhaps more accurately, precisely because the programmed events in “Representing Disability” were meant to promote disability research and representation as a social justice issue.

*Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* is well-known in the field of Disability Studies and Garland-Thomson is a major figure in the field, having published several essays and books since

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¹ My inquiries about the choice of image on the brochure went unanswered by the organizers of “Representing Disability.”
Extraordinary Bodies. But nowhere in Extraordinary Bodies does Garland-Thomson actually discuss Self-Portrait with Portrait of Doctor Farill or Kahlo herself. Indeed, while Garland-Thomson does analyze some visual imagery on disability and the “spectacle” of the disabled body in this text, her main concern is with literary representations, not visual representations. The reason to have this specific Kahlo image represent disability on Extraordinary Bodies remains unclear.

Kahlo lived with several disabilities during the course of her lifetime, acquired through illness at a young age and a major vehicle accident as an adolescent that broke her spine and pelvis and ruptured several internal organs, including her uterus (Greeley 2004, 216). Kahlo experienced chronic pain and underwent multiple surgeries between the ages of 18 and 47, when she died. Self-Portrait with Portrait of Doctor Farill was painted by Kahlo in 1951 not long after she had one of the last in a series of spinal surgeries she experienced as an adult (Kahlo 1995/2005, 93). Dr. Farill was Kahlo’s surgeon at this stage in her life; he had performed at least seven operations on Kahlo’s spine in the last few years of her life. According to Kahlo’s diary, the artist

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2 I am not seeking to “blame” Garland-Thomson or even her publishers for making the choice to use Kahlo’s Self-Portrait with Portrait of Doctor Farill as the book cover image here. Rather I am interested in the implications and potential repercussions of this choice in representing disability, no matter who made the actual decision to do so. In her more recent book, Staring: How We Look (2009), Garland-Thomson once again uses an artwork by a person of color, early twentieth century painter, Jacob Lawrence, as the cover image. In this book, however, Lawrence’s Blind Beggars (1938) is discussed (if briefly) in the text of the book’s introduction and is used to demonstrate an important tenet of the book: that staring can, contrary to conventional opinion and norms of etiquette, be useful and even enjoyable for the people on both sides of the gaze - those who are looking and those being looked at.
painted this double portrait as an homage to the doctor whom she believed saved her life and made her body more comfortable. In a diary entry dated 1950-51, Kahlo wrote,

I've been sick for a year now. Seven operations on my spinal column. Doctor Farill saved me. He brought me back the joy of life. I am still in the wheelchair, and I don't know if I'll be able to walk again soon. I have a plaster corset even though it is a frightful nuisance, it helps my spine. I don't feel any pain. Only this ... bloody tiredness, and naturally, quite often, despair. A despair which no words can describe. I'm still eager to live. I've started to paint again. A little picture to give to Dr Farill on which I'm working with all my love. I feel un-easy about my painting. Above all I want to transform it into something useful for the Communist revolutionary movement, since up to now I have only painted the earnest portrayal of myself, but I'm very far from work that could serve the Party. I have to fight with all my strength to contribute the few positive things my health allows me to the revolution. The only true reason to live for. (Kahlo, translated by Fuentes 1995/ 2005, 93-95).

Dr. Farill’s portrait posed on the easel next to Kahlo in this painting has been likened to a retablo, or devotional painting, placed on an altar. Kahlo’s diary notes seem to support this idea; she created this painting as a gift to the doctor who helped to ease her pain. Seen in this light, Kahlo’s painting appears to be less about her own representation as a
disabled female artist of color and more about celebrating a representative of the medical culture with whom she had a close relationship and who had worked diligently to try to “save” her. This latter interpretation is what several sources on the subject of Kahlo’s experience with her disabilities, medical intervention, and painting argue as they look at Kahlo’s entire body of work through a through a lens of bodily and emotional pathology (Kettenman 1999; Park and Park 2004; Wach 2005).

Based on this reading of the painting, it might seem an odd choice to visually represent disability on the cover of Extraordinary Bodies and the “Representing Disability” brochure. Yes, the artist is disabled and in this specific painting represented herself in a wheelchair, but the image seems – at least on the surface - to conform to a more conventional medical model of disability than the social model of disability that Garland-Thomson and most other Disability Studies scholars and activists espouse. While we should certainly take Kahlo’s own words on her love, respect, and thankfulness toward the doctor into account in reading this painting, we cannot take Kahlo’s appreciation toward Dr. Farill in making her physical disabilities easier to

3 The medical model of disability holds that people with disabilities (PWD) are developmentally, mentally, and/or physically abnormal - that they deviate from the typically “healthy” ideal in a pathological way. The medical model marks PWD as needing of medical intervention and cure. As a result, the medical model disenfranchises PWD because it diagnoses disability as problematic and PWD in need of “help.” The social model of disability, developed by and for people with disabilities, critiques the medical model and sees society as disabling, rather than the impaired body. According to the social model of disability, disability is based in social conventions and institutions that perpetuate lack of access in society (physical, structural, attitudinal, etc.) and which must be confronted and changed.
deal with out of the artistic and political context in which she situates them. In this diary passage Kahlo clearly relates her ability to sit with less pain in her wheelchair in a plaster corset to her desire and ability to spend her time painting in service to her political, and more specifically, her Communist, beliefs. Likewise, her desire to live and to paint in order to serve the Communist revolution go hand-in-hand with negotiating the discomfort and depression she experienced with her disabilities. In looking at *Self-Portrait with Portrait of Doctor Farill* we need to keep these intersections of emotion, physicality, political conviction, and identity in mind to see the whole picture of Kahlo’s self-representation. Art historian Janice Helland writes,

The psychological reductionism that equates the [...] imagery in Kahlo's work with a desire to "paint away" her accident, suffering, and pain does little justice to her work. It reduces an important group of paintings done by a deeply intellectual and socially committed artist to simply a visual cry of personal angst. But this was not Kahlo's intention. [...] Since she was a political person, we should expect to find her politics reflected in her art. (Helland 1990, 405).

In other words, while on the surface this painting might seem simply to be a kind of votive offering to her doctor – her “savior” - in looking more deeply we can see how Kahlo’s personality and experiences shape this work beyond a direct expression of pain and gratitude.
This is an important distinction to make because the majority of what has been written on Kahlo, her life, and her painted subjects assumes a direct one-to-one relationship between the physical pain Kahlo lived with as a woman with disabilities and the imagery Kahlo used in her artworks. But as Maragaret Lindauer writes in her book *Devouring Frida: The Art History and Popular Celebrity of Frida Kahlo*, “Any biography, like an interpretation of a painting, is not discovered but produced” (Lindauer 1999, 3). As such, we can see that most of what has been written on Kahlo as a disabled artist, including the few notes found across authors on *Self-Portrait with Portrait of Doctor Farill*, are either pathologizing and overtly ableist, or more covertly ableist because they rely on conventional disability narrative tropes that idolize people with disabilities for their (presumed few) abilities. Titles such as “Frida Kahlo and the Image of Tragedy” (Wach 2005), “The Fine Art of Patient-Doctor Relationships” (Park and Park 2004) and *Frida Kahlo: Pain and Passion* (Kettenman 1999) clearly render Kahlo and her work as one-dimensionally pathological. For example, Ken Wach’s article called “Frida Kahlo and the Image of Tragedy,” describes Kahlo’s self-representation in a different Kahlo painting - *The Broken Column* (1944):

Her face, though crying, betrays no other hint of external emotion or self pity and the painting offers no hopeful imagery or hint of deliverance in the after-life – no signs of
spiritual release are evident and no angels beckon from the sky. Her eyes are almost confrontational in their frontal gaze and, characteristically, they do not look down in dejection nor upward in hope. Her face and its courageous expression are almost truculent in their impassivity. The personal resoluteness shown in this bleakly honest painting may also be seen in real life, as can be observed in family photographs just one year after her horrific accident. She wears masculine clothes to hide her disfigurements, carries a walking cane as if to add a jaunty element to her demeanor and already, at the age of nineteen, seems to display a compensatory and brave attitude towards her many debilitating injuries. (Wach 2005, 2).

While some of the language here might initially seem to support the notion that Kahlo painted herself as a strong and defiant woman living in pain, as we look more deeply this paragraph practices a kind of disabling rhetoric in several ways. For one, it uses language such as “disfigurement” and “debilitating” to describe Kahlo’s physical status based simply on looking at the painting and making assumptions that Kahlo’s self-representation in paint on canvas is actually Kahlo herself⁴. Next, Wach uses language commonly used in describing people with disabilities not on their own, preferred terms, but via the point of view of the able-bodied: as

⁴ This happens frequently in analyses of visual art wherein individuals mistake the image to be the subject of the image, rather than a representation of that subject. Since all representations are mediated in some way – at the very least through their “distillation,” via the mind of the artist – this assumption that the subject is the representation and vice versa is problematic.
inspirational to any and all who look at Kahlo and her painted self. Kahlo here is “courageous,” “impassive,” “compensatory,” and “brave” despite, or perhaps more accurately, because of her “many debilitating injuries.” This visual and rhetorical tactic has come to be called “inspiration porn” by disability activists, as it seems to be produced for able-bodied people to experience great emotional joy (or perhaps more crudely, and accurately, to “get off”) on seeing people with disabilities manage their lives “successfully.” Stella Young writes,

Inspiration porn shames people with disabilities. It says that if we fail to be happy, to smile and to live lives that make those around us feel good, it's because we're not trying hard enough. Our attitude is just not positive enough. It's our fault. Not to mention what it means for people whose disabilities are not visible, like people with chronic or mental illness, who often battle the assumption that it's all about attitude. And we're not allowed to be angry and upset, because then we'd be "bad" disabled people. We wouldn't be doing our very best to "overcome" our disabilities. (Young 2012).

“Inspiration porn” is problematic because it marks people with disabilities as “naturally” inferior to nondisabled people; it assumes that all disabled people should take as their goal the achievement of “supercrip” status; and it marks people

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5 The “supercrip” is a disability stereotype that is used to describe people with disabilities who have “overcome” their disabilities to act like and be treated like nondisabled people. Eli Clare writes that supercrip narratives “reinforce the superiority of the nondisabled body and mind. They turn individual disabled people, who are simply leading their lives, into symbols of inspiration” (Clare 1999/2009, 2).
with disabilities as the object of scrutiny to be judged by non-disabled people according to hegemonic bodily, psychological, and emotional ideals. Inspiration porn is so pervasive in part because of the expansion of media sites via which to circulate such imagery and in part because it thrives on the neoliberal notion of individualism and willpower in which most Western nation-states have become so deeply invested. Inspiration porn can be seen as a parallel to the “American Dream” trope: if one only wishes and struggles hard enough, one can achieve any dream they have. This dependence on one’s individual emotional, physical, and psychological power ignores the institutional structures of oppression that are systematic and systemic in Western culture and simultaneously disregards the power of community, of people coming together to help one another and fight oppression by dismantling hegemonic power structures rather than changing an individual to fit society’s needs and desires. In so doing, inspiration porn – whether ascribed to contemporary internet memes or a 60 year old painting by a disabled Mexican painter – ignores structural inequity and places the blame, and “success,” for making it through life with disabilities on the individual.

Furthermore, the treatment of Kahlo and her work by critics and historians is frequently racist, sexist, and heterosexist. Wach once again provides examples of the racism and sexism exercised in an analysis that allegedly
celebrates Kahlo’s particular visions of life. He writes that, Flowers love Kahlo’s artistic inspiration came not from European intellectuals but from the things around her - Mexican sculptures, ceramics, dolls, figurines, wooden decorations, terracottas, papier-maché items and the colors and forms of her native Mexico. Some of the visual effects of this local charm may be sensed in one of her early works […]. The work is crudely painted and simple in its composition. Remembering that Kahlo had no formal tuition in painting, it is not surprising that this painting shows a naivety that remains evident even in her later and mature work. (Wach 2005, 2).

Here Wach equates Kahlo’s Mexican heritage – or “local charm” - with “naiveté” because he seems to believe that Mexican visual culture is not historically on par with European visual culture and tradition. Mexico allegedly does not live up to Europe in terms of aesthetic taste, refinement, and intellectualism in the arts, and this Mexican “simplicity” can apparently be easily seen in Kahlo’s paintings. By characterizing Mexican visual culture, and by extension, Kahlo herself, as naïve and charming, Wach “others” Kahlo and her artwork – and Mexican culture at large. He racializes Kahlo and Mexico here and perpetuates the invisibility of white privilege among European art and culture. This is an

6 Wach, of course, fails to attribute to Kahlo her European heritage or her international travel and study of art and politics. Kahlo’s father was German and Jewish and Kahlo herself was well-traveled, well-read, and well-informed about global art, politics, and society (Greeley 2004, 219).
insidious form of racism that happens all too frequently well into the twenty-first century, in our allegedly enlightened and “postracial” world. Just because Kahlo has been dead for sixty years does not mean that her artworks and personhood are no longer subject to the ableism, racism, sexism, and heterosexism she might have faced when she was alive.

Wach follows his racist attitude toward Kahlo and Mexico by noting that in Kahlo’s 1931 painting *Frida Kahlo and Diego Rivera*, “Diego Rivera looms large and holds the artist’s palette, even though it was Frida who painted the work - an obvious reference to his superior status as an artist and her subsidiary role and more diminutive status” (Wach 2005, 2). This sexist observation fails to take into account the fact that Rivera was actually physically larger than Kahlo – both taller and fatter – and that there is a painted inscription on the canvas above Kahlo’s self-portrait that specifically states that Kahlo was the artist of the double-portrait. Since both individuals pictured in this painting were artists, and Kahlo embedded in the image a description of who painted the work and on what occasion, the fact that Rivera holds a palette and brush in his hand cannot automatically be translated as a “reference to his

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7 The idea that we live in a “postracial” society, whether here in the United States, or elsewhere around the world is a fallacy. Racism and white supremacy are still institutionalized in our most basic social, economic, and political structures, especially in the U.S. See Baddeley (1991) and Greeley (2004) on the ways in which Mexican identity has been ascribed to Kahlo in racist ways.

8 In English the banner above Kahlo’s image here reads, “Here you see us, me, Frieda Kahlo, with my beloved husband Diego Rivera, I painted these portraits in the beautiful city of San Francisco, California, for our friend Mr. Albert Bender, and it was the month of April of the year 1931.”
superior status as an artist and her subsidiary role and more diminutive status.” Rivera was a well-known mural painter who, like Kahlo, traveled around the world to share his talents and engage with art and politics, but there can be no “objective” observation that Rivera was a “superior” artist to Kahlo or that Kahlo was a “subsidiary” to Rivera. The historical material simply does not support this argument and Wach’s analysis of the artwork overlooks institutionalized power dynamics with regard to gender and sexuality during the early to mid-twentieth century, after the Mexican Revolution (1910-1917) (Greeley 2004, 217). Finally, Wach overlooks Kahlo’s bisexuality entirely and presumes her heterosexuality based on the paintings she created, despite historical evidence to the contrary (Wilton 2002). By erasing this aspect of Kahlo’s life, critics further marginalize and silence Kahlo and produce a biography for her that does not allow for autonomy and self-definition.

This analysis of the criticism Kahlo has received might seem tangential to my main topic or to the ableism Kahlo faced, and that her life and work continue to withstand, but that has not been my intention. Instead, I wanted to follow this line of thought in order to illustrate why the publication of Kahlo’s Self-Portrait with Portrait of Doctor Farill as an image representative of disability is not a good choice for Extraordinary Bodies, “Representing Disability,” or any other Disability Studies endeavor that does not actually look at
Kahlo and/or her artwork in a critical way. Kahlo, as a public figure and as an artist, has frequently been admired and/or analyzed in relation to Mexican political and artistic culture of the early twentieth century, to feminism in Mexico and Latin America, and as an outspoken female artist of color with disabilities. But when Kahlo’s painting is used to symbolize disability with no reference to Kahlo, her oeuvre, or even this specific painting in the programming or text of the event series and book it is attached to, we have to ask about the kind of work the image is doing and for whom. How does Self-Portrait with Portrait of Doctor Farill serve Extraordinary Bodies and “Representing Disability,” and more importantly here, how does Extraordinary Bodies and “Representing Disability” serve Self-Portrait with Portrait of Doctor Farill and Frida Kahlo?

Despite the cliché that one shouldn’t judge a book by its cover, book covers are usually made, even within the world of academic publishing, with its intended audience in mind, to capture their attention and the money in their wallet. Indeed, it seems especially remarkable⁹ that Kahlo’s painting here contributes to the work of capitalism in representing disability – and Disability Studies – considering her devotion to the Communist cause. It seems extraordinarily problematic to use Kahlo’s painting as a way to provoke

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⁹ I use “remarkable” here as in “should be remarked upon,” not as in “surprising.” I am actually not very surprised that Kahlo’s artwork, despite her Communist politics, has been co-opted by the dominant capitalist culture that frequently exploits the subjects of visual imagery to sell ideas and products.
interest in a text and event, and put even more plainly, to make them particularly marketable or appealing to purchase and take part in. Kahlo’s painting, as a representation of a disabled bisexual female artist of color, does an incredible amount of work in representing disability with no profit to show for it. I don’t mean profit in a financial sense here, but in being deemed worthy enough to write or speak about within the context of Disability Studies. I am not looking to blame anyone here – not Garland-Thomson or the coordinators of “Representing Disability” - but I think it is an issue within the fields of visual culture and Disability Studies worth paying attention to and thinking about. Given the history of exploitation of people with disabilities, some of which Garland-Thomson relates in detail in *Extraordinary Bodies*, it seems that writers, schools, and publishers in the field would make more careful considerations before visually representing disability with an image that is emptied of its original meanings to all but a select few who might be familiar with Kahlo’s work or who might be interested in researching Kahlo and her work upon seeing it in these locations. In being placed on the front surface of these texts, *Self-Portrait with Portrait of Doctor Farill* comes to serve as a money-making device and little more.
WORKS CITED


Disability justice is an emerging field of work that is creating a shared language and shared political intersectional framework for understanding disability and ableism. Disability justice activists are fighting for liberation for disabled people and our communities.
I offer the following list of questions that can be used to continue building and growing disability justice, as many activists and groups are trying to integrate a disability justice analysis into their work. I hope this list will help to further how we are thinking about disability justice, what it is and what it is not. This is a place to begin and a reference point for all of us, as we grapple with the enormous challenge of creating collective access or mixed and cross disability spaces as well as sustainable movements. There are many activists contributing to disability justice work, most of whom are not in non-profits, that are forging liberatory visions for our communities that are grounded in relationships and interdependency.

