

Submission to Senate Inquiry into the involuntary or coerced sterilisation of people with disabilities in Australia

Stella Young

Having read many of the submissions to this inquiry before submitting my own, I'm aware that issues around the involuntary or coerced sterilisation of people with disabilities have been canvassed broadly. I also understand that much of this discussion refers specifically to women with intellectual disabilities, an area in which I have no expertise outside my position as a passionate advocate for the rights of all women.

What I can offer is my own story, as a woman with a physical disability and a deep personal connection to this issue.

I was four years old when my parents were advised I should undergo a hysterectomy. I had broken my leg, as children with my condition (Osteogenesis Imperfecta) tend to do, and my family were in Adelaide at the time. A specialist in OI advised them on management of the fracture and then said, as though it were routine, "We may as well do the hysterectomy while she's here."

My parents, to whom I'm eternally grateful, were horrified and rejected this "advice". My mother recalls that their hesitation was met with a shrug from the doctor. He told them they wouldn't want to be dealing with "the inconvenience of menstruation" down the track, so it was something that would eventually have to be done. I, of course, knew nothing of this at the time.

Eight years later, I met a woman with OI quite similar to mine. She was probably in her 20s, maybe a little older. I recall that she wore a lot of purple, and a blonde wig. I was curious about why she wore a wig but my parents told me it would be quite rude to ask, so I didn't.

When I was 18, our paths crossed again. We were at an OI conference, where I recall participating in a discussion about issues facing young people with OI. Typically, sexuality was on the agenda. I heard this woman's story of how she had undergone a "toilet hysterectomy" at 12. The procedure hadn't gone well, and had to be repeated when she was 16. In both instances of surgery, she didn't know what was going on.

As a result of the hysterectomies, she didn't experience puberty. Her breasts didn't develop, she had never menstruated, her bones didn't strengthen as they are supposed to during puberty (particularly important for women with OI), she had problems with facial hair growth and yes, she had to wear a wig. Her hormone production had been interrupted, and this affected her hair growth.

I think of this woman and her palpable distress often. The hysterectomy (I can't very well call it "her hysterectomy", given that her consent was neither sought nor given) had ongoing physical and mental health implications throughout her adolescence and adulthood. I think of this woman often,

because I could very easily have been in her position. I later learnt that the same doctor that perpetrated that non-consensual sterilisation recommended mine.

When I learnt about this as a teenage girl, struggling to forge a sexual identity in a society that told me sex wasn't for me, I was frightened by the thought that other people had more control of my body than I did, simply because I was a young woman with a disability.

More broadly, this issue speaks to the presumption of asexuality of people with disabilities. Often I am confronted with presumptions about my sexuality or lack thereof, even from the medical profession. At the age of 23 I saw my endocrinologist about migraines. It was her suspicion that they might have been caused by taking the contraceptive pill. The solution, she said was simple; I was to stop taking it. When I said I was willing to do that, but I'd like to talk to her about other forms of contraception, she was incredulous. She asked me, mouth agape, if I was sexually active. When I confirmed that I was, she laughed. Yes. She actually laughed.

She was unsure about contraceptive options for me, so she wrote me a referral to a gynaecologist. It said: "Stella Young has severe Osteogenesis Imperfecta. Surprisingly, however, she is sexually active and requires contraception." I felt deeply humiliated, as though I had no right to experience sex and to express myself sexually.

I eventually recovered from this severe knock to my self-esteem, from someone who was supposed to be educated and trustworthy. I'm now 31 and I enjoy a healthy and active sex life. I also menstruate, an experience that isn't much more inconvenient for me than it is for any other woman. I have chosen, for many different reasons, some of them related to my disability and some not, to not have children. But I am grateful every day that the choice is mine, that my parents didn't listen to the medical advice they were offered, and that they raised a strong, confident woman.

Finally, I'd like to comment on an argument I often hear in favour of sterilisation of women and girls with disabilities; the protection from unwanted pregnancy resulting from abuse. It is my steadfast belief that victims of abuse should *never* be expected to bear any of the physical and emotional responsibilities involved in lessening the consequences of that abuse.

The fact that this burden rests on the shoulders of some of our most vulnerable citizens is a disgrace; it's an insight into how people with disabilities, particularly women, are denied some of the most basic rights of personhood that should be afforded to all human beings, and we should be deeply ashamed of it. Worse, this dehumanisation comes courtesy of a system that does absolutely nothing to tangibly address the ongoing problem of sexual abuse in care, only to hide its more obvious effects. Haven't people with disabilities who are victims of abuse suffered enough without the added indignity of having their bodily rights further violated? We must shift the focus from preventing the evidence of abuse to preventing the abuse itself.

Ultimately, we must protect the human rights of all people with disabilities; this means an end to Australia's current sterilisation practices.