

MEDICAL ETHICS AND TRANS AND INTERSEX BODIES

Hilary Malatino, Assistant Professor of Women's, Gender, and Sexuality Studies and Philosophy and Research Associate, the Rock Ethics Institute, Penn State University - University Park

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I want to talk a little bit about my research over the past ten years. That research has been primarily concerned with intersex and trans rights and specifically the right to non-discriminatory medical technology and medical treatment. This work emerged out of a preoccupation of mine with what is basically non-consensual infant genital surgery performed on people with intersex conditions.

Intersex is an umbrella term. Sometimes people also use the term DSD for 'disorders of sex development' or in less pejorative language, 'differences of sex development'. It's a category that can encompass up to, depending on who's counting and what they're counting, about sixty different conditions that manifest in some sort of sex atypicality. A discontinuity between the supposedly naturalized linkage between XX chromosomes, female-typical genitalia, and female-typical hormonal levels, or conversely, XY chromosomes, male-typical hormonal levels, male-typical genitalia. Not all of these conditions manifest in genital ambiguity, like visual, genital ambiguity at birth, but some of them do. And for a very long time, the dominant medical protocol in both the US and Western Europe where it was predominantly developed, but also transnationally, has been to select a gender for these children and then perform what amounts to non-consensual genital surgery on them to normalize the appearance of their genitalia.

For technical, medical reasons, most of these children are reassigned female and they are forced to undergo what amounts to clitoridectomy. So, either removal or reduction of the size of the phallo-clitoral structure. This usually happens within the first few years of a child's life. The reason this happens, the reason the assignment is typically female is because surgically, especially when you're working with children that young, it's much easier to perform vaginoplasty and clitoridectomy than it is to perform phalloplasty. And that remains true for adults. The procedures for vaginoplasty, or the surgical reconstruction of a vagina are much more refined than

phalloplasty or the surgical construction of male-typical genitalia is. Being assigned female, coercively or non-consensually having surgery performed on them, immediately raises ethical problems. For one, it amounts to making medical decisions for another person. And the counter argument to that is, well, consent abdicates to the parents or caretakers in this instance. But, when you consider the uneven power dynamics that shape doctor-patient relationships and then try to speculate about what most parents choose in a context of a world where we understand both biological sex and gender in pretty strictly binary terms, most parents decide to do what the doctor wants when they're presented with the possibility of gender reassignment and surgical reconstruction.

So even when the parents consent, it happens within a coercive situation. And it's coercive because of that unequal power dynamic between doctors and patients. It also happens because in the context of a culture where intersex bodies are basically an impossibility, where so few people know about them, so few people are aware of the realities of intersex embodiment, and many people are invested in the construct of binary sex, in that case, you can see why parents would decide 'ok, make my child normal' right? 'I can't imagine what their life would be beyond this'.

Another red flag that might appear when you're thinking about non-consensual infant genital surgery is that as that child develops into an adult and their body begins to change, there's no consideration of what they may feel like they should be. It's not a provisional gender assignment. It would be very possible to assign a provisional gender of rearing and postpone surgery until the child is able to consent to whatever surgical procedures they desire and until the child has a sense of what gender identity they are. A lot of activists have been fighting to change the medical protocol. Currently it overrides the possibility of self-determination and bodily autonomy for those children.

From the perspective of what happens to a body in the context of performing a clitoridectomy or genital reconstructive surgery on infants, loss of sensation is a big problem with clitoridectomy. A clitoridectomy, a wholesale removal of the clitoris or a reduction performed on an infant with very, very small structures, often results, even for a reduction, in radically reduced genital sensation and clitoral sensation particularly. So many intersex people come of age and realize what's happened to them, and oftentimes it's shrouded in secrecy because parents have been told not to tell their children that they're intersex. They've been told to make up some other sort of story, so they don't feel like freaks as they're growing up. So intersex

people come of age and then are really, really pissed off that they are unable to experience sexual pleasure because some doctor decided that this was the right course of action for them. Because, to have atypical genitalia would be too psychologically deleterious for them as they grew up. That was the medical line. So there are all these obvious issues which raises the question, why does this practice persist both in the United States and transnationally? Why does this practice persist even though it's so obviously ethically troubling?