Together, we are building an analysis that includes political and historical understandings of disability, bodies, ableism, pace, illness, care, cure, aging, the medical industrial complex and access. We are filling a huge gap within broader social justice movements that have historically not included or prioritized disability and ableism.

Through our work, we are also realizing the many places where disability justice already connects and overlaps with many movements and communities’ work. For example, when thinking about what liberatory community care for disabled people could look like, many queer and trans disabled activists draw on the history and skill of our queer and trans communities that have responded to isolation,
stigma, violence and exile by building networks of chosen kin and family who have housed, cared for, and supported each other for generations. There are many organizations who are beginning to build a disability justice analysis because they are realizing their base is made up of disabled people who do not identify as disabled, but who have acquired their disabilities through trauma, violence and denied access to resources. Many of these organizations had not connected disability (or the disabled experiences of their base) to their political work of prison abolition or reproductive justice. Disabled people are one of the largest oppressed groups in the world; no matter who you are working with, you are working with disabled people. There are also organizations and groups who have been doing the work of disability justice, but just not calling it “disability justice.”

Disability justice pushes past solely access, assimilation, inclusion and equality, to justice and liberation. We are not talking about a kinder, gentler oppressive system or only access to the current violent system we have, nor do we want to simply expand the ranks of the privileged to include a few more folks at the top, while the same people consistently remain at the bottom. Disability justice is not simply an intellectual exercise or a way to alleviate able-bodied guilt, nor is it a status symbol of how radical or political you are. White and/or able-bodied activists and organizers are quick to claim disability justice work for
themselves without having done the responsible, substantial work to earn it.

We want a different system that does not rely on “good” or “deserving” disabled people or other oppressive notions of equality; we want true justice that moves us toward liberation for all people. We recognize that ableism is connected, tied up with and mutually dependent on other systems of oppression and that we cannot end ableism without also ending white supremacy, economic exploitation, colonization, and gender oppression. Disability justice requires that we no longer build single-issue analysis, but instead build frameworks that can hold the complexities of our lives. It is an exciting time, as many people are very hungry for disability justice and the unique possibilities and visions it puts forth.

As we all continue to get clearer about what disability justice is, I began drafting this list of questions in early 2013, specifically with able-bodied people in mind. However, the questions might also extend to white disabled people who are grounded in disability rights work but haven’t interrogated white supremacy. By replacing “disabled” with “disabled people of color” or “ableism” with “racism,” these questions can serve multiple groups who wish to examine their privilege.

I offer these questions as a place to start and as a way to respect the current and past work of disability justice.
activists. I especially want to acknowledge the work of disabled queer people of color disability justice activists, many of whom have experienced significant amounts of racism from the disability rights movement while also being excluded from racial justice and queer liberation struggles and political community.

As more and more people want to join disability justice work in ways that are useful, I hope that these questions help people practice disability justice in ways that are not about co-optation or the harvesting disabled people of color’s work for their own use, exploitation or status. These are questions to ask ourselves, our organizations and groups, as well as our movements; they provide an opportunity to practice reflection, respect, and care. I want to acknowledge our different, distinct and important roles in making disability justice a reality.

There is no one way to do disability justice. Like most liberatory work, it can look many different ways. Though, there are some guiding principles and core concepts that distinctly mark and distinguish disability justice work. These are important and many have come out of a history of silence and erasure of many disabled queer and trans people of color’s lives.

**Disability Justice Questions:**
• Why does disability justice matter? To you, to your community, to our struggles for justice and liberation?

• Is your motivation more about "bringing disabled people to our table" (or just making "your work accessible"), rather than a true effort to challenge and dismantle ableism and able-bodied supremacy in your organization/community (which could very well mean a shifting of your current priorities and work)?

• Is disability justice just an "add-on," side committee" or "window dressing," more for political show than work?

• What are your current relationships with disabled people in your life like? Why?

• Have you done your own work? For example, have you gone through a disability justice 101 training, learned about able-bodied privilege, read disability justice writings/media?

• Have you recognized how you have been ableist in the past and present? And if needed, made amends where possible?

• Have you supported current disability justice work and leadership that's already happening before jumping to
ask people to support your disability justice work?

● What are the appropriate roles for you within disability justice work? For example, if you are able bodied, it may be inappropriate to engage in work surrounding internalized able-bodied supremacy with disabled folks. You might be better positioned to do work that challenges able bodied supremacy with able-bodied people within your own community. Where does it make the most sense for you to be visible and where does it make the most sense for you to offer support?

● Do you have disabled people of color with lived experience and political depth of understanding of disability justice in supported and valued leadership? not just token disabled people who won't challenge the status quo?

● What has disabled leadership looked like in your life, organizations, communities and movements? Why do you think this is the case?

● Why are you committed to ending ableism and able-bodied supremacy? How can you work towards ending ableism and able-bodied supremacy impact your current work? How does your current work perpetuate ableism and able-bodied supremacy?
Alien

As a “temporary non-immigrant alien” with an H1-B U.S visa, I am legally authorized to work in the U.S. and to get paid. I have a social security number, and a driver’s license. I pay all the taxes that U.S. citizens pay.

As a “temporary non-immigrant alien” however, I do not have access to any state or federal benefits - like unemployment, disability, or social security when I retire. This means that I am paying taxes on wages from my social
justice job- money that the government is spending on war with people in my home region - the middle east.

This also means that if I quit my job, I have to leave the country within 10 days. I would have to “go back,” but not to a country I grew up in, because Kuwait has no naturalization process for non-citizens, and no permanent residency process. So I would have to “go back” to India because I am Indian by passport and ancestry.

Pain, privilege, practicalities, possibilities

I am lucky to have the benefits of paid sick time, vacation time, and an employer with fierce justice values. I have health insurance, thanks to my job. They are sponsoring my green card, which is a first in their 15 year history. I am the first first-generation immigrant on staff. I am certain that I am not the first person with a disability or chronic pain on staff, but the naming of it and the resulting conversations about access we are having seem to be new for all of us. There is the work itself (my job description), and then there is the work that makes all the other work possible - talking about illness, access needs, making it happen, structural changes, crafting flexible yet fair policies, hiring a lawyer, and lots and lots of paperwork for the green card. Most of this does not make it into a work plan. I don’t do any of this alone.

I cannot talk about illness and how it affects me, without
mentioning how it is tied to my immigration status, or my choices and access as a queer upper class woman. The axes of benefits and struggles at which I find myself leads to a particular set of options. From there, I make choices. There, I live daily.

I am a tree in a forest, your roots are my roots. Together we flourish, or die.

My struggle with invisible illness and chronic pain is this - invisibility. The tensions I live come from not appearing sick, but then trying to describe an inner, debilitating experience to people in daily life - coworkers, roommates, friends, partners, family, community members. And feeling that I have to talk about myself in a disempowering way to be validated - because it's about verbalizing pain and depression and ER visits. The fielding of comments about looking tired and losing weight. And the struggle between trying to maintain an attitude of positivity and hopefulness, while also trying to accept what is happening in the moment of intense pain and ongoing illness.

My life is not only mine. The experience of chronic pain affects everyone close to me. My roommate has taken sick days to take care of me. She has stayed up until 4am to take me to the ER, and go late to her own job the next day. My parents and sister pray for me all the time. My co-workers
spend work hours stroking my hair and massaging my back as I cry. I am blessed to be partnered with a woman I adore and admire, who is a badass WNBA referee. She is a dual citizen of the U.S. and Jamaica. She had shitty health insurance/care options. We just moved in together. She brings me food, painkillers, movies, a heating pad in bed, pretending to be the butler from Downton Abbey. She makes me laugh. She massages my feet when I am in unspeakable pain. She makes it seem doable, and she supports the choice of my bedroom’s healing environment over the ER.

**Truth-telling**

When I write about what happens within, I can touch my feelings and see them. When I name what I live without thinking about it, it helps me to recognize my challenges and privileges and give them due respect. It helps me give myself the space to deal with them, and to get support. Self-validation is the beginning of honoring the self, and a necessary step to getting outside support.

Amidst my many sleepless nights, I went to the secret facebook group for sick and disabled queers, and shared what I was going through. I got so much love from other people in the group. This love across space from people I had never met, simply for hurting, created a river of joy in me. I cried with the immensity of being seen, with the power
of reading words and feeling truly held.

What I have come to understand about my illness and chronic pain is that it is a part of my path. Each of us has joy and each of us has struggle. The pain in my life - physical and otherwise - has driven me to seek. I have sought relief, healing, root cause, solution, support, community, meaning, and more. Through these streams of intense pain or bouts of acute illness, I came to make peace with my own body. All that was wounded spoke. In hurting, it came back to life. In crying, I came back to feeling. I can’t say that I never dissociate or escape in other ways, but I do always return. And I am much more conscious now that there is nowhere else to go. I tentatively made home in my own body, and settled into a sense of belonging and safety. I learned to depend on other people, to ask for support, and I am practicing receiving.

I feel how profound it is to lie down and simply breathe deeply and continuously. When I do this, my brain and heart and gut and feet are aligned in their wisdom, all equally grounded. That internal wisdom guides me, and clarity arises like an air bubble in water, floating to the top.
Writing this, I realized: Why do I feel the need, writing academically, to distance myself from my identities? Why is this expected in academia? So I won't do so. I say “we,” not “they” for groups I am a member of. I will not feign the distanced impartiality of an outside observer: it would be erasing my own Queer Autistic voice to do so!

The intersection of disability studies and queer theory is starting to get more attention in academia. However, most academic coverage of disability focuses on the physical,
both moving neurodivergent people to the margins and reinforcing a false mind/body divide. Mainstream media representations of queerness are even less inclusive, mostly limited to able-bodied neurotypical or neurotypical-passing white Gay and Lesbian people. There is little coverage of People of Color, Disabled people, or Trans* people within LGBT? communities, and even less for the intersections of those groups. Queer Studies starts to cover people in those intersections, including disability. The examination of compulsory able-bodiedness, but not of disabilities which are not strictly physical and are not mutually exclusive with able-bodiedness is a remaining issue in that it excludes Queer Autistic people from the discussion along with other Neurodivergent Queers. On the occasion that Autistic Queerness is discussed academically, the authors are primarily not autistic, just as most academic writing on autism in general is written by people who are not themselves autistic.

Mainstream disability representation remains limited to young children and inspiring stories about people “overcoming” their disabilities- people who are generally white and presumed asexual unless married. Rarely is daily life as a disabled person covered, and sexuality even less so. On the occasion that sexuality is discussed, it is heteronormative and ignores the experiences of asexual people with disabilities.
Disability communities vary widely in their acceptance of Queer identities, both in broader disability communities and within Autistic communities. Issues affecting acceptance include myths about disability, autism, sexuality, queerness, caregiver control, and cases where Autistic people have gender and sexual identities which clearly fall under the umbrella of Queer but which do not fit under any more specific terms. Gender failing to make sense as a concept is one such possibility. Finally, Autistic and other Neurodivergent people have often found themselves underrepresented and unwelcome in Disability Studies and Disability communities, with this lack of representation often extending to the intersection of Disability Studies and Queer Theory.

Myths, Misrepresentation, and Control

People with disabilities are the subject of many myths relating to their sexuality or lack thereof. We often face contradictory assumptions of nonsexuality and heterosexuality (Thompson, Bryson & De Castell, 2001). Visibly breaking one stereotype often increases the strength with which the other is assumed. The assumption of heterosexuality comes from society generally viewing heterosexuality as the default, combined with an idea sometimes expressed as the difference slot: everyone has
their difference, singular (Elminrida, 2013). Similar to this is the idea that people should only violate one stereotype at a time, with both “Autistic people are incapable of love” and “Disabled people have no sexuality” among the relevant stereotypes being broken when an Autistic person is sexual. When asexual, it is viewed not as an orientation, but as nonsexuality resulting from being disabled. Nonsexuality, or at least a moral obligation of celibacy, is also assumed because many think people with disabilities should not have children and that those who will not have children should not have sex (Knoepfler, 1982). Considering that Queer couples are often not able to have children, the moral imperative not to have sex becomes doubly strong for Queer disabled people.

Now consider sayings such as, "Humans are sexual beings," and "Sexuality is one of the quintessential things that makes one human." Many view people with disabilities as somehow not-quite-human, and therefore exclusion from those statements makes a certain terrible sense: if one isn't truly human, why should one be sexual? It's one of the things that makes humans human, after all, and we are not truly human.

Before even considering issues specific to developmental disabilities such as autism, the label of any disability creates significant barriers to visible Queer identity. Autistics, however, face further threat: Simon Baron-Cohen's extreme-
male-brain theory leads people to assume that AFAB (“Assigned Female At Birth”) Autistics are rare regardless of gender identity and that Autistic trans women would be yet rarer. Both individual reports and academic literature show that Autistic trans women do exist, though some have expressed worry that they may be forever "socially male" (“Queering Autism,” 2013; “Autism and transsexualism,” 2012; de Vries et al., 2013). Additionally, Baron-Cohen has made statements regarding trans men which may lead to people believing that they are not truly trans, but simply believing themselves to be men due to their autistic traits.

Girls with a higher than average number level of autistic traits tend to have male-typical interests, showing a preference for systems over emotions. They prefer not to socialise with typical girls because they have different interests, and because typical girls on average have more advanced social skills. Both of these factors may lead girls with a higher number of autistic traits to socialize with boys, to believe they have a boy's mind in a girl's body, and to attribute their unhappiness to being a girl (University of Cambridge, 2011).

Faced with the concept that autism is an extreme male brain and simultaneously told that they just think they are boys due to their autistic traits, AFAB Autistic persons would find themselves with no allowable gender identities. Autistic people, after all, are presumed not to have the sort of self-
awareness to realize that we are trans* and certainly not that we are nonbinary, (if the people making these presumptions even accept that nonbinary identities exist). As noted by Caroline Narby, a Queer Autistic woman, when a disabled woman acts against gender or sexual norms, it is often considered part of her pathology ("On Lisbeth Salander," 2013). Baron-Cohen's comment only serves to make this pathologization explicit: girls with more autistic traits have social issues with girls (where does he get this assumption from?) and "attribute their unhappiness to being a girl."

Baron-Cohen has also co-authored a paper where autistic women were found more likely to be either bisexual or asexual, but in which the orientations appeared to be classified as testosterone-related disorders rather than as legitimate sexual orientations (Ingudomnukul et al., 2007).

Contrary to the assumptions of disabled nonsexuality is the common myth that those with developmental disabilities have uncontrolled and uncontrollable sexual desires (Thompson, Bryson & De Castell, 2001) generally presumed to be heterosexual in nature and in need of outside control. For those with intellectual disabilities, there has been the assumption that none have "normal" sexuality, and that thus there could be no gay people among them (Löfgren-Mårtenson, 2009). The falsehoods in such a statement are impressive. It assumes a normal sexuality and that people with intellectual disabilities are automatically excluded from
it. It then concludes that the lack of “normal” eliminates same-gender attraction as well, resembling a sexuality-specific difference slot.

Autistic people, like other people with developmental disabilities, are often assumed unable to make our own decisions, especially about sexuality (Bedard, Zhang & Zucker, 2010). Service providers often consider regulating and controlling their clients’ sexuality to be an implicit portion of their duties, due both to supposed client incompetence and to the myth of our uncontrollable sexual desire. This becomes even more true when the decision made is to accept ones own queerness, with many service providers lumping all same-gender sexual activity in with "risky" sex as unacceptable (Thompson, Bryson & De Castell, 2001).

Reliable education is also an issue. Many educators hold that long-term relationships are unrealistic for us due to the myths that Autistic people lack empathy, caring, and tenderness, along with the myth that caring requires empathy. With the assumption that autistic people will never experience sexuality with another person, sex education often extends only to issues such as masturbation, puberty, and preventing abuse, thereby neglecting dating, birth control, and marriage (Koller, 2000). In Growing Up on the Autism Spectrum, for example, the chapter on sexuality and autism lists safety risks and health as primary reasons to educate, neglecting positive aspects of sexuality. It also
suggests teaching “friendship behaviors” in a curriculum supposedly about sexuality (Gabriels and Hill, 2007). Narby notes that while this book does make a passing nod to homosexuality, it does not actually include queer autists. In fact, the book actively encourages teaching gender normativity, saying that parents should find a way to make their autistic daughters shave their legs and pits. This is hugely harmful for AFAB Autistic people who are not gender-normative or who do not identify with the gender assigned to them at birth. “When the body of literature and knowledge that seeks to address autistic people leaves out discussions of gender—and accepts and reinforces sexist, heterocentric, and transphobic ideologies—it excludes and oppresses members of the very population that it purports to serve.” (Narby, 2012).

Under these assumptions, sexual orientation becomes irrelevant: if we will never have a partner, does it matter who we are attracted to? This lines up with the idea that people with intellectual disabilities do not have "normal" sexuality and could therefore not be homosexual (an odd statement, considering that queerness is itself a form of non-normative sexuality and the abnormal sexuality of these clients is used as the reason that they are not queer). Given the large amount of control that developmental disability service providers often exert over their clients, these assumptions hold great power in preventing visible Queer identification for
Expressions of sexuality that caregivers disapprove of can be actively reprimanded and prevented through behavioral therapy. In at least one known case, staff members reprimanded same-sex couples with intellectual disabilities who kissed or hugged intensely at a dance arranged for them. Heterosexual couples, however, were allowed to hug and kiss (Löfgren-Mårtenson, 2009).

People with intellectual disabilities did have sex that fell under the umbrella of queerness, but the people they were close with tended to have trouble accepting this or viewed these as acts of friendship rather than sexual desire. The failure to accept these expressions of sexuality as such contributes to those with developmental disabilities’ common unawareness of Queer communities. Many people with developmental disabilities who express same-gender attraction do not identify as Queer, LGBT+, GSM, or any other identity of the kind due to unawareness of the communities or awareness only of the stigma faced by these communities (Thompson, Bryson & De Castell, 2001). This unawareness could be fixed if caregivers provided proper sexual education and accepted expressions of sexuality as such, providing relevant information when they note that their clients are interested in people of their own gender.

