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

After caring for my disabled daughter full time for the past 16 years I feel compelled to share my story and experiences in the hope that the senate inquiry can gain some insight into my life as a carer.

Two days after the birth of our beautiful daughter a doctor gave us the news that would leave our lives changed forever. Our daughter was born with a rare neurological disease. In consequence our daughter has a severe intellectual disability, immune-system deficiency, ataxic cerebral palsy and sensory processing disorder.

To our daughter the world is a frightening and confusing place. She doesn't understand that the 38 general anaesthetics she has had were essential to maintain her health. All she can understand is that often people including her own family stick her with needles and cause her pain. In consequence our daughter cannot tolerate being touched by anyone, having deep mistrust issues, except myself on rare occasions.

Morning and evening baths and dressing are a screaming physical battle leaving everyone distressed. Not to mention brushing her hair, cleaning her teeth, spoon feeding and nappy changing. All these situations have caused our daughter severe anxiety and distress and we are witness to her gradual withdrawal from human contact.

Then with the onset of menstruation at the age of 12 years a new set of obstacles appeared.

Our daughter relates blood to hospital and in turn to pain. Therefore our daughter self mutilates in search of the source of the blood. She suffers from PMT and we are unable to explain what is happening or provide any comfort.

She is unable to take medication orally or have any type of implant in her body.

I am constantly hearing and reading that my daughter has rights to her fertility and sexual health. She should be educated and given the chance to make a fully informed and free consent. How could a person with a severe intellectual disability and the clinically assessed mental age of a 3 yr old make a “fully informed decision” on a subject that she cannot even comprehend? My daughter cannot make the decisions on when and what to eat so how could she possible be educated in the decision of sterilisation?

As a mother of a disabled person I make the decisions that she cannot. When to eat, when to bathe, when to get dressed, etc and I will continue to for the rest of my life. Therefore this decision should include the input of the one person who cares for her every need in life. It's not about me, but about enabling me to provide the best support possible for my scared and overwhelmed daughter. It's about me providing the best care and support for my daughter in a community that gives no support to carers like myself.

Why are there not senate inquiries about situations that could actually support my role as a carer? That could actually improve the care my daughter actually receives? Where are the inquiries about the lack of safe respite services, the lack of adult placements, the non-existence of affordable dental care for disabled adults, the halving of funding once you leave the special school system, the lack of opportunity for the disabled to live independently denying their rights to freedom and equality?

How can a senate inquiry consisting of members who have not lived life with or had to devote their life to care for an intellectually disabled person decide my daughter's rights?

Talk to me. Before you make any decision sit down and talk to me, and all the others in my position. Ask me about my daily life and my daughter's daily struggles. Talk to all the family members, talk to the paediatrician who has been by our side for 16 years, meet our daughter and together let's make a decision in the best interests of my daughter.

Don't force me to go to court, hire a lawyer and stand before a judge to explain my love and devotion to my beautiful daughter, who I know better than anyone. No two disabled persons are the same and it would be an injustice to treat them under the same order. It's unjust to the mildly intellectual disabled couple who would be loving parents and it is unjust to my daughter whose life is totally dependent on myself.

This should not be a legal matter but one looked at on a case by case basis, considering the individual circumstances of the disabled person and the loving families who care for them every day.