12 March 2013

Senate Community Affairs Committee Inquiry into the Involuntary and Coerced Sterilisation of People with Disabilities in Australia

Thank you for accepting this submission regarding the above Inquiry. We write as the parents of a 33 year old daughter with moderate intellectual disability, and we have read the UN Convention on the Rights of Persons with Disabilities along with the NSW Disability Services Act 1993 and the Guardianship Act 1987, particularly with respect to "Special Medical Treatment – Hysterectomy or Endometrial Ablation". We believe the current laws make it extremely difficult for any young woman with moderate or severe intellectual disability to obtain permission for a Hysterectomy or Endometrial Ablation and the current laws do not differentiate clearly between physical and intellectual disability in this area. Most women with mild intellectual disability can cope with menstruation and would probably also be able to give informed consent for a hysterectomy if there were a medical indication. Also women with a profound intellectual disability generally have 24 hour care and menstruation is managed by carers but with women with moderate to severe intellectual disability major problems can arise. There are many moderate to severe intellectually disabled women who are extremely distressed due to their inability to cope with menstruation leading to loss of dignity In addition there are the ongoing worries regarding sexual abuse and the possibility of pregnancy. A number of such disabled women have an aversion to menstruation and the

sight of blood and are unable to independently cope with menstrual pads, etc. Some of these women are unable to attend supported employment (Sheltered Workshops) or attend respite weekends or camps or stay overnight at an intellectually disabled friend's house, during menstruation. We are aware of a number of instances where an intellectually disabled woman has remained in the bathroom at the supported employment with blood over her clothes, due to the onset of menstruation. Our own daughter used to wake up in the middle of the night the week prior to camps and the likes worried if she was going to have a period that weekend.
After years of showing her how to cope with menstruation she never did
Consequently, there can be a significant reduction in quality of life and thus damage to the person's emotional or psychological health.

The NSW Disability Services Act 1993 outlines relevant principles with respect to people with disabilities, including:-

1. Have the right to live in and be part of the community
2. Have the right to realise their individual capacity for physical, social, emotional and intellectual development
3. Have the same right as other members of Australian society to services which will support their attaining a reasonable quality of life
4. Have the right to protection from neglect, abuse and exploitation.

These principles are consistent with the UN Convention on the Rights of Persons with Disabilities.

We have met so many friends who desperately wanted to help their daughter but were Refused by the Guardianship Tribunal They talked of the experience as horrific and when we were contemplating approaching the Guardianship Tribunal for our daughter we were told it was futile exercise and not worth the heartache

We know of friends who in desperation have taken their daughter to India one to Thailand and another to New Zealand for hysterectomies after being refused here by the Guardianship Tribunal

For a country that is allegedly as caring and compassionate as Australia to have citizens undertaking such trips strongly suggests that the current situation is far from ideal and we believe that significantly greater flexibility needs to be demonstrated in our legal system and by bodies such as the Guardianship Tribunal when deliberating on applications.

We are aware that the Inquiry is into "The Involuntary and Coerced Sterilisation of People with Disabilities in Australia" and that hysterectomy, by definition, causes sterilisation. We would like to reiterate that this submission specifically relates to women with moderate or severe intellectual disability who have no concept regarding menstruation or how to apply sanitary pads, etc. However, we strongly believe that any caring and compassionate person would understand that there are circumstances where a hysterectomy, performed to prevent serious psychological damage and not primarily because of sterilisation, would be the most appropriate intervention for these women. This approach is consistent with the principals of the UN Convention on the Rights of Persons with Disabilities.

Sincerely