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Blog

We Need to Talk About Disability as a Reproductive Justice Issue

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At first blush, I don't appear to be disabled. Unless you notice subtle symptoms – like when I press on my sinuses, hold a hot mug or cold glass to my eyes, or am unable to find words when speaking — you might never know. But like 25.3 million (http://www.medicaldaily.com/stress-severe-pain-11-americans-suffer-chronic-pain-nih-states-347292) other Americans, I suffer from a chronic pain condition. Between three and seven times a week I suffer from a migraine. Every day my neck and shoulders twinge with pain. Some weeks my nausea is so bad that I'm lucky to keep a glass of water down. When a migraine strikes, I often lose vision in one or both eyes. I'm fortunate enough now to work from home, but when I was in an office with fluorescent lights bearing down on me, bouncing off the bright white walls, I would leave work a few times a month with a blinding migraine. I would take the Metro home, usually getting off a few stops early because the swaying of the train made me so nauseous I was going to vomit.

Every morning I take four pills, and every night I take an additional three. If it's a migraine day, and at least 15 days of the month are, I drink a licorice-flavor powder or take the only pill that has ever worked to stop the migraine. Without insurance, some of these pills cost thousands of dollars. Every three months I go to my neurologist's office and get prescription Botox injections in my shoulders, neck, head, and face to alleviate the migraines. The day after my eyebrows make me look like Spock, and I have bloody pin pricks all over my forehead. My disability is not always visible, but it is debilitating, and it controls so much of my life.

Folks in the mainstream reproductive rights movement do not talk about disability enough. Some of this is because they do not know how to talk about disability — the pro-life movement has successfully seized control of this conversation, a conversation where pro-choice activists *should* excel. The reproductive rights framework centers autonomy and self-determination, concepts which are very familiar to those in disability rights activism. Instead, a pro-life movement of misogynists, racists, and sometimes violent terrorists, have historically made more concerted efforts to include people who are disabled, their communities, and concerns in their public messaging. Fetal disability narratives are central to pro-life rhetoric, where they decry abortions of fetuses with disabilities as a form of eugenics. Reproductive *justice* advocates have done a far better job than mainstream ones in including a disability rights framework into the broader movement, but it is still lacking (http://disabledfeminists.com/2010/08/19/reproductive-justice-is-for-everyone-even-people-you-dont-like/). People with disabilities are routinely excluded from activist spaces — whether that's because locations are inaccessible, actions lack online components, or hashtags like "#StandwithPP" are used (after all, not everyone who supports Planned Parenthood

I think there is a certain discomfort with engaging the pro-life movement on their appropriation of a disability-rights framework (https://rewire.news/article/2014/09/24/reproductive-justice-activists-must-combat-anti-choicers-false-push-disability-rights/). No one in reproductive justice wants to advocate for a position that has been accused as eugenicist, an untrue label the pro-life movement loves to slap on people who advocate for abortion rights. They trot out the numbers of women who abort fetuses with Down Syndrome diagnoses. They frame these statistics as proof of eugenics, proof that the abortion rights movement is immoral and harmful. They manipulate them to claim that pro-choice people don't care about people with disabilities. They frequently frame disability in terms of children and fetuses to avoid drawing attention to their lack of support for programs for adults with disabilities. This is one way they try to win their single-minded battle to make abortion inaccessible.

can stand).

But what they don't talk about is the infrastructure (https://rewire.news/article/2014/09/24/reproductive-justice-activists-must-combat-anti-choicers-false-push-disability-rights/), of their own creation, that contributes to people aborting fetuses with disabilities. Like most women who have abortions, women who choose to abort fetuses with Down Syndrome and

other abnormalities do so because they already have children they're providing for, they live in poverty, and they experience other structural oppression that prevents them from carrying to term. (Just a quick note that I'm saying women here, because the statistics I refer to only studied cisgender women having abortions. Otherwise, I have intentionally used gender-neutral language, as Reproaction and I are committed to lifting up the experiences of all people who have abortions, not just cisgender women.) Studies show that between 70 and 85 percent of women (http://www.theatlantic.com/health/archive/2013/02/better-prenatal-testing-does-not-mean-more-abortion/273053/) with a prenatal diagnosis of Down Syndrome choose abortion. It is important to recognize that some of these women may consider carrying their pregnancies to term, but in addition to other reasons they chose abortion, are swayed by class and other marginalized status. Children with disabilities may require costly

(https://rewire.news/article/2012/08/16/disability-prenatal-testing-and-case-moral-compassionate-abortion/) additional care — specialized healthcare, education, diet, therapy, and more. Parents who work outside the home must pay exorbitantly for childcare already. Parents who work outside the home and have children with disabilities must pay even more, or stay home. Either way, there is a devastating loss of income. Institutions are not set up to help parents raise high-needs children (http://www.theatlantic.com/politics/archive/2016/05/sex-disability-race-selective-abortion-indiana/482856/), particularly when those parents face other barriers like racism, immigration status, queerphobia, and class-based oppression.

