We are the parents of a profoundly Intellectually Impaired 15 year old girl. She was assessed to have a category 6 intellectual impairment with a lower physical impairment rating.

To date, despite the ongoing emotional and physical fatigue associated with caring for our daughter, we have regularly been encouraged by friends and family that we are doing a sensational job balancing the specific needs of our daughter with the other pressing needs of family members.

We welcome the opportunity to submit our views to the committee.

Our Daughter's Profile

As a generally content and happy girl, our daughter enjoys the simple activities of a three or four year old child.

She has very little safety awareness – fire, road, heights, stranger danger, sharp objects or managing in crowds.

Mostly non-verbal, communication is generally pointing, single words or the use of communication cards. Great improvements have been made in this area over the last couple of years, but mostly, others outside of close family or teachers find her difficult to understand. She does not comprehend anything more than simple one-step instructions (e.g. put your hat away, or sit down please).

Our daughter can walk with limited assistance on stable surfaces and regularly absconds if left unattended – even if for only a few seconds.

Underweight, (less that 45 kilograms) she is spoon fed like a baby and relies on nutritional supplements in the form of hospital-grade milks. She is hyper-sensitive orally and tactile intolerant. Due to her nature and the need to increase oral stimulation for speech, gastrostomy procedures were never enacted.

Completely incontinent, we have been intentionally working toward toilet success for about 4 years. She has 1-3 successes each week on average and is always in nappies.

She has not yet commenced menstruating. She currently smears the contents of her nappy if it is not changed immediately upon soiling. This, of course, she cannot communicate readily.

Due to extensive and unpleasant medical procedures in her early life, our daughter has a phobia of anything medical, leading to extreme screaming and uncontrollable behaviour. This extends beyond the normal crying associated with receiving an injection: even approaching a hospital building in the car leads to anxiety from about 5 kilometres away. General anaesthetics take a team of five or more adults to pin her down (remember, she is less than 45kg) to put a gas mask over her face. Her lack of co-operation is both physically and emotionally draining for family and medical personnel, evidenced by a recent nurse losing her "cool" and yelling out for our daughter to "shut up", despite us having warned the hospital staff in advance of the expected behaviour.

Managing Menstruation and Contraception

Several years ago, we commenced investigations with medical professionals about the options available to us to manage our daughter's upcoming menstruation. We consider ourselves to be well-informed and have a reasonable understanding of many of these options. We have attached a copy of most of a paper I (mum) prepared (for study purposes) endeavouring to address the ethical questions surrounding this issue, to demonstrate that we are speaking with an informed perspective, rather than out of a sense of desperation and passion. We are also aware of routine sterilisations occurring throughout history and the obvious desire of the western world to disassociate themselves from such barbaric acts.

We agree with a recent submission by Dr Sonia Grover that some parents who have not yet consulted with medical personnel, believe that the only option available is an hysterectomy. However, we wish for the committee to acknowledge that we do not fit into this category of people. There are also many others with whom we associate in the disabled world, who undertake extensive investigation and research before determining any medical procedure on their child. Recent media coverage has suggested that the majority of parents/carers ask for "straightout" hysterectomies.[1] We would suggest that at this initial point of enquiry to a doctor, the lack of familiarisation with the subject matter leads carers to ask this question. Naturally, one hopes that doctors then use this opportunity to inform potential patients of the other options available to them. Our personal desire is for our daughter to have an endometrial ablation with tubal ligation (a procedure that I – mum - have had with great success and very little discomfort).

We have independently approached the media about their willingness to follow our journey in getting this satisfactorily resolved for our daughter so that Australian families in the future will be better informed about what to expect and what might be available to them.

Our Desire for Australian Carers of the Disabled

We believe generally that the marginalised need to be protected. In relation to the disabled, we do not believe that the sterilisation of disabled females (or males) should be routine, nor should it be a ***very*** simple process. However, we would encourage the committee to acknowledge that if the process is not in some way legal and ***more easily*** accessible, this will encourage clandestine illegal and potentially dangerous medical practices to take place, either in this country, or overseas.

With regard to accessibility, at present it seems that the legal and the medical sectors don't always use terms and language that work harmoniously to enable access. Our understanding is that the medical sector requires "informed consent" before any medical procedure. This is obviously impossible for anyone who is so severely intellectually impaired as our daughter. Ironically, we also understand that when she turns 18, the legal sector empowers our daughter more than her carers, so that anyone who cares for her in a paid capacity cannot stop her from doing as she pleases (even if her actions are unhelpful or potentially dangerous) for their interference represents "deprivation of her liberty" – a liberty that she is not even aware of!

Whilst this is a slight diversion from sterilsation, the language needs to be addressed to reflect consistency in the legal, medical and caring sectors. This will enable a

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[1] Vince Chadwick , "Rush to sterilise mentally disabled horrifies doctor", Sydney Morning Herald, 2 January 2013, 4.

clearer navigation for carers, legal and medical professionals in the sterilisation discussion.

We submit to the committee that those who are charged with being responsible for the disabled person, namely parents or guardians, should have the support of the community to pursue a permanent solution to menstruation & contraception for their charge. By this, we mean that the stigma associated with even asking about sterilisation needs to be reduced.