Even the idea that queerness can come from prior sexual abuse works against Autistic people. People with
developmental disabilities face unusually high rates of sexual abuse (Bedard, Zhang & Zucker, 2010) and Autistic people are no exception to this unfortunate fact. Many then assume that expressions of queer sexuality are instead expressions of the trauma of sexual abuse. People then prevent these expressions as “symptoms” to treat and attempt therapy to get to the root and "fix" this supposed result of trauma. However, this “result” is actually our sexuality.

It would seem then that, “Faced with the assumption that autists are a kind of "blank slate" because we cannot form our own views based on what we pick up from our environment, parents and professionals lay bare fundamental cultural beliefs about sex” (Narby, 2012). Unfortunately for us, these fundamental cultural beliefs are ones which erase our sexualities, especially our Queer sexualities.

Queerness, after all, had historically been viewed as the result of mental illness or psychological flaw in many Western contexts (Stevenson and Cogan, 2003), much as autism is viewed as a flaw in psychology today.

Autistic trans* people also face significant invalidation and attempts by others to police their identities. Trans*ness remains pathologized as "Gender Identity Disorder. For those who are also autistic, autism serves as yet one more invalidating factor in the eyes of those who police identity.
When a study noting that trans* children and adolescents were significantly more likely to be autistic than the general population (de Vries et al., 2010), the autistic blogosphere expressed worry that people might use this finding to tell Autistic Trans* people that we "aren't trans, just autistic." Simon Baron-Cohen's comment, quoted previously, shows that these fears are founded. De Vries et al. (2010) also noted that while some professionals recognize the possibility of a person simply being both trans* and autistic, others have claimed that this trans*ness is merely a reflection of autistic people's "predisposition toward unusual interests" or an obsessive compulsive disorder. In at least one case, suppression of certain expressions of an autistic person's transgender identity was an explicit part of autism behavior modification therapy and gender conformity may be a common part of therapy. The behavioral therapies currently considered standard for autism are similar in method to those used to "cure" trans*ness and same-gender attraction, with Ivar Lovaas, one of the researchers who published papers “curing” both queerness and autism using the same methods. His research is often used as the evidence that ABA, the “gold standard” for autism therapy, works, while his work on queer youth is buried.

For those of us who are genderqueer or otherwise nonbinary, there is often an implication that we should “choose one,” even if none actually fit. On top of the usual
issues regarding nonbinary identity, we face assumptions of incompetence (Bedard, Zhang & Zucker, 2010), presumptions that we can not understand what it is like to be ourselves (Grace, 2012) and contradictory stereotypes: “since nonbinaries are stereotyped as being female-assigned folk and autistics as male-assigned folk, where does that put us?” (Cat, 2011).

In these ways, our autistic identities can be used to negate our queer identities and our queer identities can be used to negate our autistic identities. If we are not self-aware enough to know ourselves, there is no reason to provide us with the language to describe ourselves. If “autism is making [us] ‘confused about gender’” (Kris, 2012) then our identity is perhaps not real and therefore may not deserve its accurate label. Additionally, many Autistic people identify in ways that are clearly queer but do not fit within any more specific queer label. We are then often without the language to describe ourselves, unable to express our identification or uncomfortable with all the available words.

**Differing Forms of Queerness and Lack of Appropriate Labels**

Sometimes, the words to explain our orientations and identities are nonexistent or unknown to us, which can erase our identities. While some gay and lesbian youth wish to consider themselves “post-gender” and argue that the words
we may fight to identify with are labels and signs of oppression, (Halberstam, 2005) the lack of a word to describe oneself can cause problems.

Sometimes, it is finding one's gender “foreign to the system” due to “not getting gender” (Ali, 2011). Others have written that they navigate a world of gendered signals, invisible to their nongendered self or compared being asked about their gender to being asked the “miles per gallon” on a solar-powered vehicle (Jack, 2012). The question simply fails to make sense! Amanda identifies as gay, and she has liked boys. She writes, “I am gay but although gender’s a hugely strong factor for me, there are other equally strong or stronger ones. But there’s not a word for this, sad times” (Vivian, 2011). She is attracted to a boy. What she is missing is not an understanding of herself, but the single word for it which others would understand and respect. Without such a word, she can wind up lumped in with a group that does not fit- in her case, placement within a subset of LGBTQ+ which does not fit her, though for others it may be the failure to be included as any sort of Queer. For Wendy Lawson, a (now) openly gay autistic woman, that is precisely what happened:

It was OK for a while because I didn't have the right name for who I was. I conformed to the label I'd been landed with, even though it was very uncomfortable. But, once reality set in and I knew the truth, I could no longer
hide behind the make-believe set-up I'd grown up in and adopted as 'my life' (Lawson, 2005).

Without awareness that “lesbian” is something you can be, she lived in a marriage that didn't fit, uncomfortable as it was. When the word doesn't exist? Lack of language makes for rather efficient erasure of things that don't fit- that was one of the main ideas behind Orwell’s Newspeak.

**Marginalization Within Queer Communities**

Even looking at Autistic Queer people who have sufficient control over our own lives to express our gender and sexuality as we wish, the erasure and invalidation continue, often from within Queer and theoretically allied groups. Melanie Yergeau, an asexual Queer Autistic, notes that "either they don't think I'm autistic enough, they don't think I'm queer enough, they don't think I'm asexual enough, they don't think I'm human enough. And on and on" (personal communication, March 26, 2013). With one identity invalidating the next, (grey-)asexuality making her fail as a genderqueer woman, autism making her viewed as an eternal child and therefore incapable of any sexuality or realizing that she is genderqueer, queerness is seen as impossible for an autistic person to realize. All of her marginalizations come with dehumanization, making her seem incompletely human, but what humanity she is
considered to have must invalidate her asexuality as "humans are sexual beings." Another finds that “people who know that I'm queer... seem most surprised when I mention autism” (Ali/Eliot, 2011) since queerness already fills their difference slot. Landon Bryce, an openly gay Autistic man, finds his domestic partner referred to as merely a friend by someone who considers herself an ally to LGBT+ communities (Ditz, 2012) and he wonders if the brain differences which make him Autistic and those which make him gay might be similar (Bryce, 2012). Kristen notes similarities between her Autistic and Queer identities, both of which can take time to understand, accept, and embrace, and both of which have and sometimes continue to be "treated" with abusive behavioral therapies including electric shocks (Guin, 2013).

Zach finds his local Gay Straight Alliance (exclusion of other queer identities included in the name!) to be inaccessible and that the nonverbal signals expected in flirtation are also inaccessible (Richter, 2013). People “read” the way others move, walk, and interact with people for cues, and this puts privilege on those who move typically, marginalizing those of us who don't (Ndopu and Moore, 2012). For Autistic people, this can be especially problematic because there are not physically obvious reasons for the differences in how we move. Neurotypical people may interpret the ways we move using the same rules they use
for “typical” movement, losing our true meanings and erasing our queer affections. We may also need people to tell us outright that a person is queer in a way compatible with our own and attracted to us, since those of us who can not read body language or tone may have nothing resembling “gaydar” (Lindsay, 2013).

**Access**

In order to avoid erasure from spaces we belong in, we need to be able to get to and function in those spaces. In addition to communicative access, there is sensory access. Sensory overload can and does exclude Autistic Queers (Erwin, 2013) and the energy required to find a partner when fewer people are compatible is energy that many disabled people don't have (Kaz, 2009).

Sometimes the lack of accessibility comes from the ideas of people more “welcome” in LGBT spaces. Amanda Baggs, a nongendered lesbian autistic person, finds explicit ableism:

I have only to walk into an LGBT community center to find a gay man who is inspired by my presence to tell me how he used to work in an institution where there were people who looked like me, where he would stand over the cribs of some of the inmates and ask (insert pained voice) “Why are you alive?” And who wants my sympathy for the agony he feels at the existence of
disabled people. Seriously. This happened (Baggs, 2009).

The exclusion from communities based around our gender or sexual identities may not always be so blatant as Amanda’s experience, but exclusion is the norm, and it is hard not to be erased from places where it is unsafe to exist. For Julia, arrival at a college “infamous for its lesbians” was arrival into a new world. “Finally, being a lesbian wasn’t an issue!” Unfortunately, “Having disabilities still was.” (Bascom, 2011). Ableism made it so, with no one knowing or learning how to navigate a relationship with someone who didn't make eye contact, know how to flirt and couldn't handle parties.

Other times, it is the assumption that Autistic people could have no understanding of Queer experiences. As Amanda Forest Vivian points out, how dare we suggest there are similarities? How dare we say that conversations about autism are similar to straight people controlling dialogue about gay people and making it about curing gayness? “After all, a gay person pointed out in this conversation, no one gets killed for being Autistic” (Vivian, 2011). While accusing us of not understanding Queer struggles, allistic Queer people show a distinct lack of understanding for Autistic struggles: people are killed for being autistic, regularly, and

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1 Not autistic
our killers are typically portrayed as saints who snapped- our killings as mercy.

Others find that they have trouble expressing their identities because of gatekeeping and their autistic traits- for a trans woman to get access to hormones and surgery, they are sometimes expected to stop displaying “male” traits that are actually autistic traits (Erwin, 2013; Queering Autism). Even within trans* communities, they may be considered failures, acting as autistic members of the gender they identify with or (possibly therefore?) not putting much effort towards following either binary gender's list of social rules (“Autism and Transsexualism”). For others, there may be mistrust: disability is listed as one of the red flags for fake trans* profiles trying to get into trans* communities (“Twenty Hallmarks of Fake Trans Personae”) and while this may be something those trying to fake their way into a community do, it also increases mistrust of Disabled Trans* people, marginalizing us further.

**Marginalization Within Disability Communities**

Marginalization of Queer Autistic people within disability communities can come from exclusion of cognitive disability, exclusion of Queer Disabled people, and from both factors working together.

In autism communities, erasures of all autistic sexuality are common, with conference presenters suggesting that we
are: not aware of our sexualities and suggesting redirection (Lawson, 2005), telling parents to dictate normative gender performance (Narby, 2012), viewing heterosexuality as more basic and other orientations/identities as too complex to explain to autistic people (Java Junkie, 2012), presenting our hypothetical relationships always as “heterosexual partnerships between a person with Asperger syndrome and a person without,” (Narby, 2012) and assuming that those of us who are asexual must be so because of our autism (Lindsay, 2010), or only believe ourselves so because of our autism (Henny, 2011). In the case of asexuality, we may also feel uncomfortable expressing it because of the stereotypes about disability in general, autism specifically, and asexuality. It’s a failure. As Melanie Yergeau states, “It makes me a bad disabled person who embodies the stereotype that disabled people have worked so hard to avoid” (personal communication, March 26, 2013). Privilege: for a neurotypical, asexuality is not taken as evidence that everyone of their neurotype is asexual, but for an autistic person, it might be and so we may be afraid to admit to our own asexuality (E, 2012). In Aspergers and Girls, Temple Grandin’s contribution was both the only one to speak of aromantic asexuality as a possibility and the only one to bear a statement from the editors that she does not speak for all women on the spectrum. Heteronormative contributions seemed to require no such disclaimer.
Even Autistic communities\textsuperscript{2} are not exempt from exclusion and erasure. One Black Autistic woman points out that “Autistic students of color, who are women, gay, have additional disabilities, [are] transgender, or financially disadvantaged, that I work with at my job are all too often silenced at group meetings, skipped over for input, and generally discounted as participants” (Girljanitor, 2013). Much of the relationship advice given seems to be directed towards heterosexual Autistic people, often sympathizing with straight white Autistic men who feel that autistic traits lead to “friendzoning” (Richter, 2013). Queer Autistic groups are less focused on this, but the dominant culture remains fairly heteronormative within the Autistic community, and most Autistic Tumblr bloggers with any other marginalizations are likely to be considered “bad apples” and either ignored or attacked by much of the Autistic community (Girljanitor, 2013). In ignoring these voices within our own communities, we make it that much harder for those outside our communities to become aware of the existence of multiply marginalized Autistic people.

Books written by Autistic people/Aspies have similar issues. Aspergirls throws in a few feminine pronouns and leaves inclusion there, speaking about heterosexual relationships with the occasional “she” instead of “he.”

\textsuperscript{2} Autism communities and Autistic communities are both diverse, but very different from each other.
author seems ignorant to the existence of trans* Autistic people and to differences between heterosexual and non-heterosexual relationships (Amialone, 2013). Sex, Sexuality, and the Autism Spectrum by Wendy Lawson, a gay Autistic woman, has its own issues: it may be the best book addressing autism and sexuality I have seen, but it is not perfect. She erases nonbinary Autistic people by referring only to “same gender” and “opposite gender” in her book. Her description of feeling more male than female but accepting that she is a woman who feels this way may affect trans* autistic people who prefer to get sex confirmation surgery as Lawson admitted to wanting. Professionals who read her work may encourage them to wait, to learn to accept their status as a member of the gender they were assigned at birth who feels more like a member of a different gender as she did. Her reference to bisexuality possibly being a third “gender camp” also falls under possible erasure via conflation of gender identity and sexual orientation: when the two are conflated, trans* people may find themselves erased.

Queer Autistic people face anti-Queer prejudice of all sorts within nearly all autism and Autistic communities that are not specifically focused on Queerness. We face ableism from Queer communities. Asexual communities often react with ableism to the implication that they are all autistic, excluding those of us who are asexual. We face anti-
cognitive-disability prejudice within many disability communities, and this generally extends to Queer Disability communities. The idea that people will have a singular difference or should only violate one stereotype at a time keeps even more of us hidden. And how could we separate our identities, even if we tried? Melanie Yergeau has it right: “I don't know what makes me queer vs. what makes me autistic vs. what makes me asexual vs. what makes me depressed vs. what makes me gender-whatevered” (personal communication, March 26, 2013). Treating these all as separate pieces, we need to put each trait into one box, one difference slot, even for those of us who have multiple differences. That too is a form of erasure.

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Anxiety

It is a ritual. When the appointment with the doctor looms on my calendar, a creeping sense of discomfort begins. As each day passes by, as the date grows closer, my anxiety rises. I worry that I have gained weight. The fact that my jeans fit me just fine doesn't console me. I eat lightly the day before the appointment. I skip breakfast and sometimes lunch on the day of, even if I will have to wait a long while to see the doctor. I am tempted to restrict my fluid intake, not because it will have a lasting effect on my overall weight, but
because those ounces might, just might, save me from the shame.

Shame

I take my shoes off. I have already carefully considered what might be in the pockets of my pants. I have shifted the Leatherman multitool that is always in my pocket of my bag; it weighs 4.4oz. I've emptied the change in my pockets into a jar at home. My wallet is with my Leatherman before I step onto the scale. I move the little black slides that point to numbers on the scale by myself. Somehow, it is easier for me to direct them to where I know I stand than to have a nurse bustle around. I wear my fat well, so if I allow them the task, they start at a number far too low and I painfully stand, trying not to squirm as I feel my cheeks ignite.

"Your weight is up," the doctor says.

I am looked at as if I am expected to explain this, as if I am expected to say, "It must be that I switched from skim milk to heavy cream in my sugared cereal in the morning, and I eat it in the largest salad bowl we own." Or that I am expected to admit, guiltily, that I have been stealing sacks of Halloween candy from children, and eating a whole night's hunted and gathered chocolate in one sitting. I am never asked what I am eating. It is only assumed that I am eating the "wrong" things.

Usually, I do not say much, unless the doctor really
confronts me. Instead, I internalize the feelings. It isn't my weight, but this experience that pushes my usually average blood pressure upward, causing a cavity of despair to open in my chest.

As I sit there, the cloud of judgment hanging thick in the room, I think of the things I wish I had said from the start. Occasionally, I manage to head a nurse off at the pass, turning away their cheerful, "Let's have you hop up on the scale," with a casual, "That's ok, I know what I weigh."

The thoughts in my head, in self-defense, are that my good habits - not smoking, eating plenty of fruits and vegetables, and exercising as much as my chronic pain allows - are my healthy habits. But getting enough sleep is also a healthy habit, and that is one I cannot accomplish without medicine that keeps the weight on. The chronic pain of a rare collagen disorder coupled with rheumatoid arthritis makes sleeping tough, but it is fibromyalgia that truly sabotages my sleep. And after more than a decade of extreme insomnia, of being so tired that driving is unsafe, of trying pills that leave me hungover without even leaving me rested, I have decided. I would rather be fat than never sleep.

To the doctor I say nothing, except when pressed. I rarely get to defend myself because the space that my fat and my feelings take up is actually quite small, as the rest of the room is filled up to the edges with the doctor's ego. There is
an almost physical pressure from time- the doctor is in a hurry to move to the next patient, but they cannot yet. Before renewing my crucial prescriptions for managing my pain, or before even prescribing me an antibiotic for my strep throat, they must, once again, address how gigantic I am.

After the appointment, I am hungry because I did not want to eat before I was weighed. If the doctor has bullied me enough, I continue my fast. A pill bottle rattles at the bottom of my bag. Take with food.

Acceptance

There is a wild dissonance between my daily life and days with doctors. My life is generally so full of positive people, anti-oppression radical queers who believe in body autonomy and fat acceptance and tattoos and health at every size and dance parties and Yoga To The People and fucking. We say no to bariatric surgery and yes to fatshion. We eat kale salad because it makes us feel strong (and is delicious), and we eat local handmade ice cream because it make us smile (and is delicious). We eat because it nourishes us; we eat because it is pleasurable.

I am a sick, fat, queer & genderqueer crip, and I am doing "healthy" the best way, the most holistic way I know how for me.
I.

Beauty. For an artist, there is the beauty of the subject. Maybe everyone can see it, or maybe only you. Then there is the beauty that comes from technique, that ongoing, messy altercation between your ability and your vision. You try to braid together these two flickering streams. If you make an image of a person, every move you make will reveal, conceal, invent, or deny their beauty.

