

## **Inquiry: The involuntary or coerced sterilisation of people with disabilities in Australia.**

Nearly 18 years ago I gave birth to a daughter who was born with a very rare syndrome. This is the result of a random mutation, it is not carried in my (or my husband's) genetic material as far as research can tell. However, it is now present in my daughter's genes.

My daughter has moderate intellectual disability, complicated medical problems with reflux disease, cleft palate dental issues, eyes, ears, leg bones and the list goes on. She has had 27 General Anaesthetics in her short life. She has behaviour problems resulting from a severe anxiety disorder, she has sensory difficulties, will only wear a certain type of clothing, is tube fed half of the time, brushing her hair and teeth cause major melt-downs. We have to assist her with toileting, showering, wiping. She is mobile.

Of course the onset of menstruation when she was 14 years old was a major difficulty for her and for us. She refuses point blank to wear a bra, and there was no way in the world she would tolerate wearing a pad in her underwear. It was not even possible to put one on her and have her try it out. She would just pull it straight out. When you think about the day to day management we already deal with, having a monthly period on top of it drove me nearly to breaking point. She would just bleed all over her clothes and it was impossible for school to be able to manage her.

Many people may say that my daughter's fertility is her issue and not mine but you would be wrong. You see, the way that mother's like myself are expected to care for our children until we die, it does become my issue because I am totally responsible for my girl in all ways, and I will continue to be because society has washed their hands of the responsibility of children like mine. Not just financially either.

What I don't understand about our society is that when the issue of fertility and "rights" comes up they jump up and down about my daughter's "right" to have a child if she wishes to. But no-one jumps

up and down about her "right" to be able to live independently (which she has no chance of doing in Australia at this present time because places just don't exist). They don't jump up and down about her "right" to have a job or a meaningful adult life (because the money is not there to enable this for her). They don't jump up and down about her being able to access affordable dental care (which she can't as an adult with a disability). They don't jump up and down about my life. Yes, you say it isn't about me, but you are wrong. Our society makes it about me. Why don't you protest about something that could improve my daughter's life?

Allowing my daughter to have a medical procedure to stop her periods for the rest of her life would only be a blessing to her (and to me). Why does she have to tolerate the stress, anxiety, mess and distress to keep a portion of the "rights" community happy? This is actually something in her life that CAN BE FIXED! and it is forbidden! There is no need for her to suffer a monthly period for the next 40 years of her life.

You see, she would never be able to have children. There is no way in the world she would survive through a pregnancy emotionally or physically. I have no desire to "rid" the world of people with her syndrome, not at all, despite the fact that any of her offspring would have at least a 50% chance of having her syndrome and much more severely than she has it. I am a very strong advocate with regard to her life and am against abortion. But what puzzles me about this whole issue is that if my daughter became pregnant (by means fair or foul, and let's face it her risk of sexual abuse is far above a girl of her age without an intellectual disability!) then the law would allow her to have an abortion, and I would have to go against my beliefs to allow it as well.

And if for some reason the pregnancy went ahead who would you suppose is going to care for the baby? She can't even tolerate the sound of a baby in a shopping centre and will hit her own head in fear and frustration if she hears one. Does society expect that I would care for her (probably disabled) baby as well as care for her? So where is my

right here? So the law would allow the death of a baby over allowing her to not have the risk of getting pregnant in the first place. Makes no sense to me.

If people need surgery to fix something in their life that improves their quality of life then they can have it. There is one surgery that can improve my daughter's quality of life and remove the risk of pregnancy and she can't have it. Why? Become someone who doesn't live in my house, in my shoes and in my daughter's thinks they have a right to decide that my daughter should have the "right" to her own fertility.

This should not be a legal problem. This should be between the person with a disability, their family and their doctors. If people are going to stand up about the "right" of my daughter to be able to have children if she chooses, then why don't you stand up about all her other "rights" that she is refused in this society on a daily basis? Put your energies into fighting a fight that WILL make a difference to her life, not towards an impossible dream.

So don't judge parents who make the decision to go overseas to have their precious children sterilized, because you don't know the half of it. You don't lie awake at night worrying about them being abused and getting pregnant, or how you are going to manage for the next day, week, month and year caring for them. You don't know the love we have for our precious children. You think "rights" are more than love, but they aren't. You misunderstand. Each case should be looked at as an individual decision. No hard and fast rules apply here because no hard and fast humans exist.