It's this moment where the cultural entrenchment of this investment in binary gender and also binary sex, seems to trump medical common sense, and in such a way that first principles like 'do no harm' are being completely violated. A lot of my work is about grappling with that fact. Why is it that this investment in binary gender and sex can run roughshod over the rights of whole, large demographics of people? Why is it then understood as both socially and medically acceptable for it to happen? And why are activists that are doing advocacy work around these issues so routinely ignored? And also, by extension, why are so few people educated about the realities of intersex embodiment and the ethical issues that attend it? So that is the background to the research in my first book that was mentioned earlier: *Queer Embodiment: Monstrosity, Medical Violence and Intersex Experience*.

One of the things I was really keen to look at in that book is that I went back to look at medical archives and sexological archives concerned with intersex conditions and I got a lot of case studies. Case studies that were drawing on patient interviews with intersex subjects but then sort of interpreted and evaluated by medical professionals who were invested in this dominant medical treatment protocol of choosing a gender and then non-consensually performing surgery at young ages. So, you can imagine that as they interpreted those patient interviews and those case studies, they were really radically, at least I think, and I argue, that they were really radically misinterpreting what the patients were saying. There are moments in the archives where you see kids actually actively arguing with physicians and telling them that they don't want to see them any longer. And then the physicians arguing, the psychologists they're working with, arguing that this is just happening because of the psychic cost of being intersex, or having a mixed sex body. So they completely deny even the moments of resistance that they're receiving from the patients, which is really bonkers, I think. This happens over and over again. There's no continuity, no long-term, qualitative studies on intersex folks and in large part because most of them refuse to see doctors at a certain point. Because they've

encountered such traumatic treatment at the hands of medical professionals invested in this paradigm that at some point, they're just like 'no, I'm not going to see you anymore.' So most folks are going AWOL from the medical record which means we don't have any quality longitudinal medical studies on intersex conditions. At the same time you have this really troubling ethical protocol. It's a hot mess. That's like the summary that I have of a lot of the work that I've done over the years.

I just want to mention a little bit how it dovetails with questions of trans rights and biomedical stratification that shapes trans access to health care. By biomedical stratification, I just mean the stratification to access to biomedical technologies and procedures. And that it may be of no surprise to many of you that for a very long time, and still, trans subjects were paying entirely out of pocket for surgical transition and for hormonal transition because it was explicitly excluded by insurance policies. It remains explicitly excluded by insurance policies, in many states, depending on the insurance you have. But at the same time, the technology that was developed, that trans subjects are fighting for access to have been greenlit by insurance companies for years and years for intersex subjects. So you have this situation where access to the very same technologies, genital reconstructive surgery, hormonal treatment etc., is being imposed on intersex subjects and then really rigorously gate-kept for trans subjects. Covered for intersex subjects and not covered at all in many instances for trans subjects. And that seems a little bit baffling to me. It raises questions like why is this happening? Why do intersex subjects have these treatments forced upon them in many instances while trans subjects are not allowed to have them?

And I think, to answer that question, or to explore that question I've had to think a lot about the way that intersex subjects are constantly positioned as natural errors that can be remediated with the wonders of modern technoscience and restored. So somehow it's like using contemporary biomedical technologies to correct a natural mistake for intersex subjects. When you can obviously say, ok, well maybe we could just grant that biological sexes are way more complicated than a binary conception of sex allows and then reform the way that we understand nature when it comes to sex differentiation. But apparently that's not acceptable.