I’ve always had a complicated relationship to beauty. I am
a person with visible disabilities. There are parts of me that have been admired, but much of me has been called deformed, in need of fixing. This certainly led me to feel alien to, or uncomfortable with, beauty. Recently, though, this discomfort with beauty has become newly disturbing. What happened was that I fell in love with someone who tells me every day that I am beautiful. Instead of finding this pleasurable, I've found it rather frightening. It's quite a problem, since I don’t think my lover wants me to snarl at her and run out of the room.

At first, I thought I was upset because being told anything about the way you look is a judgment. I'm quite aware that my body is judged, in public and in private. Even compliments make me uncomfortably self-conscious, as they’re part of the lifetime history of comments about my appearance.

This acute self-consciousness has shaped my approach to portraiture. My subject, perhaps predictably, has always been the human body and its variations. My disability gave me an acute awareness of the interplay between inner self and outer vessel. I know what it’s like to have no control over how you’re seen, or what you’re told about yourself. I found that if I worked in a collaborative method, people were able to trust in the experience of seeing themselves in another’s eyes. We start with a long series of interviews, in which I ask my portrait subjects about the effect that their body has had
on their life, and vice versa. We talk about their work, their personal lives, their politics, and anything else that leads to a multi-layered picture of a human life. Of course, then I have to figure out how to pare that down to a single still image.

My method is also dictated by the fact that the majority of my subjects are disabled, most of them in visibly identifiable ways. In other words, they are people who for the most part share a history of being stared at. In recent years I've begun to work with non-disabled, or invisibly disabled, collaborators as well. I want to explore the similarities and variances between these populations, so I work in thematic series. I set a central question, and watch how it plays out between very different bodies and lives. Some of my series include Totems and Familiars, which looks at personal symbols as sources of strength; Mirror Shards, which depicts collaborators in animal costumes, in order to address themes of global loss and personal metamorphosis; and the related projects of If Body and Ghost Parade, which document the invisible bodies (those which we used to have, wanted to have, or expect to have) that haunt our embodied memories.

Disabled bodies have been used as exemplars of what is unbeautiful. Western culture (everything from art history to advertising) is saturated with illustrations of what was thought beautiful. Disability rarely shows up in this millennia-long slide show. Impairments often affect normative standards of beauty, such as smoothness, shininess,
symmetry, and grace. Let’s call these the animal standards, biological indicators that let human/animals choose a mate that might produce healthy offspring. We see these standards enshrined in every painted odalisque and bronze warrior in the Louvre.

One can see the tides of taste as we move between eras, but overall, due to these biological flags, human beauty has had certain constants. Ironically, though the beauty industry is founded on the perfect body, it compels us towards the pursuit of novelty, to startle us into finding the conventional body endlessly surprising and new. Fashion magazines feature extreme, exaggerated examples of attractive features, offering these plastic-surgery inventions as our era’s archetypes of beauty. I was amazed, then, when I read studies that said that a predictable appearance (average proportions and conventional features) is more highly rated as beautiful than we’re led to believe.

But disabled bodies are not predictable, not even to ourselves. We monitor our own bodies even while the world is watching us. And when we are told we are beautiful, it can feel like a kind of consolation prize. Often we’re told that we are “beautiful on the inside,” which hardly makes you think you’re not a total dog. Or told our beauty is of a saintly, disembodied nature, a floating halo with no erotic component at all.

We forget that beauty is an illusion. Human beauty has no
objective reality. Beauty is just a swamp of taste, history, fashion, politics, inheritance, location and fetish. What you find beautiful is the result of the sum total of who you are. You fall into love through the rabbit’s hole of your own mind, taking your body with you. Human beauty is a relationship. It’s something we bestow on each other, and as such is a power dynamic. When someone calls you beautiful, they’re inviting you into a shared illusion. You enter this exalted state by the grace of the beholder. In submitting to be found beautiful, you both gain and lose autonomy, as you let another hold the mirror.

We find the story of Narcissus disturbing because he’s locked into his own body and in no need of anyone else’s regard—an amputation from the human bond. It’s a selfish and disconcerting dead end, but it’s also a very protected place.

II.

I would like to suggest that there are (at least) two kinds of beauty. One I call “Simple Beauty.” It does not depend on knowing anything about a person, apart from their appearance. Simple Beauty conforms to cultural standards and may agree with one’s own taste, though not necessarily. I know that Taylor Swift is beautiful, even though she doesn’t do a darn thing for me. I don’t even need to know who she is
to understand why she’s on the cover of a bazillion magazines. Simple Beauty is a static experience. Your perceptions and opinions about a person’s attractiveness do not change, even after many viewings, if nothing new is learned about who they are.

“Informed Beauty,” though, is the kind of thing we undergo when we fall in love. As you get to know someone, he or she literally becomes more beautiful in your eyes. This can happen even if you had not, at first, found them especially attractive. It’s easy to understand where tales of love charms, spells and potions come from, if you undergo that kind of disorienting shift. Informed Beauty can cause a change in all your senses. My beloved’s features become more delicious; her voice grows musical; her skin is a shock to my fingertips. I don’t hold these as conscious opinions, but enjoy a rising visceral, aesthetic and sexual pleasure.

When we fall mutually in love, we are mutually informed as to each other’s beauty. It’s a powerful state of mutual recognition. We feel that we are completely seen and recognized in the most intimate detail. This is what we craved from our parents; we know that we exist, because they perceive us so totally and so thoroughly. In Judaism, even God wants to be mutually recognized—to be named, and called, and loved—for exactly who God is, even if God is wrapped in unknowability. Communion comes when we are each other’s witness.
Rachel Youens: Still Life, 2008, Totems and Familiars

[Image description: Rachel is holding several broken objects (a cracked white glass cup, a torn paper fan, and a broken stick) up against the wall through the weight and pressure of her body alone. She keeps these items (similar to those in her paintings) safe and stable through persistence and dedication.]
III.

When I’m the subject of intense scrutiny, my reflex is usually to hide. Flee. Pretend not to see I’m being seen. It hardly ever feels like an invitation to intimacy. Rather, it’s as if I’m being looked at through a telescope—someone is observing me, clearly craving detail, but they’re intent on gathering their information at a distance. If one person aggressively examines, while the other disavows their scrutiny, this makes seduction out of the question. Seduction is a dance of proximity; we bring some parts of us forward and shroud others, teasing and sliding with our eyes, two people engaged in raising and dropping our veils. Being regarded with a cold stare strips away any trace of glamour.

So I have mostly taken myself out of the beauty game. I know, from talking to other crips, that many of us have the same fears. We’re afraid to let informed beauty happen, even if it could, because it means letting a potential lover into our truths. It’s hard to tell these stories when they’ve been received with as much pity, judgment and misunderstanding as our bodies themselves. The pursuit of intimacy risks bringing us both into proximity with disgust. I veer between secrecy and over-sharing, having no idea what should be known or when. Keats was wrong. Beauty can be destroyed by Truth. It’s easier to navigate this territory with ironic humor
and caution than to leave myself open to the risk.

Even if you believe, as I do, that beauty is not a condonable measure of value for anyone, the fact remains that our society has put beauty at the center of the wheel. Our relationship to beauty matters and must be reckoned with. It can affect how we take care of ourselves, where we go, and what we imagine we deserve.

IV.

I am a professor of anatomy and figure studies (at the School of the Art Institute and Northwestern University) and inevitably think in terms of embodiment. I wanted to know what happens in the brain during the experience of Informed Beauty. I’ve read multiple published studies, and I’ve talked to scientists, but it seems that so far no one has studied the perceptual and cognitive shifts that might happen as one moves from simple observation to aesthetic transformation. I did find reports wherein test subjects looked at static pictures of faces in fMRI machines. They rated these faces according to various standards of attractiveness, but the scientists did not document any changes in aesthetic perception over time. They simply recorded the subjects’ one-time assessments. This seems to me indicative of how our culture sees beauty: not as a relationship, but as a binary yes-or-no.

Several studies said that we assess a person’s
attractiveness even before we determine an individual’s identity. That is, I decide if you’re pretty even before I know who you are. When we see a pretty person, surges of dopamine are released in reward centers of the brain. Associative learning posits that pleasurable associations are made, via neural connections, between disparate facts. For instance, we forge links between the color of a beloved’s hair and the happiness this person makes you feel. Associations have a long shelf life; just think of the many times you’ve been reminded of a lover by a certain song or scent.

The so-called “Beauty Equals Good” concept is frequently cited in beauty studies. Individuals who are considered beautiful are more highly rated as moral, trustworthy, and competent than people of average (or unattractive) appearance. It comes down to the fact that we think well of pretty people because they feel good in our brains. The converse (that “ugly” people “hurt”) is not exactly true; endorphins are not “sucked up” when looking at “ugly” people. Rather, stimulation also occurs when we look at people who are novel and/or body-variant. This may frame an unusual body as compelling, but not in an erotic fashion.

The wonderful thing about beauty is that we can’t predict who is going to enthrall us. You may find yourself smitten with a body that is not at all what you expected. You may even find yourself desiring against your will. If you imbue beauty with meaning, it will never be unseen, but leaves a
permanent alteration in your brain. Unexpected desire drives a wedge into the narrowsness of taste. The chaos of desire widens your erotic vision, and changes your very template of beauty. It’s crucial to remain conscious of this reciprocal shift — I can attest that I am altered when someone makes me see myself differently. It’s been harder for me to believe that the person who invites me into the beauty illusion is changed as well. When someone finds the sight of you thrilling, they’re not in control. Fascination is not a stable or impregnable place. Desire wants to see itself reflected, and in that there are never any guarantees.

If disabled bodies are seen as entities of pleasure, then they become connected to aesthetic happiness - in art, in nature, and sensuous and sensual adventure. Beautiful things are valued, are rescued, and are removed from harm. This can mean everything from personal assistance to political action.

Exile from beauty is distance from your own skin, born of shame, that shuts down the body and makes it guarded, opaque, and secretive. Shame snares the beholder and the beheld. Someone might be afraid to look at my variant body, lest they be repelled, and then be ashamed of their reaction. Informed Beauty takes time. It’s a long period of risk for all involved.
Mat Fraser: Sealo Seal Boy, 2006, Totems and Familiars

[Image Description: Mat is standing naked in a circus tent that has been pierced with viewing holes. His hands are clasped at the ends of visibly shortened arms. A straight razor is falling by his thigh, the handle of which is engraved with “Sealo.”]
As an artist, I am a professional beholding eye. When I think about painting any person’s body, I’m torn between my love of variance and the urge to present their complicated, hidden story. I want to inform the viewer of their beauty via a single image. In a perfect world, because I love bodies for themselves, I might do nothing but nudes. But I’ve seen so many viewers reduce nude, disabled bodies to mere specimens. It’s hard to make that choice. Instead, I embed the body within the life, inside a story full of objects, places, clues, clothes and symbols.

One of the ways I select a portrait subject is erotic pull. This rarely means that I have explicit sexual feelings; rather, it’s an urge to inhale the space between us. Everyone I’ve worked with is in some way variant, whether that stems from disability or not. Variant bodies are infused and vibrating with lived histories. I feel as if I can see the intersection between how that body was born, how it was altered, and how its choices have formed its present, as a time-lapse film. Variant bodies are wondrously alive and inhabited in ways that make unmarked bodies seem silent and vacant.

Yet, my variant subjects have been taught to be unhappy with their markedness. I may be enraptured, but it can be hard to show them what I see. For that reason, I avoid
flattery. Flattery becomes a falsehood that just leads back into exile. I want to show them a beauty that will stay for a lifetime, through a portrait of what they actually possess. I don’t cut them into acceptable and unacceptable parts. I try to depict the intensity of the whole body, its knotted graces, its lyrical asymmetries, its well-lived textures.

Some of the most fraught egos I’ve worked with have belonged to non-disabled people, perhaps because those with marked bodies are forced to negotiate levels of peace with their appearance. Self-portraiture lets me explore images of the body that might be too difficult to ask of someone else. When I picture myself I don’t have to worry about hurting another human being. I know what I can tolerate. Still, I’m trying to push that line with my newest collaborative works, by asking portrait partners to go to edgier places than ever before.

Being disabled doesn’t automatically give you an eye for our beauty. For me, it only came through my struggle with self-loathing. As disability rights attorney Harriet McBryde Johnson said in a 2003 interview in the New York Times, “It's not that I'm ugly. It's more that most people don't know how to look at me.” It took me until I was thirty-five to learn how to look, but when I did, I was invited into the spacious intimacy of cripples.

I will continue to try to depict a beauty that has nothing to do with animal standards. Beauty in no need of symmetry.
Perhaps the most human form of beauty. At the same time, I can’t help thinking about my recent conversation with performer Brian Lobel, who thinks beauty is a bankrupt word. He prefers those that avoid its trap altogether, that call beauty irrelevant and unimportant and opt for idiosyncrasy and power. Our task is to discover those words that keep the walls from growing around our skins.

But for now, when my lover tells me I’m beautiful I won’t ask her what she means. She’s made me understand what I’m asking from someone when I ask them to let me really look. I may still struggle with my alien position at the border of love, but as an activist, I’ll celebrate the shock of my body in bed. And I’ll believe in a mutual illusion that sustains both our hearts.

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When someone is being traumatized they have a few options: flee, fight or disassociate. I'm not saying that the trauma I endured in grade school from my teachers compares to that of people who have experienced sexual or physical trauma. I have what my therapist called “little ‘t’ trauma,” consistent, traumatic experiences from persons in authority who were supposed to instill self-esteem. These experiences had a significant impact on me, my adult life and relationships.
Years ago I experienced what I later named my “special ed depression.” This depression carried into my adulthood, and often manifested when I was still, not working and sat with the feelings from my childhood. As a kid, I had internalized the messages from my teachers, extended family and the media that I was less than. When I became an adult I felt that anything that was subpar in my life (whether it was material goods, friends or lovers) was deserved because I was a product of a childhood significantly impacted by disability.

Growing up with a Learning Disability, I suffered numerous emotional infractions at the hands of teachers, which I then internalized. Because I was “little ‘t’ traumatized” by my teachers regularly, I had to find my own way of getting through the school day. My favorite coping mechanism in 8th grade was avoiding class, and I found preposterous ways to escape the classroom. My escape plans ranged from collecting “mission money” to fund evangelizing people in developing countries to spending the better part of December and January hanging out in the school’s storage closet (insert obvious joke about the Catholic church and closets here).

Like many Catholic girls and women, I had a hang-up about the Virgin Mary. I suppose this came from third grade when I was selected to bring the offering (communion and the money collected during church) for the All Saints mass.
For the non-Catholics, let me explain. This particular mass is one of the funner masses that you have in Catholic school. All Saints Day is celebrated the day after Halloween, so there’s an opportunity to wear costumes.

I was selected to bring the offering because I told my third grade teacher my costume was “spiritual.” My plan was to get a bed sheet, cut multiple holes in it and be Charlie Brown’s ghost. My mother thought this was unacceptable and instead made me dress as the Virgin Mary: long, white gown, blue satin headdress, and China Flats with embroidered flowers (total old-school Lowrider style). Since donning this costume I suppose I overidentified with her, so later, when the part of Mary in the 8th grade Christmas play went to Lori (a Protestant with short hair!), I was pissed. I wasn’t going to play a frickin’ angel! Instead, I volunteered to “do costumes,” meaning I organized the decades-old costumes that were stored in a chaotic, musty closet. Inside it were remnants from the 1950s so it was obvious that no one had touched the space in years. I saw an opportunity in the dank clutter, and somehow parlayed the duties of “costume coordinator” into overhauling the entire storage room. I had become the 14 year old, stuttering, Italian Martha Stewart. Reorganizing took weeks, which meant some days I wouldn’t even attend class. It was a relief to be out of the classroom and spend a day going through tinsel and old pictures. Anything to save me from diagramming
sentences, reading out loud, or being shamed for giving the wrong answer was better, so I welcomed the isolation.

Why did my teachers allow a student to basically cut class? My guess is that I was easier to deal with away from the classroom. Every year in Catholic School my parents were told “if your daughter requires accommodations, then she does not belong here.” I never understood this because I’m pretty sure that Jesus would have made an accommodation. Compared to spending time with my ableist teachers, being alone in the Christmas storage closet was a sanctuary.

When I wasn’t busy cleaning closets or collecting mission money for the heathens of the world, I could usually be found in the girls’ bathroom. These excursions of elimination took at least 20 minutes and usually occurred when taking turns reading out loud in class. Teachers, if you want to get rid of a kid who stutters and has dyslexia, tell them you’re going to have the class take turns reading. They will either send themselves to the nurse with a stomach ache or head to the bathroom to avoid the “little ‘t’ trauma” of reading in front of an audience of unforgiving peers.

As if 8th grade isn’t difficult enough for your average thirteen-year-old girl, for the first time in my Catholic school experience I had two teachers, not just one. Unfortunately, both teachers were assholes which meant I was never asshole-free that year. They made my life hell. They were
inconsistent with the accommodations I needed, embarrassed me in front of my peers for things related to my Learning Disability, and just generally bitchy. Once, one of the teachers indirectly called me a “twat!” Who does that?

Each day was peppered with little verbal and emotional aggregate assaults on my self-esteem. The teachers complained that my 1980’s Espirit leggings and big sweatshirts were signs I was immature, yet I was dressing like everyone else if not better. As an adolescent- especially one who watched entirely too many comedians- I started to respond in ways that bordered on the inappropriate. But let me first tell you what they did, so when I tell you about showing the boys and teachers used maxipads, it doesn’t seem so bad. (Yes! My first period joke—a passage into womanhood for all female comedians).

The times where ableism would flow most freely were parent-teacher conferences. At a typically tense conference my mom yelled at my teachers when they acted like I wasn’t going to do much with my life. My dad had to kick her underneath the table to get her off her “my kid isn’t just going to work at McDonalds her entire life” soapbox. That didn’t make me very popular with the teachers, but at least I knew my parents believed I was an intelligent, capable person because they were advocating for me.

In another conference, my parents talked about
appropriate accommodations for my learning disability. Everyone agreed I would only do half of the inordinate amount of daily Math and English problems. The homework was all drill and kill, practice without learning anything new. It was busy work. After the end of the semester I received my grade: an F. I approached my teachers about it.

“Why is my grade an F?”

