

REPORT TO SENATE ENQUIRY REGARDING THE STERILISING OF DISABLED FEMALES

SUBMISSION

I am writing this as a concerned grandmother to a 15 year old girl who was born with profound intellectual disabilities. I have always been closely involved with the family and am passionate about the future wellbeing of our young girl as well as the physical and emotional toll taken on her primary carers. Our girl will always be unable to protect herself from harm, and cannot verbalise any intrusion upon her person.

FAMILY BACKGROUND

M. was born in 1997, the second in a family of two children. Her brother, two years older, ironically, is intellectually gifted. Her father has, over many years, experienced serious health issues, that have necessitated long periods of hospitalisation and longer periods of being unable to work. The mother has often struggled to cope with the many demands thrust upon them. As grandparents, my husband and myself have been called upon many times in family emergencies; such times we have only been too willing to help. We are now in our 70s.

This is the family situation, a family that has had just about everything imaginable thrown at them over a period of time.

ABOUT M

M was born by C-section, unusually small at birth, despite the fact that she was full term. Her first few months were unbelievably traumatic for both baby and family. There were feeding difficulties from the time of her birth, reflux pain, and a lack of reaction to the world around her. Night-times were a nightmare for the family when reflux afflicted her and protracted screaming happened.

At around 3 months the truth dawned that there was a serious problem, and disability was later confirmed by her paediatrician: after significant testing, she was categorised) with a level 6 Intellectual Impairment – the highest rating in this country.

Despite the intense grief felt throughout the family, life had to go on: therapy, medical appointments, and sleepless nights continued, leaving the parents worn down. They had no idea what lay ahead of them. M walked at 4 years, was non verbal, and at 5 attended a Special School.

The mother experienced frequent migraines, both parents experienced depression, and M's brother showed signs of stress, developing nervous tics and depression. During this period the father was hospitalized several times, which added to their burdens.

TODAY

M's physical development is slow: she has not yet started menstruating (though this is doubtless imminent) and the prospect of this causes her parents great anxiety. As a happy, socialized child, M is still mostly non-verbal, requires spoon feeding of pureed foods due to oral hypersensitivity and requires assistance with all aspects of personal care. Having no awareness of safety or stranger danger, she has a variety of (female only) carers coming and going to assist with her care. Sadly she is unable to express her experiences – both positive and negative – about her day at school.

She has not yet successfully been toilet trained and therefore always wears nappies. One of the difficulties encountered by the family is her tendency to “fingerpaint” or smear the contents of her nappy at the most inopportune times and places.

From this picture, you can imagine further problems when menstruation commences. Doubtless her older brother will also find this time difficult as he deals with his own adulthood.

THE FUTURE

The family dread her approaching menarche for countless reasons. Firstly, with M being more or less non-verbal, communication of a source of pain is impossible; thus symptoms such as stomach cramps would be difficult to manage.

The taking of tablets to either reduce pain or prevent periods is physically impossible for her due her oral hypersensitivity and resultant food refusal.

The other options presently legally available to manage M's upcoming menstruation are not suitable for M: regular needles, tablets or 5 yearly surgical implants are not viable.

M's right to remain fertile is not one that could in any way be communicated to, or understood by her, let alone decided by her. Her mother necessarily has to be her advocate in everything. M's life is currently very simple and happy, revolving around childish pleasurable activities.

As regards the physical possibility of childbearing, M's daily kilojoule intake with nutritional supplements is barely enough to sustain her alone, let alone a growing foetus. At 15, she currently weighs 44kgs. Childbearing could be impossible or even dangerous to her own life, and giving birth, even if it were possible, would be a risky procedure. She would have absolutely no capacity, physically or emotionally, to become a mother, thus an extra burden would be laid at the feet of the parents or the state.

There are enormous concerns regarding the possibility of M being abused at some future date. At 18 when she finishes at Special School, the parents have little idea what lies ahead for them or M, nor how to manage any unknown risks that may be "out there" for their daughter.

WHAT WE WANT FOR M

- Her safety and wellbeing are our primary demand.
- Presently M is happy, and enjoys a stable family life. The home is loving and full of laughter, despite the challenges that exist.

- We want this to remain the status quo for as long as possible, not knowing what is further down the track in M's life.
- The parents are the only ones responsible for M's well-being; their wisdom to decide what is right for her is proven and their decisions should be the only ones that are relevant to M's management. With help, they have done extremely well over the last 15 years. We want the Commission to understand and empathise with this family scenario
- We feel that no-one has the right to dictate a path which could well jeopardize our girl's health. M's own medical team, we know, have empathised with us, but their hands are tied by those who "Know not what they do".
- We want her medical team to be empowered to authorise the required procedure, knowing that it is right, humane and appropriate.
- We want the parents to rest easy in knowing they have always done the right thing by their daughter, and not have to face any guilt insinuated upon them.

WHAT WE DON'T WANT

- We don't want to have to take M overseas to get what we know to be the best outcome for her. Travel by aircraft would cause extreme stress for her and discomfort for other passengers; however, if we must, it may have to happen.
- We don't need judgment, or decisions regarding M's future from those who have no intimate knowledge or experience of our situation and others in the same situation.

HUMAN RIGHTS

In my simple understanding, the term "human rights" concerns the well-being of humans whatever their status, and empathy with human experience. To put more value in a healthy, yet unused, organ, to the emotional, physical and relational detriment of an extended family and community seems misplaced. Whilst I do not think the sterilisation of disabled females should be routine, I do

believe that in circumstances like I have described, the process should be readily available with medical recommendation and primary-carer advocacy. These decisions should not rest in the hands of a tribunal whom have no intimate knowledge of the family circumstances.

This is my submission, and it concerns my personal experience as a grandparent and parent. I am certain there will be many other families who experience what has been written here and feel as passionate as I do about safety and wellbeing for vulnerable girls and women and the constant anxiety endured every day by their carers.