

Submission to the Senate Inquiry into the Sterilisation of people with Disabilities.

11th October 2012

To the Senate Inquiry

I am writing this submission particularly as this question impacts greatly on my family.

I have a twenty-seven year old intellectually disabled daughter, who is now living independently in the community.

Something I thought was not possible has happened. My daughter is in a unit out in the community and has developed a life of independence, yet still within a bubble of support. It is through this network of support that she survives in this world – it is a group of people who have put their hands up to say we will accept responsibility for this person in our community.

So my daughter's bills are paid, she has food and can clean her clothes (although now I acknowledge there are many new shades of white). She has a carer come in to help, mainly to touch base, see if she has problems that might need addressing.

It is a responsibility we have taken on, just on the chance that maybe all the unhappiness she was experiencing was because she needed independence just like normal people her age. Well it has paid off. This 27 yr old woman has developed a life for herself beyond any that I could have dreamed for her. Instead of wandering from room to room staring out the window, she now has a life. She is experiencing what other people experience, and in doing so is thinking more and being challenged towards growth. Part of that growth has included the acquisition of a boyfriend.

Fortunately for all concerned my daughter had a Mirena (contraception) device implanted four years ago due to her inability to manage her periods. So the solution for one problem has in fact been the answer to the problem of falling pregnant.

All these transitions have caused me great anxiety, and yet propelled me towards questioning why – what is it that is behind all this anxiety?

The answers I have come to sit with I will now share with you. I have put them in dot point for easier reading, and hopefully they provide clarity and insight from a parent's perspective.

- It has taken me many years to openly accept and acknowledge how difficult it has been for me to reach this point. As I would not make this decision for any other person I have struggled with my right to make it for my disabled child. So with much thought, agonising and honesty it is with powerful conviction that I hereby claim “NO, My disabled daughter should never have a child”
- What has led me to this conclusion? **Her own life is not stable enough to support another life.** Advocates who say she has the “right” to have a child need to factor in her ability to be RESPONSIBLE for that child.
- The reality is if this person had a child, that child would be dead within a week. Human services would have to be involved.

- Bearing a child, and giving birth to a child, would be traumatic experiences for my daughter. She rings me or other family members every time she bumps her knee or gets a scratch, so I cannot even fathom the mental trauma childbirth would induce for her.
- So traumatic would be this event that I firmly believe no services or supports put in place after the event would help restore her spirit or loss of self.
- A child born to my daughter would have limited life and prospects.
- Care for this child would have to be picked up by others. I have a well-developed sense of responsibility – I guess I always have and always will. So if my daughter did have a child, I would be the person most likely to make sure mother, baby and all are as well as can be.
- **But at this point I have choice, and I am stating emphatically**, that at my age (fifty-four years), **I do not want to rear a child.** I have reared three children, loved them and given them as much direction, support and caring as possible. And it was all done when age appropriate.
- I do not dare to tell any one of you on the Senate Inquiry committee how to live your lives, yet the direction of my life is somewhat under the direction of the findings and outcomes determined by others.
- Leaving this vulnerable woman without sterilisation is now what I would consider negligent. The possibility of someone experiencing trauma when unnecessary is negligent, it is a severe denial of compassion, responsibility and duty of care.
- I understand that not all cases are the same, and I hope you understand not all cases are the same.
- Denial or disregard of my voice is what creates a lot of my anxiety. The catch cry of all parents of a child with a disability is **“What will happen to my child when I die?”** I hear it and think it often.
- Sterilisation of my daughter is one thing that I can ensure for her before I die, otherwise who will? I feel like it is being proactive rather than reactive. Whilst her caring doctor and I could make it as comfortable experience as possible now, why would we wait until tragedy strikes and then in hindsight wish things had been different.
- I finish with the important point that led me to find my voice. I believe that we all assume that we have rights, and fortunately we are born to a country which encourages and supports this belief. Yet humanity decrees that with rights comes responsibility. If we assume rights without responsibility we are simply loose cannons on a path only concerned about self, and not mindful at all of the impact we have on others we share this world with.

Thankyou for your time and consideration of this submission. It is important for me that I be heard, not only for my daughter, but for all the other people with disabilities who have no parent to speak on their behalf.