“Well, you only did half of the work. So I could only give you half of a grade.”

I explained, “Well, my accommodation was to only do half of the work and then you base my grade on that.”

“Well, you only did half of the work so you get an F.”

Now I could have done none of the work and still have gotten an F, but it was a total abuse of my teacher’s power, and it remained on my report card despite my objections. Another “little t trauma” strikes again!

Once I had to give an oral presentation with one of my friends. I worked very hard at it, felt like I did a really good job, and I did. I got an A-. My friend got an A. The only reason I got an A- was, and I quote from my teacher, I “didn’t speak clear enough.” Really Ms. Nolan? Really? You’re going to give a stuttering kid with a learning disability a lower grade because their speech isn’t as “clear”? I knew at that time she was wrong, and it really upset me. This was the
moment I started to fight back against ableism in the 8th grade. And when I say fight back, it wasn’t in terms of advocacy or activism. I didn’t have an identity as a person with a disability at that point and didn’t know that there were people fighting for our rights. Instead, I made fun of the teachers.

During recess, my teachers always used the childrens’ bathroom. Like most bathrooms, there was space between the floor and the door so you could see their feet. Because these women hadn’t gone through menopause yet, when they pulled their panties all the way down to their ankles, it often revealed a bloody maxi pad. Now for someone who despised these teachers this was a goldmine. I spent most of my recess and lunchtime hanging out in the bathroom just to catch a glimpse so I could laugh at the teachers and mock them. Once I opened up the bathroom door to expose the boys to the teachers’ panties and their maxi pads. The boys cringed and the teachers had no idea. I was never caught! On the last day of school I got a picture of my teacher’s feet in the bathroom stall. Unfortunately she wasn’t on her period that day.

I’m sure from the perspective of an outsider my behavior must have seemed obnoxious. In fact, many of the teachers and kids in my class saw me that way. In the 8th grade I learned that the stranger I acted, the less my stuttering or Learning Disability mattered because they were
overshadowed by my weirdness. I would have been much better off socially if I had started to wear all black and paint my face like Robert Smith of The Cure, but that wasn’t my style. Having been exposed to comedy at an early age and idolizing people like Steve Martin, Richard Pryor and my favorite comic at the time, Emo Philips, absurdity was my genre to identify with. It was a defense that I would embody for years to come.

Naturally, I continued to stutter throughout school and my Learning Disability never let up, even with the Fs on my report card. The treatment from the teachers added to my already growing sense of learned helplessness. Learned helplessness is the idea that if you try and you fail, and try yet again and fail, then soon enough you stop trying. This is intensified for some people who feel that no matter what they do, they will fail because they have little control over things. If they’re successful, it’s because of luck and not something that was within their power. If you have a Learning Disability or you work with people who have them, then you can recognize this. If there is a success, it’s because of a reason outside of their control (the test was easy and that’s why they received an A). Even successes are met with this mindset, so it can be difficult to change. Luckily for me there were people in my life (my parents) and others who would soon come into it, who would help to modify how I thought about myself.
Unfortunately, activism wasn’t yet on my radar. I didn’t know how to protest in the traditional sense of the word. Instead my protest was one that you see in many “mild-moderate” special education rooms across America: protest through silly acting out. I later learned there are better ways to advocate for yourself and to act out with purpose. My need to act out in more absurd ways was repressed until I was able to go back to my comedy roots and use standup as a means for activism and self-expression.
There I was in his office, my heart pounding as I read the fine print on his multiple gold-leaf diplomas. Though I had tried not to get my hopes up, I couldn’t help but wonder if he’d recognize me after nine years. Sure, I hadn’t looked my greatest then, but I could bank on my bright eyes and sparkling personality having distinguished me, right? At the time I thought nothing of the fact that I was wearing a hospital gown, and still attempted to charm the man in the manner to which I was accustomed. Having been born without arms or legs, I have a lot of experience impressing
doctors with my abilities and pride myself on the jovial air that I bring to routine appointments. It had always been easy because, until that hospital stay, I’d never been unwell.

It seemed serendipitous how I found him again. My regular ear doctor was spending the winter months in a sunny clime and I could not wait a month to have my hearing back (my indelicate and completely mundane ailment was an overproduction of ear wax that occasionally plugs the canal). Although my regular doctor’s receptionist offered me a referral, the suggested practice was not in my insurance network so I took matters into my own hands, so to speak. Scrolling through the ear-nose-throat listings online, I saw his name and gasped at my good fortune. Of all the specialties, who’d have figured him for otolaryngology? He’d been on a surgical rotation when I met him, and a few weeks later when I bumped into him, obstetrics. He looked haggard (yet smiled sweetly) that day in the hospital cafeteria and admitted that he’d enjoyed his surgery tour more. He was only replying to my question about his preference, but I hardly heard the answer; I was fully focused on the fact that he’d crossed the atrium and, to my giddy delight, had taken a seat with my mom and me to inquire about my follow-up appointment.

Chief resident of otolaryngology at the university hospital, an undergraduate degree in German and integrative biology, membership in Alpha Omega Alpha… these were the honors
and distinctions that I tried to commit to memory, quickly, in case he came before I could finish studying his diplomas. No photos of the 2.5 children, but I was fully prepared for him to be married. This wasn’t about me batting my eyelashes and draping myself across the leather exam chair, though I was terribly curious how he’d look. He must be 36 now (four years older than I) and I wondered if he was still cute in that baby-boy way. I’ll never know if the drugs had made him look like Noah Wyle to me, or if he just happened to be attractive to me in my time of convalescence. As an intern, he’d had more time to chat and had not yet become as jaded and burdened as the other doctors seemed to be; his innocence had been endearing, and I liked to think that my own youth and relative naïveté had inspired his kindness.

On an otherwise beautiful fall day in 1999, I was struck by a car as I crossed the street to catch a city bus to my office downtown. It was gorgeous weather, and the driver later claimed to have been blinded by the sun. For what it’s worth, the light was red and I was in a crosswalk. Accompanied by a student crossing guard with an orange flag, I was in a bright yellow wheelchair. It would be difficult to make yourself more prominent as a conscientious pedestrian. Witnesses say that I flew 30 feet, and to this day I still feel badly about how horrified those elementary-school children must have been to see me bite the dust. And bite it I did: face down and
to the detriment of my beautiful new eyeglasses from Italy. My eyebrow was bleeding, but I was quick to use my tongue to count my teeth and glad to find them all intact. I’d taken headers before and figured that after my ears stopped ringing, I could roll over and go about my day—after all, my usual bus had stopped and was waiting for me (yeah, they were all traumatized too). Never in my wildest dreams did I think that this splat scenario would warrant a trip to the hospital.

The otolaryngology waiting room was rich in masculine touches, including distressed oars that decorated the walls and leather chairs in a deep mallard green. It was the most patrician waiting room I’d ever been in, so I took it as an indication that he’d really arrived in the world of private practice. I’d always imagined he was a product of the East Coast, merely passing through Oregon because he’d matched at the university; now that he’d chosen to settle here, I could give him credit for having good taste and attribute to him all sorts of very Portland traits of character. I am skilled at making matters of health, and one’s relationship to the practice of medicine, character issues.

My mother always proclaimed that there is no value judgment attached to physical appearance, yet our family views various bodily infirmities, such as the common cold and indigestion, as character weaknesses. Thus I was raised
to think fairly rationally about measures of beauty, and am glad of it; however, measures of fortitude are another thing altogether. My Irish Catholic family is several generations deep into a pronounced martyr tradition, an attitude that only aided and abetted my enjoyment of conditions that require medical attention and general fussing over. Near the end of high school, when I was diagnosed with otosclerosis and was losing my hearing, I was tickled to learn that it would require a delicate surgery. Moreover, I felt quite important about the fact that I’d get to spend the first fall break of my college career recuperating, while others used that week merely to have wisdom teeth removed.

Dr. X could not have known that day, nor the one in the hospital nine years earlier, how much time and energy I’d invested in nurturing this complex about treatment and convalescence. He had no inkling of the fact that television hospital dramas were a guilty pleasure for me or that I had written my undergraduate thesis on the sickroom motif in the British novel. The poor man was completely unprepared when he walked into the room that day, interrupting my daydream about the diplomas and effectively putting an end to the delusions I’d held so long.

“Hello, I’m Dr. X,” he said, coming through the door. “And you must be Robin?”

“Yes, good morning,” I replied.

“What sort of symptoms are you having?”
Wow. Not only does he not recognize me, he clearly hasn’t consulted notes made by the nurse nor thinks it necessary to get acquainted with a new patient.

“Oh, just the usual overproduction of ear wax. Pretty mundane, actually, but I’ve got a business trip coming up next week and cannot wait for Dr. Y to return from South Africa.”

“Ah yes, his yearly vacation… glad to help out,” he said flatly.

So he knows Dr. Y and cannot even draw a connection?

“You should know that I selected you from my preferred provider website because I recognized your name,” I volunteered.

Silence.

“I never forget a name; it’s my thing,” I added nervously, but with a confident smile.

No mild amusement, just a blank stare.

“You were a surgical intern at Emanuel Hospital; you treated me several years ago after I was struck by a car.”

“Did my residency there as well… seems like a very long time ago now,” he said absentmindedly.

No other acknowledgement.

“I received excellent care,” was my last attempt.

“Well, small world!”

Sure is, but couldn’t you at least throw in a generic “Glad to see you’re still alive”? 
So maybe he doesn’t recall the conversation about the flower arrangements in my hospital room or the fifteen staples that he removed from the incision on my abdomen as I quizzed him about internal hematomas. I had the bravado at the time to be above roses (yet not ungrateful, as my room had been filled with them), stating that I preferred more “exotic” flowers. When I asked about his favorites, he’d offered that he preferred iris when making a present of fresh flowers… to his mother (this had made me smile, a slight indication that he might not have a lady love). So he saw extreme and unusual trauma in that rotation, but how many patients have a shortage of four limbs—before or after the trauma?!

When the EMTs arrived on the scene that September morn to scrape me off of the pavement, I said “Don’t search the bushes for the arms and legs; I was born without them!” Honestly, I thought that I was doing them a favor, dispelling alarm in the same self-effacing way that I’ve done for the general public over the years. Besides, in my family, if you can still crack a joke… you’ll be fine. A sense of humor was handy as I lay there on the street immobilized—come to think of it, make that a sense of humor shored up by a strong sense of delusion. I truly thought that I could shake it off and get to work in time for an important client meeting; really, I’d taken tumbles before and always bounced. The EMT folks
did not find it so amusing when I said, “Just roll me over to the gutter and let me lie there for a few minutes, then I’ll be fine.”

I thought about tossing off a joke to Dr. X in his elegant office but, frankly, I was too shocked and demoralized that he did not recognize me. Not to mention, it would have been slightly inappropriate to strike such a casual tone--no matter that I’d already created an elaborate personal history for him in my mind just fifteen minutes earlier. Maybe that was the hitch: protocols for professional behavior prevented him from acknowledging previous patient-doctor interactions? I appreciate the Hippocratic oath, but would a knowing glance have killed him? If not from the hospital, then from zipping around town? I’m known to many, after all, as “that chipper young lady with the hi-tech wheelchair.” I mean, didn’t he know that I was famous?! Apparently not. He went through the motions and evacuated my ears quite capably. There was no small talk, I never cringed at the excavation, and I only piped up once, asking his theory about my propensity to produce such volumes of wax. “You do have very narrow canals,” he offered dryly. Well, I felt delicate… and deflated.

When I left the office he was cordial, but did not try to poach me as a patient. Worse yet, he turned toward the break room and did not offer to get the external door for me. Wow, I thought, being a wet blanket is one thing, but being
inconsiderate of a wheelchair user is another! Had success turned him aloof? It was too painful to consider, and by the time I reached the street, I realized it didn’t matter anymore. Whether he had a bad memory or simply bad manners, the fantasy had been DOA. It served me right for having built him up as a golden boy and imbued his memory with all of the goodwill that lingered in the halcyon days of my convalescence. After surgery to repair my small intestine, I recuperated nearly two weeks in “The Mothership” (my affectionate term for the womb-like existence I enjoyed at the hospital). While I received exceptional care and felt fondly toward the medical staff, none of them had given me special treatment or called attention to my notoriety as an “inspiring local personality”. In fact, the thing I liked best about being a patient was that everyone one else was equally laid up and there was an egalitarian ethos to it.

While I waited at the streetcar station and observed my fellow citizens, I thought about the anonymity of illness. At some point or another, everyone’s life is affected by sickness or injury. There is a certain humanistic value inherent in the fact that such afflictions make no distinction between class, ethnicity, or education. The great equalizing effect of infirmity is not a highly original idea; it goes back centuries in literature. The plague, in the Albert Camus novel of the same name, did not discriminate and I’ve always found this oddly comforting in a cosmic sense. Sure, many of the characters
die, but they certainly are humbled and/or enlightened in the process! My favorite British novels can pull off elaborate and convoluted marriage plots only after characters are knocked down from a high horse (sometimes literally) or laid low by a debilitating fever or some other nineteenth-century malady. My romance narrative was derailed by a lack of recognition, but I’d had to confess that being swooned over by Dr. X may not have been the brand of attention Charlotte Brontë had in mind.

On the streetcar I’d taken to the appointment earlier that morning, I had noticed our former mayor a few seats ahead of me and realized that she might be headed to the same medical center. It was public knowledge she’d been suffering from a very rare and aggressive form of cancer. She had been gracious in the press when responding to peoples concerns, but clearly wanted to keep private the intimate details of her treatment. I had met her a couple of times previously at various events, but on that day I decided not to approach her or draw attention to her presence. I could appreciate “the fourth wall of transit,” though I’d only ever enjoyed such a barrier for myself in bustling NYC, never here in provincial Portland.

As I sat quietly and considered my own minor celebrity status, a boisterous woman approached the mayor, saying “Hey, weren’t you the mayor a few years back? No “Good morning” or “Pardon me for imposing.” No obvious excuse of
drunkenness, though it is not unheard of at this hour, on this route—just the compulsion to ask a rhetorical question and receive validation by inserting herself into another’s quiet consciousness. I felt for the mayor to be disturbed from early morning reflection (on life, death, or maybe just her hope to snag the best magazines in the waiting room), but subconsciously I was simply glad the obnoxious citizen was not accosting me, as often is the case. The woman carried on to the extent that we could all hear her, yet she never broached the subject of health nor waxed inspired—and I could tell that the mayor was relieved. Thankfully the loud woman’s stop came quickly. Mine was next, the first of two that served the adjacent medical offices. As I debarked, I nodded in the direction of the mayor and gave her a knowing glance—the very least I could do.
Growing up, I expected that I would be living the good life by now: doing work I love, earning a decent salary, and owning my own home. Instead, I am a thirty-four year old woman with a bachelor's degree who does not work, subsists on Supplemental Security Income and resides with her parents. Why is my reality so different from the future I once envisioned? I became "disabled."

I am not alone. I am one of twenty-seven million women with disabilities in the United States. Women with disabilities
face major obstacles towards achieving economic security including a historically higher unemployment rate than men with disabilities. The U.S. Department of Labor reports that men with disabilities are almost twice as likely as disabled women to be employed, especially in full-time positions. Women with disabilities faced an unemployment rate of 14.7% in 2012, nearly twice the national average of 7.9% for people without disabilities. More problematic was the labor force participation rate: Only 28.9% of women with disabilities were working or looking for work- less than half the national average of 63.6% in December 2012. (Men with disabilities fared slightly better with a still dismal unemployment rate of 14.5% and labor force participation rate of 34.4%).

I never imagined I would be one of the more than 70 percent of women with disabilities who have dropped out of the labor market. I have always had disabilities. I am hearing impaired in both ears. I also have Dandy Walker Syndrome and hydrocephalus. As a child, I did well in school, often bringing home report cards full of A's and B's. Living with hearing loss and two congenital neurological conditions took a daily toll on me. I frequently had headaches and unexplained fatigue. When I got to college, I struggled to maintain my health and my classes. Still, I graduated with a Bachelor of Science in Computer Information Science in December 2002.
Entry-level jobs for new IT grads in that post-9/11 recession were about as rare as closed captioning in movie theaters. After working at a few dead-end jobs, I decided to go back to school in the fall of 2004. While still attending classes the following spring, I had a spinal cord infarct at the C4 level. Without warning, I was paralyzed from the neck down due to complications of Dandy Walker Syndrome.

When I realized the paralysis was probably permanent, I asked my mother to apply for SSI, or Supplemental Security Income, for me. Mom filled out the forms for SSI with the assistance of a social worker. The social worker helped me sign the paperwork with an "X" by holding the pen in my fingers and guiding my inert hand in a criss-cross motion. He also convinced me to sign over financial power of attorney to my mother. Practically, this was the right decision: the paralysis showed no signs of subsiding and I couldn't fill out paperwork or sign forms. Giving Mom power of attorney would allow her to do both. She could pay my bills and handle the daily battles with the health insurance company.

I trusted my mother. She knew I was fully competent and could make decisions. If there was anyone I wanted to stand in place for me legally and financially, it was my mother.

But no matter how much faith I had in my mom to act in my best interests, the only reason I gave up power of attorney, that fundamental legal right, was because my hands didn't work.
It was terrifying to give up control. There was no time limit on the power of attorney so I had no guarantee it would ever be revoked. I did not know if I would be considered capable enough to manage my own affairs again. Part of my humanity, my ability to make decisions for myself and be respected as an adult, felt like it disappeared the moment the forms were signed.

I was quickly approved for SSI and have received benefits ever since. When I left the hospital three months after the spinal cord injury, I went to live with my parents. I still needed round-the-clock care. This decision also made sense financially as paying rent for even the cheapest apartment in my area would have consumed the bulk of my monthly SSI check. My parents and I settled into a routine: my father went to work and my mother, now retired, became my primary caregiver. The months went by and I needed her less and less as I improved in my outpatient therapy. My fears of never regaining control of my financial and legal matters turned out to be unfounded. Mom signed forms relinquishing power of attorney the following spring.

