SENATE INQUIRY INTO THE INVOLUNTARY AND COERCED STERILISATION OF PEOPLE WITH DISABILITIES

We recently watched a recording of last Tuesday's Insight broadcast concerning motherhood in disabled people. We were surprised to learn that audience participants John and Merren Carter received permission for a hysterectomy for their moderate to severely intellectually disabled daughter, as we believed that such approvals are exceedingly rare. We also learned of the Senate Inquiry into coerced or involuntary sterilisation. Following our enquiry to the Senate office on Monday 29 April we were invited to forward a submission, which we make on behalf of our daughter, who feels unable to involve herself in what she believes will be yet another unfair outcome.

In 2001 our daughter was refused permission by the Tasmanian Guardianship Board (the Board) for a hysterectomy for our profoundly intellectually disabled now 22 year old granddaughter, who is non verbal, bowel incontinent, self harms when distressed and requires 24 hour care. On the onset of menstruation two types of oral contraceptive failed to manage bleeding, one being accompanied by increased episodes of self harming and other side effects. This experience convinced our daughter, (she had been seriously been considering the Mirena insert), only hysterectomy could reliably solve our granddaughter's problems.

Our daughter made a second application to the Board in 2004. This second hearing seemed to us to be a "show" hearing to justify an already decided outcome. Our daughter invited Board members to spend some time with the family to see for themselves the problems associated with a profound intellectual disability, but this offer was declined. One of us (RA) attended the hearing, along with our daughter and her husband and we all found this a most humiliating experience.

We were again surprised to find a submission by Sydney University Professor of Medicine John Carter AO, a person who would be best placed to present an effective case to a Guardianship Board. In his submission Professor Carter discloses that alternatives to hysterectomy cannot guarantee cessation of blood loss, carry serious medical risks, and do not provide the long-term security that any caring parent could reasonably expect for their daughter. We therefore believe our daughter's second request for a hysterectomy because of the unsuitability of alternatives was fully justified .

I bring to attention John Carter's Insight appearance where he stresses the importance of recognising degrees of intellectual disability. The Carters' successful Guardianship Board application appears to be based on the problems associated with a moderate to severe intellectual disability. Our granddaughter has a profound intellectual disability, which arguably makes the terms "coerced" or "involuntary" meaningless. We suggest Guardianship Boards are inappropriate instruments to deal with applications for hysterectomies associated with profound intellectual disabilities.

We hope the Commitee fully recognises that caring and loving parents request hysterectomies only after many years of loving care and careful consideration. We therefore propose that, in cases of established mental incapacity, decisions are best made by proven responsible and caring parents and their doctors.

Robert A and Patricia A Greenfield

Attached: Insight.mp4 - 3 Min video of John and Merren Carters' Insight appearance.