While at the same time you have trans subjects being positioned continuously as these like unnatural and monstrous threats to the social order who don't deserve rights and who don't deserve access to biomedical technologies that might make their lives and indeed do make their lives infinitely easier in terms of their ability to navigate

the social environment, their ability to experience pleasure in their bodies etc., etc. I just want to mark that division. Even though the technologies and the doctors that were working on developing these technologies were working on both intersex and trans subjects, in the same clinics, at the same historical moments.

It's very clear to me when you look at the medical records and the archive, and also when you look at the terrain of intersex advocacy over the course of the last 25 years, that the psychological costs that intersex subjects who have experienced non-consensual or coercive surgical treatments, the negative psychological consequences they've experienced, come directly from that treatment. And that that far outweighs the potential difficulty of living in a non-surgically modified intersex body. So, if bodies aren't modified, that doesn't necessarily matter, right? Because people go about their daily lives, not everybody's genitals are visible in the context of social interaction and there are many many ways that even folks with very diverse and sex atypical embodiments can generally pass as one gender or another, especially if they decide to take hormones later in life, or not. And even if they don't, if they're visibly atypical or non-binary, that's still far less deleterious than the sort of fall out and trauma that most folks have from these medical practices.

It isn't worse to wait until the person grows up. I think that the trauma and the psychological difficulty stems pretty intensively from being the subject of what amounts to really unethical medical treatment. I think that causes much more deep psychological trauma for intersex subjects, and I also say this as an intersex person, far more trauma than being non-medically intervened upon. You could not be in a provisional gender. You could be raised male or female without having non-consensual surgery performed. And it's also important to mention that when talking about these forms of surgery, it's not just a moment of surgical treatment, there's also months and years of things like post-surgical vaginal dilation that the parents have to perform on a child. Meaning that you insert something into the reconstructed vagina to keep it open and allow it to not heal itself as a child ages. That's traumatic. There's an echo of trauma from that practice. And of course, being in the context of a parent-child relationship where that's what you've been told to do as a parent by a medical professional or a team of medical professionals puts you in a really strange position. Because the practice itself is deeply problematic I think for obvious reasons.

I could go on listing all of the possible traumas from the treatment, but I'll stop there, and just say, most of us, before we hit puberty, are raised in a gender that is not directly manifesting at the level of

embodiment in terms of secondary sex characteristics. And we now have the ability to put people on hormone blockers if they're not sure when they hit puberty what they want to identify as, what gender they want to be. So we can postpone these things until somebody is at an age of consent when they can decide how they want their bodies to develop. And that's been the big ask on the part of intersex advocates, of the medical profession. Not to end gender as we know it, but to just postpone surgery until consent is possible on the part of the child. I think that doing that is much more healthy for intersex folks in the long term than whatever possible fallout there would be with having sex atypical genitalia for the few people who will encounter them as you're growing up. You might have to avoid locker rooms or have special consideration for where you change in public institutions. Those provisions can be made pretty easily if parents are on board and supportive of their children. And not kowtowing to the dominant medical protocol

I would argue that female genital mutilation is the same thing. A clitoridectomy is a clitoridectomy is a clitoridectomy. I think they're all forms of mutilation if you want to use that language. Where we're removing healthy tissue that is also a source eventually of sexual pleasure for no purpose other than to shoehorn bodies into a particular form of social arrangement that is typically negative for the people who experience that. So I would think of them as essentially the same or at least on a continuum with one another.

I think that intersex bodies trouble our entrenched cultural investment that's also mirrored and reified at every institutional level that biological sex is a binary even though biologists know better. Most folks move through the world with this common sense that sex is binary and when bodies manifest otherwise, the entrenched medico-scientific belief has been that they're just natural errors. And that's specifically the language that's been utilized for a very long time. So until with shift that deep epistemological underpinning in how we think about biological sex differentiation, which would also entail restructuring education, restructuring institutional life in the way it relies on gender binaries, it's much easier to fix or remediate individual bodies than it is to shift toward a non-binary culture when it comes to both sex and gender. But I also think that we're in the process of making that shift culturally currently which is why trans issues such an enormous issue politically right now.