Around this time, I took the first steps towards re-entering the job market. I enrolled in one of the computer courses I had been taking when I was hospitalized a year earlier. Doing the homework was torture. I struggled to sit at the desktop computer long enough to finish my assignments.
The pain in my neck and arms was excruciating. Since I knew I had a passing grade, I didn’t go to the last week of class or even turn in the final assignment. I was too overwhelmed and exhausted from the pace and amount of work being asked of me and my body. My mind could handle it but my body couldn’t.

I felt defeated after taking that class. I knew I would probably never go back to an information technology career. I had a first-class mind but a changed body that might never be able to work in the traditional labor market again.

On the surface, it looks like I have had a remarkable recovery from my spinal cord injury. I can walk, talk and move freely. I am grateful for all of those things. But my body was still devastated. On the outside, I may look "normal." On the inside, I live with the effects of a spinal cord injury every single moment of every single day. Disabilities or not, I still deserve a decent quality of life. I deserve the American dream. To paraphrase President Bill Clinton, "if you work hard and play by the rules" you shouldn't be poor in this country.

I am willing to "work hard," to contribute as much of my talents to society as my health will allow in exchange for a living wage, and I have "play(ed) by the rules," getting an education and looking for work. But by most definitions, I am poor. I receive $889.77 per month in federal and state SSI benefits. Over twelve months, that adds up to $10,677.24, or
93% of the U.S. Federal Poverty Level (FPL). My monthly budget is quickly exhausted: my parents get a significant portion for room and board. I also contribute to utilities. Despite Medicaid, I frequently spend cash on medicine and medical supplies. And occasionally, I need money for miscellaneous extras, like new socks or a toothbrush.

I have no savings. SSI income limits allow me $2,000 in assets, such as cash, stocks, or money in bank accounts. I have nothing saved for retirement. I live month-to-month, terrified in the knowledge that if I didn't have my parents' financial support, I would be struggling very hard to pay for housing, utilities, transportation - and, oh yeah, food. SSI is supposed to be a safety net - and it is - but barely.

According to the U.S. Census, the poverty rate for people with a disability aged 18 to 64 was 27.9 percent in 2010, more than double the rate of people without disabilities. The number of people with a disability in this age group in poverty was 4.2 million. Those statistics are staggering - over a quarter of people with disabilities of working age are living in poverty - but unsurprising at the same time. The system is not working for us.

Too many people with disabilities have left the job market. I think it is because we don't fit into the present economy. We are a wasted resource. Take me: I am relatively young with a bachelor's degree in a technical field. I know how to program computers, fix them, and I have
strong writing skills. In an ideal world, employers would be pounding on my door with job offers, but they are not. Very few companies are looking for workers who live in a semi-rural area, need flexible hours (sometimes as few as five to fifteen hours per week) and must work from home.

I have spent much of the last nine years terrified and angry about my financial situation. My body and the laws of society and the economy are denying me the right to support myself. People with disabilities, especially women, deserve - and have a right to - to earn a living wage. It is time for society and this economy to adapt to us. SSI is not a sustainable quality of life. It is meant to keep you poor, as an incentive to get off the program. I do not have any policy prescriptions. That would probably require a book of its own. I am open to suggestions, though. It is time for society and the economy to adapt to people with disabilities. We are valuable members of both.
Flashback: Fall 2011

He was attacked. Now he’s engulfed in doctors and all of them are squirming at his softened face and shortened manly hair. He’s a man. He’s a man and doctors don’t know what to do with him. He’s a man? He’s a transgender (trans) man. His gender markers are Female on every application and contract. The law directly discredits his spirit. Nurses speak slowly and suggest that he doesn’t speak English,
that he doesn’t know how to make decisions of his own. Medical staff continuously swirl medical jargon as though he’s not even a speck of dust in the examination room. His movements are as delicate as moth wings. He feels like there’s no light to fly to, but he delves toward hope nonetheless.

He’s never faced this extensive medicalization before. Swollen foot. Another swollen foot. His feet are shades of grapefruit and plums. The lumps of his digits resemble the gradations of a Midwestern sunset. Post-operation care and now he is at home. Throat parched. When did he last eat? Has he asked? Who knows. An alarm is set every 3 hours for painkiller reminders. There’s even a song he made to loosen the load, make some laughs. Gotta keep his spirits up. He sings it to himself- an inside joke that tapers off once his nerves start to rile up. It goes: It’s time for the Percocet! It’s time for the Percocet! (in the melody of house music classic, “It’s Time for the Percolator”). The medicine is out of his reach. He feels the sharpness like bees hoarding over his toes, the tidal pricking of needles. The sting lopes from the shriek of his swollen instep and ankle to the rest of his leg. He’s asked her for medication for over ten minutes now. He asks and asks and asks. He asks his lover for the medication and she says, “hold on.” She says, “Just give me five minutes,” which turns to ten, which turns to surges unable to stifle. He’s biting his pillow, stuffing his hands into
the cushion of the couch to bear his weight. He doesn’t want to be bossy, the pain just overcomes him. Medication is like this. Food is like this. Eternal waiting and no respite anywhere and everywhere. There is no negotiation with his body, with doctors or this lover turned stranger. With every protest and workshop and every theory dwindling further away from life, he wonders how many of us are at home, wedged in between a parent’s/lover’s/sibling’s resentment and the gritted teeth of an inescapable yelp? This is not what strength is. This cannot last forever. It can’t.

No one believes this body.

I was born able-bodied. I politically involved myself as a teen and then as a queer brown person, facing violence and harsh gender-normative conditioning. There was no room for a queer body in my upbringing. I had to alter mores of the gender binary just to create a masculinity that was accepted. I wore lipstick then baggy men’s clothes. I had long hair, but wore baseball and fitted caps. A transgender body like mine is pressed to conform. One has to change ultimately who they are in every aspect to assure safety.

Growing up in the Filipino-American community I felt imposed racism and nativism that comprised grandiose scripts of what binary gender meant- the same scripts rooted in U.S. colonialism and impinged on brown bodies. The
script that says, whatever brown you are, you are a mistake. Women behave this way, men behave that way and in the end everyone gets married and wins the American Dream. You will be the big jackpot of life! Just erase all that you are! That's the story that was passed on to me.

The pity and savior complex entrenched in ableism feels similar to the experience of shaming perpetrated by U.S. racism. Racism teaches us that People of Color can be fixed, be more anglo, act however is perceived as white, and then be valid human beings in the mainstream. Ableism expects people who are disabled to change their bodies for a system that deems their bodies not valid. Both systems dehumanize people for who they are. Both systems are founded in demanding people change without asking mainstream institutions to change. Blame is defaulted on People of Color and the disabled community. Instead of honoring difference, we are asked to assimilate. Supposedly, this is to help us but it only inevitably erases who we are and diminishes the experiences we face. The brown body, the transgender body, the disabled body is my spirit that currently has no model for existence. Here, in this lonely intersection of avenues and complexity, is where I'm discovering disability justice.

Currently in disabled, sick, political and academic spaces, my life as a brown person is stigmatized with racist
assumptions from White crips/ disabled/ chronically-ill communities. How many times have I been instructed to regulate my experience facing injustice solely based on my disability? This interpretation is void of true experience as a brown person and non-heterosexual person.

Every space where nondisabled, rigid queer masculinity is celebrated, we are minimized. We are perceived less manly and less able to acquire the capitalist dream. Those of us unable to maintain jobs due to ableism are viewed immediately as de-masculinized in humanness, and even in queerness. We fail in the criteria of the U.S. empire gatekeepers driven by capitalism and capital as self-worth. Men apparently face no hardships but what does it mean to be transgender and disabled then? Where hardship and survival are uncanny landmarks of experience? In the conventions of white straight American consciousness (and sadly even some queer people of color (QPOC) radical communities), we Trans Crip Men of Color are presumed less than. Less than men, less than queer, less than transgender, and less desired unless we somehow succumb to the anti-immigrant bootstraps of accomplishment and get supposedly better, supposedly fixed. This is the case for being brown, for being transgender, for being disabled.

When the doctors in the medical industrial complex demean and touch someone of varying experiences without consent, do not engage in conversation about our pain and
care, we are being disrespected on all fronts. The negotiation of the treatment of people of color, immigrants, queer and transgender people comes into active play, without a doubt in a harrowing congruence with the oppression that being disabled involves. One way or another, there’s a vicious isolation that occurs: a detestable presumption that divvies up knowledge as a person living and surviving an intersection of communities. It’s impossible to hone in on one aspect of our lives when people’s lives do not exist in a vacuum.

I believe simultaneity is the way of a transgender man of color seeking power and love. I am the evidence that there are many stories singing and overlapping and seeking self-determination all at once.

“People with disabilities are often seen as “flawed” beings whose hope of normalcy rests in becoming more like non-disabled people or by becoming “cured.””
-Sins Invalid

As a transgender mixed brown disabled person, nothing about me or my chosen pamilya is normative. In public spheres I am constantly under question. Am I real? What exactly does it mean to live everyday as an accusation, a denunciation, a packed world where accountability of your life is in question? When honor and intimacy are a constant
ache and constant negotiation? When your very breathing is oversimplified as a disturbance? When you are deemed flawed and something that can be fixed. It’s my skin color. If I could just erase my race, I could truly dedicate my understanding to real disability rights. It’s my disability. If I could just get better already, I could be the man or queer or any other unyielding fabricated dichotomy of humanity. If I could just dress differently, If I could just make money, If I could.... be precisely someone else. This rifled sense of self leads me to carve perspectives that can re-imagine and survive conflicts faced everyday. Certainly, resilience is the buzzword in each of the marginalized communities to which I belong, but make no mistake: there’s havoc when this is a constant way of living.

How is this body that challenges conventions ever deemed appropriate or beautiful, desirable, real, human? How long does it take for me to unhinge every piece of U.S. colonialism, spit out the unsettling glorification of various identities that I just don't seem to fit? Let's get right to it: with any given public interaction, say at the convenience store, a job interview, or at someone's party, my body is under policing. Is that a man or woman? Is that a child or an adult? (I appear fairly young so ageism begets me despite my older, ornery mannerisms). How did he hurt himself? Will he get better? Is that a man or woman? What is this brown kid doing here?
Now, imagine all of those questions storming from someone who is in a position of power. Say for example, a cop or a judge. How many times are you a target? What types of harassment are possible if someone happens to abuse their power? Imagine the waves of dissonance and pain overwhelming each daily interaction you have. What if that affects your financial access or access to a safe place to live? Your mere existence carries the information and lineage of so many spirited communities and this repressive world wants nothing to do with any of them.

"[Gender dissonance is a] form of cognitive dissonance experienced by trans people due to a misalignment of their subconscious and physical sexes. Gender dissonance differs somewhat from the psychiatric term ‘gender dysphoria,’ which typically conflates this cognitive dissonance regarding one’s sex with the mental stresses that arise from societal pressure to conform to gender norms."

- Julia Serano. From her book, Whipping Girl: A Transsexual Woman on Sexism and the Scapegoating of Femininity

I'm a trick, a breathing apparition! I am a man, but no one seems to understand that and constantly misgenders me using "she" WITHOUT my consent. I'm sick and disabled
and I'm never going to be the able-bodied person systems
destine me to be. I never believed that I could be
empowered and self-loving as a disabled person. I use
corcepts of man, of brown, of disabled and am circuitously
shamed in these identifiers. Trans disabled people of color
are instant others- those whose bodies are unwilling to cater
to outmoded traditions of what is powerful, hot, charismatic,
and most importantly, valuable. We are engaged in what
transgender writer and speaker Julia Serano calls, "gender
dissonance."

The implications of feeling systematically
impacted by not being identified as the gender(s) you identify
with are laborious. We are an atrocity; our bodies are
undetectable and unfamiliar terrain.

I live in a world where it’s understood by the mainstream
LGBTQ community that my masculinity is compromised and
dehumanized by being disabled, a person of color, and poor.
In gender binary and heterosexual masculinity, so much of
what is manly is narrowly defined by able-bodied physical
access and prowess. Am I still masculine or a man if I cannot
walk a few blocks or am not driven by the inadequate, able-
bodied aesthetic of skinny, muscular, and able? Punishments
by way of gender binaries work their fullest when access to
medical transition, accessibility to the bathroom or any
building, and sex-positive spaces are brought to the surface.
If we embrace gender as something non-linear but ever
changing, it allows us to examine and elaborate a more
comprehensive and loving existence.

I have acquired my disability. I have insurmountable privilege in that. Mourning this, I realize how much of my healing was in fact housed in able-bodied and inaccessible practice. Truly, to be an able-bodied person in the struggle might mean helping a sick homey with groceries, creating a schedule around consistent visits, and not asking for the gazillionth time if someone is “getting better yet?” The momentum around tactics that encourage us to push harder and healing/wellness narratives that isolate and victim-blame, are some of the obstacles that we might face in the SDQ (sick & disabled queer) community, with heightened affliction to those who are people of color, indigenous and native peoples, and immigrant people of color.

Winter 2013: Journal Entry

Today the physical therapist was an asshat. A blaming, shaming, insulting asshat. I know my body. I've lived with him/them for all 32 years. From the embarrassing sweat blotches that resemble islands scampering across cotton to the spasms that warp my nerves to the sweetest decline of breath once my body has had an orgasm. I know what this gracious body of mine is capable of. A person who bludgeons what could be a healing experience with trauma is painful. It feels as though they take great pleasure in calling me anything but the name I claim for myself. Forget
about pronouns, using he/him/his would be a miracle at this point. I’ve seen research that says transgender people are unemployed at 2x the national rate– 4x for transgender people of color. Disabled people are unemployed at 2x the national rate. The insinuation that I am lazy and that’s why I am not getting better debases all the work I’ve done. Doesn’t consider how systematically I am denied work. Disabled people and children of immigrants MUST be lazy (eye rolls). Queer people: lazy. Transgender people: lazy. That’s why we can’t get any fucking jobs and be real citizens. These assumptions are killing me and pervasive and they are endless. If economic success is the premise for worth, it kills us all. No one wins. It hurts. It hurts to be constantly referred to someone who doesn’t match your personhood and who you understand yourself to be. To be told that you are invisible and invaluable. I wonder if I were a white person, would there be such an insistence to police my gender? I wonder if I surrendered to standards of normalcy and didn’t wear the markers of the young, people of color, hip-hop community, and genderqueer physicality, if I would be seen with some sort of authority on my body and experience in the medical industrial complex. I have no doubt that my time would be easier here. Problematic and traumatic of course, there’s so much victim-blaming here, how could it not? However, my unique experience mustn’t be in the brochures of what a typical patient is. Or more terribly, queer people of
color and disabled people of color have been institutionalized for so long that the degradation of our lives is unblinkingly common. Nothing about our lives are weapons, so why does it feel this way? My identities aren’t in opposition to one another. I know this but I don’t think society has gotten the memo.

I don’t have to prove my humanity to anyone-- cisgender, straight, able-bodied, wealthy, and white people situated in unmitigated privilege. To those who can't be bothered, who can't fathom how much warrior I can get, or comprehend the warrior I've had to become, My time and my tools aren't there for you. Seriously, thank goodness for that. If they were, I'm sure the very best of me would be at stake.

Let’s celebrate the unions that uplift my brown trans queer crip communities/ homies/comrades that aren’t limited to or focus solely on hierarchies of ignorance. The reticent pivot of our dances; the sweetest throbbing collaborations; our safety as we deserve it; our most lonely moments when we still create to archive and live; the deep breaths as we swap stories as easy as rain drops come spring; the ache of release when some system, any system doesn't eat our veins dry; the pintig of finding resources for one another; the poems we edit and revise and keep and offer; the open palms that believe knowing there is an onslaught of ready fists; the sweat we dedicate to constant necessary quality change; the chosen family who lend you change for the bus
or lunch or a bed for the night; our kindred hum of ancestors when we move; the knowing gaze of nourishment in our cuddles, sparkles, swag, honor.

Feminist of Color Janice Mirikitani’s poem “In Silence, Giving Tongue,” exemplifies the life lived in simultaneity, where everywhere we go our truths are faced as dares and challenges to mainstream institutions. We are ecstatic and taxing bodies of celebration. Wherever we be, whether in the public assistance office line to the full-gamut of progressive and social justice enclaves it is clear: “We give testimony. Our noise is dangerous.”
The first time that a clerk offered me a senior discount, I was 54 years old. I was in the local Salvation Army store buying a small table for my outdoor plants. The clerk didn't ask for my identification, she didn't inquire about my age, and she didn't tell me that she was giving me the discount.
She just saw my graying hair and rang up my purchase accordingly.

When she asked me to pay less than the amount on the price tag, I asked why and quickly found out that I had unwittingly entered the ranks of People Who Look Old.

It didn't particularly bother me. It was a bit of a shock but, for that moment, that's as far as it went.

I've since learned that, in the city I live in, simply giving a senior discount is the exception, not the rule. Most businesses give a discount only if the customer explicitly asks for it. I began to notice this pattern within a couple of months of coming to town, and the reason for the pattern rather shocks me: It is considered insulting to suggest that someone looks old.

The evidence of this pattern is everywhere. On the local bus, the driver is not allowed to tell elderly passengers that they are entitled to a senior discount or to offer one if the passenger mistakenly pays full fare. Apparently, people had become irate that bus drivers thought they were old. In the face of this response, management drew the rather ironic conclusion that offering a discount was poor customer service.

At the local food market, the one small sign for the senior discount program is all but hidden among other announcements by the door. When my 68-year-old husband noticed it, he asked the clerk why he hadn't suggested to him
that he take advantage of the discount. The young man said that he used to offer the discount to elderly customers, but that people had become hostile toward the cashiers for doing so, and the policy changed.

At the Goodwill store, I have to notify the clerk that I want the senior discount applied to my purchase, despite the presence of a sign as big as my head that states that I am entitled to it. I can only guess that this policy is in place to avoid provoking hostility in customers.

Of course, the question that arises is “Exactly what is insulting about suggesting that a person is old?” That stance implies a tremendous hatred of what bodies are and what bodies do.

Bodies wear down. They age. They break. They die. That is the nature of living in a body. Because we are all so thoroughly immersed in culture, I generally resist using the words nature or natural to describe anything in human life. But the frailty and ultimate breakdown of the human body are facts that go beyond cultural narratives. They are basic to the body as a body.

