Date: 20/02/2013

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

This submission highlights the key issues outlining why a child with a physical and intellectual disability, should be provided with a either a reversible form of contraception or a hysterectomy. Recommendations for consideration to address this issue are to ensure parents and medical professionals, both make an informed and ethical decision, in view of the individual's circumstances, on a case by case basis.

Currently, this is a highly sensitive issue affecting parents within communities who have a child with a disability, and particularly raises concerns from the broader community who are not faced with the complications of raising a daughter who has a disability and is at risk of and/or is pregnant and/or has already given birth to a child. Creating an awareness for those who have no definitive idea of the complications involved in raising a child with a disability, who has fallen pregnant or given birth to a child, is critical if this issue is to be appropriately actioned.

My daughter is 12 and has a physical and intellectual disability. If she fell pregnant, regardless of her age, it would be considered sexual abuse because she is not capable of understanding the implications of sexual intercourse due to her significant intellectual impairment. Given her level of understanding, processing and comprehension I believe that should she fall pregnant and give birth to a child she would be traumatized beyond repair. Left in my daughter's sole care an infant would be lucky to survive for longer than an hour. Furthermore, in the event that my daughter should fall pregnant and have a child, the raising of the child would become my responsibility which is unfair to both my daughter and me.

The slightest hint of bleeding causes my daughter to have horrendous melt downs. How is she expected to cope with a week of bleeding during her menstrual cycle? She does not cope with pain and will not take any medication unless it is administered by force. How do I ease her discomfort during menstruation, when forcing her to take medication is near impossible and brings with it unimaginable emotional distress for her and me? Is my daughter not entitled to a quality of life that is free from pain and bleeding that she does not understand and never will? Where are my rights as her Mother, to give my child/adult child a quality of life that is, in her eyes, as comfortable and uncomplicated as humanly possible.

As much as I admire advocates of women with disabilities, I am strongly opposed to many of the views on this issue. Many of those advocating for the banning of sterilisation of women with disabilities either do not have an intellectual disability and/or are not caring for a child with an intellectual disability. Each individual’s capacity to raise a child of their own is what needs to be looked at here. One comment from a well known figure within the disability advocacy sector states that “sterilisation of disabled people only happens to women", and that this makes it clear it is to do with a woman's sexuality. "For women with a disability it's seen [that] sexual impulses need to be regulated." This latter comment makes me wonder exactly what this person’s agenda really is here. My opinion on this matter has nothing to do with my daughters “sexuality” but everything to do with my daughters right to live her life as comfortable and stress free as possible, to keep her life within “her” realms of control, within “her” understanding. And as her parent it is my responsibility to make every effort to ensure that society does not impose on my child “its” own values and beliefs pertaining to what “it” deems as right for her.

Every child/adult has the right to not have society impose and thrust "their" beliefs upon them, more so, a child/adult with an intellectual disability who does not have the cognitive capacity to make their own choices. Is it wrong to assist "my" child to lessen her struggles of daily life? Is it okay for society to impose standards that compound and complicate them?

I wonder how many of those who oppose sterilisation of women with disabilities actually work with “Parents” who have an intellectual disability. I do. And if those in opposition know the numbers of children who are in state care because they were brought into this world by an intellectually disabled mother and often disabled father who cannot take care of them? I do. Have they considered the “traumatic” emotional and physical impact that bearing a child has on a woman with an intellectual disability and/or of having that child removed from their care? I have. Have they considered the traumatic impact that this has on the children who have to be removed from their parents and placed in state care? I have. Do they know the happiness and contentment of an intellectually and physically impaired adult - that having been sterilised at the age of 18, now living an independent, sexually active and fulfilled life with her intellectually impaired husband free from the responsibility of children whose emotional needs they are incapable of meeting? I do.

Every female has a soul - a spirit - worth, strength and a purpose that way surpasses their ability to bare children. If my daughter was not born with a womb, does this stop her from reaching her full potential as a human being? If my daughter never has a period, does this affect her reaching her full potential as a human being?

