

Our submission is written from the viewpoint of parents and grandparents of intellectually disabled girls.

Our daughter had always been classified as “a slow learner’ without any particular diagnosis. We thought it to be in her best interest that she be unable to have any children of her own. She was barely able to care for herself let alone have the responsibility of a child. Medical advice that was sought at the time offered the use of the contraceptive pill. The doctor told us after a 5 minute interview with her “That she knows all about sex!” and the pill was all that he could offer.

Sometime later, despite our best efforts to ensure that she did have the contraceptive pill as prescribed, she did fall pregnant and delivered a seriously ill baby girl. This child required urgent heart surgery and many months in hospital after birth. Further heart surgery was required at 9 months and 6 years of age.

By now medicine had advanced and the child’s illness, as well as the mother’s, was able to be diagnosed. They both have a genetic illness that becomes progressively worse with each generation. The mother’s disease was apparently caused by a genetic mutation.

As suspected the mother was unable to care for the child so the responsibility for this fell to my husband and me following a 4 year protracted court case.

The doctors have advised that the odds of this disease being passed on are 50 – 50. Even if our granddaughter was able to carry a child full term, it is very possible that the child would not survive and the mother’s health would be severely jeopardised.

If permanent sterilisation is not available is it to be our choice for her to have a pregnancy with all the risks involved, have an amniocentesis and then decide if termination is an option?

This is too much to expect from a young woman who is unable to care for herself. Yes, she may be able to walk, feed and clothe herself but has no understanding of the effects that a pregnancy would have on her own body and that of her child.

This disease has left her not only with cardiac problems, as well as an intellectual disability. She is also very vulnerable and someone could easily take advantage of her. In her world, everything is beautiful and she has no responsibility.

It has been reported that “health care costs of between \$300,000 and \$2.5 millions are spent on one individual with fragile X during a lifetime.” (Daily Telegraph 16th October 2012)

This could easily be repeated for this genetic condition.

We are of retirement age and do not wish to pass onto any family member the responsibility of caring for another child.

Yes governments can say that support is offered to families such as our but our experience is different. Support has been hard to find, if at all.

We understand that each case is individual and would like to see this recognised in law. Parents and carers know the child better than anyone else and only want what is best for that child.

A 5 minute consultation with a doctor does not take all facts into consideration nor should a law that tries to cover every possibility.