As I've aged – and as I've acquired a visible disability in addition to my invisible ones – I've realized how much this hatred of aging parallels the hatred of the crip body. The object of hatred is the body that shatters the youthful, strong, and independent ideal of what bodies are and always should be.
Of course, the reality of the body is that it moves through time and is never perpetually in one state. In fact, that reality of the body is that it is extremely vulnerable. Anyone who has held a newborn knows just how vulnerable the body is. Anyone who has ever comforted a person through a seizure knows just how vulnerable the body is. Anyone who has ever tended to people in hospice knows just how vulnerable the body is.

But vulnerability is not something that we in America do well. Vulnerability is for the weak, the unmanly, the lazy, the broken, and the dying. So we crips come along, with our bodies that break the ideal, and all of the hatred for vulnerability starts to flow.

To say that the body is vulnerable is just a fancy way of saying that we are defenseless against death. As a culture, we do not want to hear this basic and undeniable fact. In fact, we relentlessly deny it.

This denial takes many forms. The most common is to suggest that disability and illness are somehow the fault of an individual's choices and attitudes. If only we ate organic food, maintained a positive attitude, cleared out “negative energies,” let go of stress, did the proper detoxification regimes, used herbs instead of pharmaceuticals, and nurtured a “can-do” attitude, we’d be the picture of health. What, then, of death? Death itself becomes our own fault, a product of our own choices, as though death were not the
most natural and inevitable fact of life.

More evidence of this denial is the way in which elderly and disabled people are cordoned off in public places with assigned entrances and seating. When I get on a bus with my aging body and my cane, I go straight to the separate seating for elderly and disabled people. Am I happy for an accessible seat at the front? Absolutely. But I grieve the idea that we have to mark these seats at all, because marking them marks us, making us both very visible (“Look at that woman with the cane!”) and altogether invisible (“Oh good, she's over there and I don't need to think about her!”).

What if, instead of giving us an assigned seat, others on the bus simply saw us as alternative versions of themselves, and made room for us in our frailty, in our unsteady gait, and in our mobility devices? What if it were a question of simply honoring the fact that we inhabit bodies that change? Why does the mere fact of having bodies that do what bodies do merit a separate section, a separate entrance, a separate class at all?

My aging body and my cane mark me for social invisibility. They are highly visible markers that result in apartness.

Now, it's abundantly true that in my apparently able-bodied youth, I was never particularly enamored of the intrusions that came with hyper-visibility: the boys who shouted out of their car windows as I jogged by, the men who leered with a “Hey baby, I like your tits,” the eyes that
followed me down the road. There is something to be said for leaving all of those intrusions behind. Few people cat-call a 55-year-old woman with a cane, and it is a relief to be able to walk down the street unmolested.

But the reason that I am being left alone sometimes stagers me. I often feel that people don't want to look too closely or get within a certain level of proximity because my aging, disabled body has mortality written all over it.

Truth be told, when I look in the mirror, I see mortality. I see that I am just passing through. Suddenly, I have lines, and wrinkles, and grey hair. Suddenly, I'm holding a cane. Suddenly, my right hip is loose, and my nerves are impinged, and my knees occasionally feel as though they could give out from under me. Suddenly, I have to deal with the reality that I am mortal, that my body is inexorably changing, that I am vulnerable. Suddenly, I find myself turning away from my own body.

Some time ago, I decided to do a photoshoot of all of the parts of my body that I didn't want to see: the lines that encircle my neck, the wrinkles above my breasts, the belly that gets thicker with every passing year. I decided to look at them through the eye of my camera so that I could see them for what they are: signs of my body doing what bodies inexorably do.

What I found was that my greatest difficulty was not in looking at my own body. It was in realizing that the body I
saw was actually my body.

I had become invisible to myself. Inside my own mind, I was still 20. I would look at other bodies moving through time and frailty and vulnerability as though such things would never happen to me. Other people's bodies age. Poor them. Other people's bodies become visibly disabled. What a shame. Other people don't look quite so young and lithe anymore. But not me, thank God. Not me.

All those other people were aging and becoming more disabled, but not me. No. Not me.

What is this strange exceptionalism we are taught, as though the vulnerability of living in a body is reserved for others, but not for ourselves? This exceptionalism implies an astonishing cultural failure of empathy and imagination. Nondisabled people look at disabled folks and defend against the possibility of ever walking in their shoes, rolling in their chairs, holding their canes. Young people look at elderly people and do not see their future selves, but something alien and apart. An aging disabled woman looks in the mirror and does not recognize her own body because inside her head, there is a 20-year-old assuming that she will be 20 years old forevermore.

I find that I can no longer feel angry at other people for their attitudes toward aging and disability, because I am neck deep in these attitudes as well. My response now is not
anger, but pain and grief. Despite all of my disability writing, all of my crip theory, all of my disabled friends, I am still stuck in a cultural narrative that denies death and rejects the aging and disabled body as the avatar of the fragility of human life.

Each of our lives is, indeed, very brief. There is terror in that understanding, but there is also sweetness. How extraordinary to be given these bodies in which to taste life, and how painful to have to give them up in the end! If as a culture, we could hold the wonder and the pain in the palms of our hands, then suggesting that a person is old would be not an insult, but a recognition of the beautiful, painful, inescapable brevity of it all. Some of us find that recognition, in the end, and embrace it. But as a culture, we flee that recognition. In so doing, we flee the reality of what it means to live in a human body.
ON RADICAL EMPATHY AND SCHIZOPHRENIA

BEN G.

“It will not help to try to imagine that one has webbing on one’s arms, which enables one to fly around at dusk and dawn catching insects in one’s mouth; that one has very poor vision, and perceives the surrounding world by a system of reflected high-frequency sound signals; and that one spends that day hanging upside down by one’s feet in an attic. In so far as I can imagine this (which is not very far), it tells me only what it would be like for me to behave as a bat behaves. But that is not the question.
I want to know what it is like for a bat to be a bat.”
- Thomas Nagel, “What Is It Like To Be A Bat?”

Try to imagine it: you find yourself at the center of a world conspiracy centuries in the making. Its purpose is to organize humanity around a new principle that extends beyond race, class, gender and creed. Each generation, a few individuals are initiated into this secret, powerful sect, which is based on an ancient spiritual belief system as old as the Egyptians. Presidents, Prime Ministers, and world leaders don’t belong to this group—they defer to it. You are the most powerful, the most sought-after of your generation. In order to accept your fate, you must give up the life you have known until now. Your friends, your family, and your lovers will never understand your new calling. In fact, their lives are in danger if you remain close to them. Your mind is becoming so powerful, one errant thought could kill them.

Despite this fact, you’ve been living in your old childhood bedroom in your parent’s house in the suburbs because you can’t hold down a job or cook yourself meals—you are too busy communicating with members of the sect by a form of telepathy. They are slowly transforming your mind and melding it with their own. The process is as beautiful as it is terrifying. You have never felt a connection to the world this deeply religious before. At the same time, you feel terribly,
utterly alone. Left to your own devices, you might not eat every day, but then, you have bigger things to worry about—the future of the world.

One day, you get a message. You are to go to a special facility in another state for the telepathically gifted, people who have been initiated into this secret, ancient sect. There is a man there, a kind of modern day wizard, a member of the sect, who you see four times a week. After several visits, he asks you if you know why you’re here. You are hesitant to tell him what you know, but eventually you do, plainly and honestly. You don’t realize it right away, but it’s the beginning of the end. You start taking pills that have been prescribed to you, and the world slows and dulls. A couple weeks later, the man tells you that you aren’t at this facility because you have special telepathic abilities. Actually, you’re in a mental hospital, and you’re here because you have something called “schizophrenia.”

The word has a strange effect on you. You repeat it to yourself while you’re alone over the course of weeks. It is something like a magical spell. You’ve heard the word before, you know what it signifies, and so you feel as though you’ve been handed a death sentence. And yet, the same part of you that feels condemned is suddenly and vividly alive. There is a tear in the fabric of the world you had occupied until now, and a flood of thoughts, which are your own thoughts. You’re grasping at a new world—this world—a
feeling you had forgotten for years, and from the very back of your mind, as if you were having an extended epiphany, one that refuses to end.

In Thomas Nagel's famous 1974 paper, “What Is It Like To Be A Bat?” the philosopher concludes that we cannot know what it is like to be a bat for a bat, because we’re stuck with the experience of being singular human beings. Yet, importantly, if we refuse the idea that other animals have an experience of what it is like to be them, that other animals have what we call consciousness, we suddenly lose perspective on what it means to be ourselves—to be human.

A radical approach to the consciousness of people with schizophrenia might operate by the same principle. Every time I come out to somebody about having had an episode with “schizophrenia,” I’m struck by how little the word conveys about the conscious experience of what it was actually like. The wild extremes of emotion, the bizarre beliefs, the hearing of voices, the seeing of witches and warlocks, the paranoia, the feeling of being completely isolated from others. The contents of those experiences are generally perceived as being so different, so horrific, that when compared to the experience of a so-called normal person, I sometimes feel like I might as well have been born a creature as strange and alien as a bat.

I believe that at its root, it is the foreignness of this
experience that makes it so repugnant and stigmatized in our society. Given that fact, maybe this approach, in which I attempt to communicate what my episodes were really and truly like is part of the problem. What I want to do is something altogether different, however subtle it may seem: I want is to describe what it’s like for a schizophrenic to be a schizophrenic.

But what does it mean to describe this impossible thing? This question begins a process of empathy—for those who haven’t experienced the disorder toward those who have, and for people who have experienced the disorder toward themselves. The goal is to open the door and let the madness enter the world, though always keeping in mind that you can only remain at the threshold.

To be sure, this process of empathy is a difficult one. Told straightforwardly, the story of psychosis elides too much though I believed it for several years. The truth is, even I can no longer imagine what it’s like to be a person with telepathic powers at the center of a world conspiracy. The grip of those delusions has faded, because I’ve returned to life in a shared reality. But I keep going back to that time, like a long and mostly illegible letter from a forgotten friend, trying to understand its strange symbols, as if it holds the key to knowing who I am now, having gone through the crucible.

Now that I’ve arrived, so to speak, on the other side, I can’t help but come to the conclusion that what happened to
me is by its very nature, unrelatable. Nagel writes, “Reflection on what it is like to be a bat seems to lead us, therefore, to the conclusion that there are facts that do not consist in the truth of propositions expressible in a human language.” We cannot say in words what it is like for a bat to be a bat without falling into a thought-experiment; the same is true for people with psychosis. But that doesn’t mean that the realities of people living with psychosis don’t exist in and for themselves. I want to shout this, to hurl it at the world, that my experience with psychosis is not to be compared to the experience of someone without it; that there is such a thing as what it’s like for a schizophrenic to be a schizophrenic.

For Jung, madness has healing, generative powers. It is a chrysalis in which an untenable place of existential anguish is transformed and made tenable—or, if you like, a process in which our true, egoless selves are allowed to rise up and take up space in our consciousness. For people who have never experienced madness—and for many of those who have—this can be a bizarre, irrational idea that flies in the face of modern psychiatric medicine. But there is a lot about modern psychiatry that ought to be questioned. According to the profession, my experience at the time of my psychotic episode is more or less meaningless. It signifies only that I have a brain disease, or a defect of
genetics, or possibly an unfortunate set of life circumstances. As for transforming anguish, it’s a nice thought, but has nothing to do with biology, or a neurochemical imbalance.

What a terribly shallow view of life!

More importantly, and to be very clear, I didn’t cease to be myself when I had a psychotic break. Even if my experience is fundamentally unrelatable in language, I lived through it. I was there—I just wasn’t here. To say that those years of my life correspond to a brain problem and nothing more, is to view the experience from the outside looking in. It is to reduce my own experience of myself, and at worst, to rob me of the experience altogether.

Certain writers and theorists go as far as to say that modern psychiatric medicine, which relies on prescription meds, interrupts a natural process of a regeneration of the psyche. That to return to life in a shared reality too quickly is disorienting, jarring, and potentially harmful to a natural process that’s trying to resolve itself. That the stigma of having such experiences in the first place makes it impossible for people to find proper avenues of support that takes their lived experience into account.

Yet there is hope, too. A method of treatment known as Open Dialogue, pioneered in Finland, seeks to curb the use of antipsychotic medication with a form of talk therapy that includes family members in the work. The goal is to create a
shared reality which is inclusive of the person struggling with psychosis, and not stigmatizing in terms of labeling that person as the one who is “mentally ill.” In a study performed in Finland from March of 2006 published in Psychotherapy Research, 86% of patients experiencing first-episode psychosis either returned to their studies or were holding down a full-time job within five years of treatment using the Open Dialogue method.

Doctors in the United States are beginning to take note of the effectiveness of Open Dialogue. For example, the Howard Center in Burlington, Vermont is hoping to incorporate aspects of Open Dialogue therapy into its treatment plan. A respite program in New York City called Parachute NYC, which has roots in Open Dialogue, recently received a large grant to provide a “soft-landing” for people in psychiatric crises and to avoid hospitalization. And the Institute for Dialogic Practice in Haydenville, Massachusetts offers a three-year training program in Open Dialogue therapy, the first of its kind in the United States.

Here is a practice of radical empathy for people living with psychosis; one that doesn’t explain away the thoughts, beliefs, and visions of the person living through the experience by simply calling it a brain disease. In fact, that might be what it means to describe what it’s like for a schizophrenic to be a schizophrenic: to acknowledge that
although each person living in an extreme emotional state like psychosis has a different experience, the process of opening the door to madness and letting it speak could mark a similar kind of healing and communion. Nagel posits: “…to deny the reality or logical significance of what we can never describe or understand is the crudest form of cognitive dissonance.” Experiences with psychosis go beyond everyday perceptions, and mark out a territory that can be terrifying and difficult to understand. Yet, those experiences are real, and they have things to tell us, if we would listen.

If there is such a thing as what it’s like for a bat to be a bat, and if we can never know exactly what this is, it sheds light on the inherent limitations of what it means to be human. The same can be said of understanding the experience of people living with psychosis: if we can never fully grasp what happens in those experiences, if we cannot know whether indeed it is a form of spiritual and psychic regeneration or a disease of the brain, at least we can try to understand these experiences on their own terms. We can do this by practicing a form of radical empathy which incorporates these experiences and builds a shared reality between family members and friends over time. Ultimately, a process like this enhances and makes more complex our understanding of what it is to be human.
The Ballad of Wednesday Addams
by Jen Rinaldi

My history includes a diagnosis of anorexia nervosa. According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, or DSM-V (APA, 2013), the diagnostic category is characterized by a distorted body...
image, a pathological fear of weight gain, and behaviours that result in extreme weight loss. These markers of the condition are often carried out quietly. My thoughts of inadequacy came to me behind closed doors, where I would stand before mirrors and contort my back to expose bones, or claw at my stomach to find fat. I would prepare meals to consume on my own, so that no one could judge the care taken to render portion sizes consistent, or the timed intervals between bites. The experience before diagnosis was a solitary one, buried in the folds of oversized shirts and dinner napkins.

I was young when I began starving myself. I moved through my adolescent years empty, undernourished, rendering myself too small to be noticed by the boys I was supposed to want. I did not lament lost opportunity, though, for I felt no desire to be seen, nor touched. I could not imagine my body being handled by a boy, in part because I could not imagine a kind boy. But also, my first childhood crush was a girl with dark locks like Wednesday Addams’ plaited pigtails, and a penchant for posing metaphysical questions. I might not have understood my impulses at the time, might have brushed off my fantasies, so ill-suited for my blue-collar town, but she moved me, and her lessons lingered with me for years.

My lunch hours were filled with extracurricular activities ranging from rosary club to theatre when my crush was the
model student; when she began acting out, they became opportunities to skip school for downtown excursions. I became vegetarian, this seemingly principled and difficult stance, the day she lectured me on animal cruelty and never had a decision seemed so simple. She used to make a game of watching me eat, of rattling off her daily caloric intake, and for the first time in my life I realized I was fat. It had not occurred to me then how these small seeds would take root, what a hand she would have in defining me, but in the throes of young love girls have a way of giving themselves over to oblivion.

I never spoke of her, of just how much she affected me, to spare myself some embarrassment; though, in the years since, my diagnosis had the effect of stripping me bare. Stein and Corte (2007) as well as Vitousek and Ewald (1993) claim that anorexics have a negative identity or poor self-concept. The former set of authors argues that lacking in a sense of self renders anorexics susceptible “to cultural standards regarding body weight/shape” (p. 64). Diagnoses empty people of agency, and imply that internal deficit rather than external context results in disordered eating.

Feminists who disagree (Brumberg, 1988; Chernin, 1981; Wolf, 1994) look to the development of anorexia relative to social standards: the cult of thinness that occupies the current cultural imagination, and more broadly the historical interest in controlling female bodies. Anorectic
behaviours are different only in degree, not kind, from now commonplace ways in which women are expected to engage in body management strategies: “the obsessive and destructive relationship that most women have with their bodies is an internalization of society’s relationship to women’s bodies—simultaneously one of contempt and worship” (Hutchinson, 1994, p. 154).

But standard recovery processes do not acknowledge the extent to which body management strategies are culturally informed. Poor self-concept—not the context within which we were entrenched—renders myself and the brunette I worshipped exposed and explicable. So recovery focuses entirely on developing the self. Yet the assertion of self is construction of a certain sort of self, one entangled in concepts of femininity and health (Gremillion, 2003). Far from being abandoned, calorie counting and regimented routines are taken up as treatment modalities that, when recalibrated, enable women to build better bodies, as well as better identities to inhabit those bodies. To recover, I embraced routine—eating according to a schedule so that I might eat at all, setting time aside for exercise rather than giving over every spare moment—and in so doing I became something other than anorexic, something close to cured—even though obsessively restrictive routines had gotten me into trouble in the first place.

I have engaged in identity and body management since,
for the purpose of passing as healthy. I rarely speak of the continued pinching and prodding I carry out before mirrors, of the calculations I run through before bringing food to my mouth. Part of this newfound self has been to deny my Wednesday Addams, and all those who came after her. Psychiatric studies claim women diagnosed with anorexia tend to have decreased sexual desire, and attribute this decrease to past sexual trauma (Arnold, 1986; Schechter et al., 1987; Waller, 1994). It was important that I be read as healthy, recovered, whole; not as a shrew, and certainly never as a victim. So I found an interest in the opposite sex, or at least learned to withstand their interest in me.