I believe that every individual has a right to make decisions that will impact their life and well- being. However, my daughter cannot and never will have this right because she does not have the intellectual capacity that allows for it. So putting this in the correct context, to what extent does society propose that I need to consult a professional person when it comes to making decisions that will impact on my daughter’s life and well-being? Is this just an issue of her bodily functions and if so, why is this so? Should society not be jumping up and down when my daughter can’t access appropriate out of school care, within main stream schools, enabling her to enjoy the benefits of social interactions and stimulation with children both age and ability appropriate? Should society not be jumping up and down when my daughter can’t find employment? Should society not be jumping up and down when the only way that my daughter can access all of the services that she needs, is by being placed in state care? Should society not be asking to have some input into her choice of partner? Her choice of food? Her choice of medical advice? Don't all of these factors impact on her life and well-being?

Every child has the right to equality, access and opportunity- to reach their full potential. In fact that is exactly what we want for our children, but we must bring that to their understanding, not ours. What this means for “your” child is not necessarily what it means for mine. The question needs to be - what does my daughter view as equality, access and opportunity? Not what does society view as equality, access and opportunity for my daughter.

I don’t attest to having all of the answers, but I do know my beautiful daughter and I know her struggles in life, I know her limitations and strengths. I know that my daughter does not need to have a womb in order to fulfil her full potential. Anyone who suggests otherwise that does not know my daughter, is arguing that point based on their own limited understanding. Personally, I am not wanting or seeking to have my daughter sterilised. There are surgical – “reversible” contraception options that will suffice however, at this point I do not know how her body will react to these or any type of contraception for that matter. Therefore we may need to look at sterilisation at some point however, I do not believe that anyone has the right to take this decision out of our hands or the hands of any family who has the sole care of a child/adult with a significant intellectual impairment and has their best interests at heart.

I have heard during many conversations around this issue that "parents of children with disabilities need more support" but I am yet to hear what that support might be regarding my daughters monthly cycle. In addition I have heard that parents with intellectual disabilities need support and to this I say YES they do!! However, although we have come a long way in the disability sector in Australia, we still fall a long way short of giving those with any form of high needs disability the intense one on one support that many of them need to function in daily life.

This argument undermines every parent who has a child/adult with an intellectual impairment, by undermining and ignoring the child’s specific, intricate and very unique needs and the parent’s capabilities of assisting their child to meet those needs. This is far from a human rights issue. It is a daily occurrence for woman all over the world to make an informed decision to have a hysterectomy; it’s a choice that is made in conjunction with professional medical guidance. Unfortunately my daughter will never have the cognitive capacity to make such a choice. Every day I am making choices for my daughter – not choices I want to make but choices that are in “her” best interest. I choose to send her to a Specialist

School because she cannot cope within main stream school. I choose to send her to a specialised after school program because main stream is not equipped to cater to her specific needs. I choose to send her to a dance school specifically formed for children with disability because typical dance schools are not within her capabilities/needs. I choose for her to have dental work done under general anaesthetic and to have teeth pulled, that my other children would cope with keeping, because she does not cope with the pain of tooth ache and will not take medication if she is in pain. Even in the case of a severely abscessed tooth she has refused medication. Every choice I make for my child is made with careful consideration and often is not the one I want to be making for her but it's not about me – it's all about her - her comfort, her ease, her peace. The same goes when it comes to her fertility. Just as every other choice in my child's life has been made with informed, careful, loving consideration, by me and the professionals involved, so too would be a decision regarding her fertility.

The objective of my submission to this inquiry is, to create awareness amongst those who oppose sterilisation of women with an intellectual disability of the importance of free and uninhibited access to suitable contraception or sterilisation for young adults with a disability, as deemed appropriate by the parent / guardian and medical professionals involved.

This submission is written for my amazingly beautiful 12 year old daughter, who has diminished cognitive and adaptive development and struggles to perform simple everyday tasks. When she begins menstruation and/or in the event she should fall pregnant, I ask the enquiry to consider the significant traumatic effects that this would have on her and why one would want to subject my daughter to such affects when they are simply avoidable.

Yours faithfully,