Reflecting back on my own experience with disability, if I were to get pregnant, right now I would have no choice but to have an abortion. I cannot survive without taking my medications, and they would cause severe fetal abnormalities if I became pregnant. Pregnancy would cause hormonal shifts that could drastically worsen my chronic migraines. Beyond that, I know that motherhood would be incredibly difficult for me. This is *not* to say that people with disabilities are not fit to be parents, or cannot be good parents, but I feel that the chronic pain I experience daily precludes me from raising children. Any noise during a migraine can take me from a five instantly to a 10 on the pain scale. Holding something heavy for too long can trigger my cervical spasm (in my neck) and prevent me from moving my head for a week.

I worry constantly that I will miss incredible moments in the lives of the children I don't even have. Some nights I've wept for hours just because I missed dinner with a friend. I simply can't imagine what it would be like if I had a migraine when my child had a piano recital or a big game or graduation. And most importantly, I can't fathom the regret and pain I would feel if I had a biological child and passed migraines on to them. My grandmother, father, mother, and both sisters experience migraines to varying degrees. The fear that any child of mine would have them is enough to make me not want to have children. Controlling my own reproductive future is absolutely vital to me as a disabled woman. It ensures I can stay on my medication guilt-free. It means I don't have to worry about passing a genetic disability onto future children. It means that I can continue to afford my medications and not worry about how the money I spend on those impacts my family.

Choosing not to have children due to my disability does *not* mean that I think other people with disabilities should not have children. Disability has long been an excuse for the medical establishment has used to forcibly sterilize women. Parents with disabilities are stigmatized as being unable to appropriately care for their children. People with disabilities are also sterilized due to the rationalization that they would birth children with disabilities (https://rewire.news/article/2014/11/17/disabled-people-still-forcibly-sterilized-isnt-anyone-talking/) — in other words, children who are considered to be undesirable and a drain on resources in the eyes of a capitalist society. Furthermore, the US Court system has repeatedly affirmed (https://rewire.news/article/2014/11/17/disabled-people-still-forcibly-sterilized-isnt-anyone-talking/) the rights of guardians of people with disabilities to request sterilizations for the people who depend on

them. As the Human Rights Watch notes (https://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities), some people with disabilities who are sterilized are unable to comprehend or consent to the procedure, and are particularly vulnerable.

This reprehensible practice is a damaging symptom of the larger societal narrative about people with disabilities. The narrative, as I mentioned before, is that people with disabilities are a drain on resources. We are undeserving of public funding for our care, which is why it is so expensive for families to raise children with disabilities. We are incapable of making our own decisions. We are burdens. I have heard that I am lucky to have a partner who is so understanding of my migraines, anxiety, and depression. My sister (who is on disability due to the severity of her migraines) has heard that her former partner was "brave" to be with her. We are told we are defective, defunct, and pitiable. We are told we are not worthy or capable of making our own reproductive choices, and we are not fit to be parents.

The need for reproductive justice activists to talk about disability is clear. People with disabilities and parents of children with disabilities are disadvantaged by the healthcare, childcare, education, and economic systems. In addition, it is appalling that pro-life leaders do more to include folks with disabilities in the narratives in of movement — especially because ultimately they do not practice what they preach. Like they do with other marginalized groups (women, people of color), they care about fetus with a disability when it is utero and then do absolutely nothing (https://rewire.news/article/2014/09/24/reproductive-justice-activists-must-combat-anti-choicers-false-push-disability-rights/) to support a child with disabilities when they are born. We — reproductive justice advocates — are better than this. We want to upend these systems and make them work for marginalized people. We want all people to be in control of their reproductive futures. So we need to talk about disability — what reproductive freedom looks like for those of us with disabilities, and what it looks like to radically change culture and institutions to better support folks with disabilities.

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