Eating disorder diagnoses have long been associated with sexual dysfunction. As outlined in Coovert, Kinder, and Thompson (1989), early psychiatrists characterized anorexia as a kind of hysteria—a female mental health problem caused by heteronormative sexual frustration (Freud, 1902; Janet, 1929; Laseque, 1873). Early treatment of hysteria included pelvic massages conducted by male medical professionals for the purpose of bringing patients to paroxysm (Maines, 1999). I suppose my early efforts to walk a straight path bear some resemblance, in that my sexual partners—the cowboys and the soldiers and the frat house alphas—cemented my identity as recovered. I could claim to have a healthy body once it was worthy of being sexually consumed, and of course consumed by the right
My recovered self could not simultaneously be a bisexual self, not when alternate sexual orientations have been framed as mental illnesses. Krafft-Ebing (1886) first identified homosexuality as a deviant psychosexual practice, and the diagnostic category was only omitted from the DSM-II (APA, 1974) after significant activist efforts. Today we still see conversion therapies and Jesus camps, so the old associations with psychological deficit have not died. Bisexuality itself remains invisible via what Yoshino (2000) calls social erasure, as well as a fringe identity even within the LGBTQ community (Owen, 2011). I cannot claim an identity that would still mark me as mentally ill, not if I hope to leave behind the stigma of diagnosis; nor can I so easily take up an identity that does not exist, not socially, without risking the loss of a socially recognizable and acceptable subjectivity. It took so long, after all, to convince my keepers and juries that I possessed a positive self-concept.

My activities of passing are thus complicated, for I have to bury much of my history and my thoughts in order to be recognized as no-longer-sick, a label tied to a strictly opposite-sex orientation. Readers might protest that passing at least ends here, with this written piece serving as my coming out. But self-identification is not a “static and singular event [nor] an over-the-rainbow shift that divides one’s life before and after the event” (Samuels, 2003, p. 237). My
mother, who might just know me best, is more comfortable referring to my bisexuality as a finite phase in my life, and offers up as evidence the romantic choices I have made since my reveal, so my coming out to her is further troubled by my having to explain the motivations driving many of those choices. I tend to refrain from those explanations because heteronormative privilege lends some credence to my status as a recovered anorexic. I was fixed, as was my interest in men, so the grand narrative goes. My interest in women goes unmentioned alongside my running calorie count—not always, but often enough. But Wednesday haunts me: she still watches me eat, still wonders whether this reality of mine is dreamt up.

Dainty Damsels and Damaged Goods
by Samantha Walsh

I have craved sexual acknowledgment since the age of eleven, when it first came to my attention that I should. Everyone in school was pairing off, even if dating at that age meant little more than holding hands at recess. When boys continued to pass me by, I approached a pretty girl who had found success on the playground. I asked for her advice, in an effort to clear up my confusion. Her best guess: “Maybe they don’t know girls in wheelchairs can date.”

She brought about a revelation for me, that my sexuality
would not be taken for granted as a part of me, but would be something I needed to make manifest and tangible. Her words felt like a call to action, a challenge to convince those boys that I could date, that I was date-able. The project entailed a personal overhaul: I found friends in more popular circles, I coordinated outings to which I could invite people. Further, I altered the way I dressed and the make-up I applied. I carried out beauty rituals that Bartky (2013) has examined at length: “[A] woman’s face must be made up, that is to say, made over, and so must her body: she is ten pounds overweight; her lips must be made more kissable, her complexion dewier; her eyes more mysterious” (p. 453). She goes on: “The disciplinary practices I have described are part of the process by which the ideal body of femininity—and hence the feminine body-subject—is constructed; in doing this, they produce a ‘practiced and subjected’ body, that is, a body on which an inferior status has been inscribed” (p. 453). I reinvented myself, without realizing that in so doing I was giving up power.

The results were mixed. When I finally worked up the nerve to ask, after all those times he felt fit to kiss me, a boy who up until this point had identified as my friend, was adamant that he could never date a disabled girl. I was catapulted into very adult scenarios, all too quickly and aggressively, with someone I had assumed was only a friend. I was trapped in a car with a blind date who claimed
my cleavage justified his advances. I was attractive, consumable, but never anybody's girlfriend. Mairs (2002) considers why women in my position might encounter such a problem: “[I]f you view women as commodities (and being social products, none of us can altogether escape such an unconscious assumption), then a disabled woman must inevitably be damaged goods. How many people do you know who would willingly take home a television set that displayed only snow...?” (p. 159). In the eyes of all these boys parading through my adolescence, I was too damaged to keep.

At seventeen, I traveled out of town to a soup kitchen where an older man sought out ways to corner me in inaccessible spaces of the mission, a space I could only leave if I was carried down the staircase. The situation spun out of control, to the point where my safety was threatened. Yet the kitchen staff and the police officers called in assumed I either did not understand what had happened, or wanted it because I, the disabled girl, must otherwise experience a poverty of touch. Neither story was empowering; far from it, both were incredibly frustrating. I had worked to create a sexual persona, but I could not control whether and how it was received.

Not for lack of trying, though, for I have sought out narratives that would enable me to remain unapologetic about my sexuality. I pursued higher education, positions of
authority, feminist politics. And yet, I am not rethinking sexuality, only avoiding the mantle of victim. My goal has changed little since I was eleven: I still want a boy to hold my hand at recess, to commit to me. Sometimes I tire of being subversive, of always having to advocate, of struggling to convince people of my sexuality. I desire a traditional sexual self and a heteronormative intimacy, because heteronormativity facilitates power and legitimacy.

When the work is especially trying, I dream a dominant narrative, of fair knights swooping in, lifting me up, and carrying me off into that sunset. I dream of Lancelot and Richard Gere. The narrative they champion is contentious especially for my social position. As a disabled woman, I spend much time combating assumptions that I am submissive by seeking to illustrate my agency and autonomy. To become a damsel, to be read as dainty and waif-like enough to be carried off, signals the embracing of a decidedly un-feminist story, a story that strips me of agency. This story traps me in the towers of soup kitchens, potentially with sexual predators lurking in the shadows. The more I dream of this particular narrative and aspire toward it, the more I risk returning to my most vulnerable and frightening moments with men.

But what am I to do about my desire for a traditional relationship? It would afford me some privilege. It would affirm that I am a sexual being, that I can simultaneously be
a sexual and a disabled self. It would do all these things without my having to be consumed, that is, subjected to dangerous advances. And perhaps most importantly, it is what I want - for all the sexual alternatives to be available to me. I want awkward initial dates and a lavish wedding ceremony and the promise of growing old with a man. Now, long past eleven, far away from seventeen, I have had relationships and lovers. This has not solved the puzzle of the reading of my sexuality. This has not changed that I am not always read as a sexual being. This has not changed that I am sometimes read as a victim. I still struggle with these tensions, perceptions, and readings of my body-frustrated they are out of my control.

**Conclusion**

These stories are tied together through the precarious nature of the social consumption of the female body. Both Jen and Samantha seek to manage consumption, and do so by performing heteronormativity, even if our means and motivations differ. Jen’s orientation became bound up in habits she has had to bury in order to avoid the stigma of a mental health diagnosis. The psychiatric narratives imposed upon her account for her refusal of both male company and food; and a conventional orientation struck her as a preferable alternative to assumptions around her agency and the violence of eating disorder treatment. So too has
Samantha invested in reinventing herself because cultural interpretations of her embodiment overlook her sexual agency. Heteronormativity may well be her salvation in a context that accords privilege to those who live the story of boy meets girl, boy marries girl, girl lives happily ever after; but her efforts to reach for that story have exposed her to violence. We both contend with cultural readings of our bodies that assume we are lacking subjectivities, and that force us to rewrite our subjectivities. While the narratives presented here highlight the complications to carrying out this task while still navigating oppressive cultural contexts, the very act of their presentation, entangled in disclosure and vulnerability, illustration and reflection, may contribute to conversations around how to critically approach and deconstruct ableism and heteronormativity.

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KRIPT POWER THROUGH IT:

Disability Scholarship & Activism Helped Me Resign & Rebuild

BETHANY STEVENS

For over a decade, I have been immersed in disability scholarship and activism. Now, I am turning to this knowledge and strength to help rebuild my sense of self after resigning from my job. It was my first job, a good one at that - working as a faculty member and policy analyst within a
public university. For a proud nerd, it was a true thrill to land a decently paying gig in a disability research center just after finishing a fellowship. Since quitting, I have felt rather emotionally raw when discussing this experience, working hard on decathexis – “disconnecting from the unhealthy aspects” of my job. I like the word because it really gets at how much work it is to untangle all the unhealthy coping mechanisms and life patterns one can develop when dealing with anything that lacks fit.

I left my job for many reasons, most of which stemmed from ableist barriers that many disabled people experience in our lives. An example of a physical barrier that I experienced every semester was the need to request accessible classrooms to teach in. Every semester I was scheduled in inaccessible classrooms and I spoke with the same person every semester to change the locations. I remain baffled as to why I needed to repeatedly negotiate access after the first request process. I suppose I am naive enough to believe the burden should not be on the disabled person to ensure access on the job.

A more egregious barrier was erected when my office moved to a building that is not compliant with the Americans with Disabilities Act (ADA). Though I could technically get inside, the entrance was through the back of the building
next to a large dumpster and loading dock. It was not a safe, nor welcoming entrance. Entering required going up a non-ADA grade slope sidewalk with a bump that could easily tip a wheelchair over, or through the parking lot up a slab of concrete fashioned into a very narrow ramp. I wish this was all a joke, but I am not creative enough to come up with a story of an inaccessible disability center at a public university. Within the center I was laughed at about the possibility that I might not get into the building, that I had to enter through the back just as black people had to do for too many years, and that the real fun might be me flipping over and fracturing to getting in the space. Several of these statements were made in staff meetings with collective laughter bursting afterward. Thankfully, I had colleagues in the department – outside of the center – who validated my feelings that this environment was unwelcoming and unsafe because it was really difficult to figure out whether I was the problem. That is one of the powerful aspects of oppression – marginalized people are told so much it is our fault that some of us actually believe inequality is created through us and not by larger structures of social power.

The most insidious part of the job was that I internalized ableist garbage for years. I believed I did not add value to the organization. Aside from adding diversity to our committees and our group (a message reflected to me
repeatedly), I was JUST a token. Negative statements about
disability (e.g., curing and intervention narratives being
wonderful for disabled folks, making fun of disabled people
for not being socially acceptable enough to deserve
accommodations), often prompted me to shut my office door
and cry. I really wanted to be stronger and not let it get to
me. I felt the weight of representing disabled people
professionally and my emotions often made me feel as
though I failed. It hurt too much when it could have been just
a job. Thankfully, I realized I needed more help than my
chosen family could provide and finally sought out therapy.
Every other week, I felt like I could breathe easier after my
session because I had a person outside of my life validating
how problematic certain things were on the job. If I had
known earlier, I would have been in therapy much sooner!
And I likely would have quit sooner too.

**Leaving the Job**

My passion for teaching had kept me there. I found
comrades in people who worked elsewhere at the university,
as well as through the disability network. Ultimately, the
positives of the job did not outweigh the negatives, yet I did
not get serious about resigning until four months prior to
doing so. Until the night before, I was going back and forth
on whether I should just suck it up, be miserable and
continue to draw the check. I thought about so many people
who labor harder, work in worse conditions and are paid less. The social comparison game is never healthy and in this instance, it just helped me further self-flagellate. I finally knew I had to go after having a significant meltdown in April 2013. More than my job, I needed to maintain my health and my marriage. I made the decision to quit.

Maybe you, like I, believe the narrative that the day you resign entails a montage of bursting champagne, cheering, and happy tears flowing. Alas, contrary to the narrative in my head, my post-resignation feelings jumbled. For a few hours after having the final discussion with my boss and the associate director of our center, I felt like a champion. My commute home felt like a music video in which I was dancing in triumph. The happy dance party continued in my apartment. I felt great. And then the music stopped and the feeling of loss took over. I spent the rest of the evening crying on and off about why I was quitting and the fear that a next step may not be open to me. I wondered that night and continue to wonder what my next steps will be and who I am supposed to be. It is terrifying to think I may not ever have the truth.

**Remembering Where I Came From**

In this period of emotional and psychological discontent, I have had a lot of time on my hands to think about the path that led me to this position. When my former students were
feeling stressed or troubled, I often encouraged them to recall things that would prompt feelings of gratitude and self-pride. Reflecting on this, I recognize how easily I can rattle off wonderful self-care methods for dealing with life’s trials, yet find myself unable to apply some of the basic precepts.

To ground me in who I am, I offer a few highlights to illuminate why I am a badass gimp, leader, and not (just) a federally funded token. At the ripe age of 22, I marched from Baltimore to Washington DC with 300 other disabled people and protested with ADAPT. Just before I left law school, I cut the ribbon on a multi-million dollar building testing center for students with disabilities that I worked for years to have built. For many years, I have taught myself and others disability social justice knowledge. I am often that girl in the classroom, dinner party, meeting, etc. who raises issues of disability access, inclusion and representation. Sometimes though, I just want to have dinner or sit in a classroom and talk about something else. My younger self may not be as willing to forgive and allow the need to rest, but it is something I have realized I needed. Some things have changed, thankfully my “uppity crip activist” email signature and hemp necklaces included, but the diehard disability advocate remains true today. When I was 20 years old, I promised myself I would dedicate my life to the social amelioration of disabled people. That decision has not wavered. It has morphed into exploring various methods
toward disability justice, such as becoming a member of the California Bar and expanding the voices around sexuality and disability.

Law never felt right however, and in 2005 I knew sexuality would be my professional focus. That April I directed a conference on the nexus of disability and sexuality bringing together lawyers, scholars, activists and artists. The keynote speaker, a former adult film star and dancer Bridget the Midget Powerz, rocked the conservative campus. It was then I felt the true merge of my scholarship and activism. Though so many scholars are pushed to think that praxis through activism does not fit with academe, I want to always hold true that they are mutually beneficial. Disability activism is aided through scholarship grounded in the truths of our communities and activism benefits from the political tenets of disability studies.

**Five Life Lessons from Disability Activism & Scholarship**

My activism started simply through fighting against a discriminatory barrier that made me angry, as is the story of many people. I won through working with other people and not stopping when ‘No’ was stated for days. I become involved in disability organizing and along with fellow disabled students, helped bring events and structural change to the campus.
From the first day I complained about the issue that jump-started my activism to today, I have zealously waged many battles for disability access and inclusion. Though I have not won all of them - and I am still learning which battles are worth “falling on sword” for- I have learned a few lessons along the way. Most of them I learned through failing- a beautiful catalyst for realization. Here a just a few of my (obvious but important) bits of knowledge garnered through the process.

1. Naysayers exist at every stage and you get to decide if they stop you.

Every part of the path, from finding the problem, to addressing it, to finding and implementing a solution, will include people who will say whatever action is planned will NEVER work. One may be called pejorative terms while one’s messages are shot down to enhance the punch of these statements- I have heard a quite a few. Those in power who assert “things just are they way they are” may even get others to believe that nothing will change, ever. Intimidation may be a component of this too, but I have really tried to view others’ fear, anxiety and anger as signs that I was doing something right. The naysayers I did not anticipate were people within my own group, who needed changes to occur but believed I was not being a “good
southern girl” because I was pushing too hard. That hurt.

2. **No one can do social justice work alone.**

   We all need a world outside of our professional passion. Some programs and ideologues would suggest a merging of all of the pieces of yourself professionally and personally, however having friends and loved ones outside of one’s discipline can be quite grounding. Discussing some of the squabbles may help defuse frustration. Regardless of position, we all need space to process and to escape.

3. **You do not always have to be the teacher or activist.**

   One of the most powerful tools of the master is to be fooled into believing that they (the dominant social class) need to be coddled when learning how they are discriminatory toward marginalized people. When someone learns of their privilege they do not deserve handholding or a hug- perhaps a kudos and head nod. A problem with social justice work is that everything feels like a teaching moment. It is exhausting to believe it is one’s duty or purpose to educate all the time. Even as irked and uppity social activists, we do not owe anyone our knowledge or our presentation of the Other.
4. Engage in difficult dialogs to strengthen your group and alliances with others.

Work on being an ally with people within and outside your social movement(s) or group(s). With social justice work, we often have discussions about how to be ally. We’ve read the checklists and perhaps engaged in workshop exercises in which we explored the concept of privilege. Some of this ally work has been rightly read suspiciously. Many feel-good stories around supporting disabled people reek of the problem with a proposed ally. Yet there are so many ways to work to understand aspects of disability oppression (e.g., being viewed as bodily problems, focusing on very basic of needs like a ramp as a primary civil rights issue, our needs and rights being as something special). Becoming educated through reading or working with a group outside one’s identity group can be thrilling. There is synergy to be had, as well as innovative ideas to share to strengthen bonds with other people in the community and build understanding between people. Through investing in other people and movements, all of our movements are strengthened. The more nuanced we are in our understanding of life – the more comprehensive and inclusive our solutions will be.

5. Get proud by practicing
Weathering all of the social forms of inequality (or –isms) build up in our bodies. The hatred, disdain and discomfort are stored in our cells and marrow – to borrow from Eli Clare’s work. We live this crap and we have to work to get it out. Becoming aware of the political nature of disability radically shifted my world. The first speech I gave about disability was the first speech I gave where my voice did not shake. Though some ideas disability advocates espouse, as I have here, may seem truly basic, they continue to be personally revolutionary for myself and those who learn of the sociopolitical understanding of disability. When I was younger, repeating tenets about disability being beautiful, the importance of disability access, the need for more media representation, and that we were basically awesome helped me begin to believe what I was taught. Though internalized ableism and other –isms are complex experiences that may never be personally dismantled, it is really exciting to know I took a few pieces of disability hatred out of my soul. I continue to work and struggle with this. The late Laura Hershey was right when she wrote:

… Remember, you weren’t the one
who made you ashamed
but you are the one who can make you proud.
Just practice,
Practice until you get proud, and once you are proud
Keep practicing so you won't forget.
You get proud
By practicing.
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