Those who have not spent more than a couple of hours with anyone whose intellectual impairment is as severe as our daughter's, do not have a right to have their views published by the media more than the views of carers who have sacrificed dreams, time, energy, finances, careers and their own health over many years. We feel that the media need to be encouraged to paint the realistic picture of how devastating it can be to live with such disabled persons. Comments recently published in the Sydney Morning Herald are an example: Carolyn Frohmader, the executive director of Women with Disabilities Australia is quoted as questioning the Family Court's decision to proceed with a permanent sterilisation in 2010 – "How can you have your periods start at nine, admit that it is irregular but have tried, evaluated and failed every conceivable alternative within an eighteen-month period?"[2]

We ask the committee to acknowledge, firstly, that it should not be expected to try and evaluate "every conceivable alternative" for this is not only ludicrous, but not expected for any intellectually capable person before they can choose surgery. We secondly ask that the committee may realise that the inability to swallow any pill, for example, is a fair reason to eliminate all the available pills from the sterilisation "menu". We sympathise with the 2010 case and can easily see that an eighteen month period is considerably long enough to come to this conclusion if, as our daughter, the person in question is needle-, blood-, tactile- and hospital-phobic, leading to uncontrollable behaviour.

The committee must understand that these are individual cases where the medical personnel use their vast knowledge and experience, as well as common sense and

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[2] Ibid

compassion, to make an informed evaluation. Comments by organisational leaders who have no intimate knowledge of the case should be discouraged from making uninformed judgments to the potential detriment of others. Hence, our family has approached the media about this journey upon which we are embarking.

We further submit to the committee that the medical profession, rather than the legal profession, should have greater weight in this discussion. We believe that if two (or even three) specialists concur that a permanent procedure is in the best interests of the family situation (i.e. not just the intellectually impaired person, but the ability of the primary carers to continue to cope without instigating other arrangements that are not ideal), then this should be sufficient to endorse the procedure without any further interference from other bodies.

Please understand that families caring for the disabled do a great service for the country. It is in the country's financial interests to support these carers to be able to continue in this role. Where families are already exhausted and struggling to manage this role, the present difficulty associated with obtaining permanent sterilisation presents another risk to relinquishment. Having investigated the process of relinquishment several years ago in our desperation, we implore the committee to favour the protection of the family unit.

In closing, be it known that we are both willing to stand before the committee to present our testimony if this would be helpful, and we would appreciate the opportunity to do so.

It has been argued that the "grossly retarded" are less human in some way, and therefore do not command the same rights and respect as those who are not so disabled.[3] Clearly, those who are unable to care for, and express themselves, need a trustworthy advocate to promote their best interests. This paper considers the role of the parent/carer as trustworthy advocate of a severely intellectually impaired person, and the limit of their authority in decisions regarding permanent sterilisation for the person in their care. Specifically, this document will attempt to identify the issues awakened in response to the following question:

> ***Is it right or wrong that the Parent/Carer of a severely Intellectually Impaired Person should seek the permanent sterilisation of the person for whom they care?***

How do we define "Intellectually Impaired"?

Intellectually Impaired Persons[4] are assessed by a panel of experts[5] to ascertain their level of function. The resultant score then allocates a number ranging from one through to six: one being a mild impairment, six being an extreme impairment. These ratings are recognised by Government agencies, such as Centrelink, Medicare and the Public Guardian[6].

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[3] Glen H. Stassen and David P. Gushee, Kingdom Ethics (Downers Grove, Illinois: Inter-Varsity Press, 2003), 222.

[4] Herein referred to as IIP

[5] The panel is usually a multi-disciplinary team comprising medical and allied health professionals (e.g. physiotherapist, speech therapist, occupational therapist, psychologist, etc.) and teaching staff.

[6] The Public Guardian (also known as the Public Trustee in some states) was established to protect the rights and interests of those with disabilities through the practice of guardianship, advocacy and education.

To the uninformed, a person assessed to be II (Intellectual Impairment) 1 or 2 may be considered to have minor learning difficulties, but still capable of attending mainstream school and functioning in society with minimal support. Those assessed as II5 or II6 are in need of full time supported living and learning. Many are non-verbal, and also require physical assistance in personal care, mobility and transportation. This paper considers the authority of the parent/carer of a person assessed to be II5 or II6.

Why seek sterilisation of the Intellectually Impaired?

There are many reasons for seeking sterilisation for the intellectually impaired, including pain management for the menstruating female. Sexual safety is an obvious reason as these vulnerable people are relatively frequently the victims of sexual abuse.[7] The consequences of an "accidental" pregnancy for both the IIP and the parent/carer would be devastating, and potentially life-threatening for the IIP.

In the event that the pregnancy went to full term, the IIP would not be capable of caring for the child. In this situation, added burden would fall upon the parent/carer, or potentially the State, if the child were surrendered or forcibly removed by the State Department. In the more likely event that the IIP was

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[7] A benchmark study of sexual assault against people with an intellectual disability was prepared for the Women's Coordination Unit in New South Wales (Carmody 1990). The report acknowledges the difficulty in obtaining accurate statistics particularly since disability services rarely collect data on this issue.
However, in Victoria, nineteen agencies agreed to monitor their cases of alleged crimes against people with an intellectual disability for a three-month period. During that time, 144 alleged crimes were reported to agencies with 130 involving sexual offences. The researchers indicated that there was strong evidence of under-reporting of crimes by people with intellectual disabilities themselves and by workers. The data suggested strongly that sexual offences and physical assault were the most frequently recorded crimes against intellectually disabled people.
Susan Hayes, Sexual Violence Against Intellectually Disabled Victims (Australia: University of Sydney), 202, retrieved via Internet at http://www.aic.gov.au/publications/previous%20series/proceedings/1-27/~/media/publications/proceedings/20/hayes.ashx, accessed 3/8/10.

unable to physically or mentally manage the pregnancy, termination of the foetus would be considered, introducing another ethical dimension to this discussion.

Full time carers suffer physical, mental and emotional exhaustion in their role.[8] All have sacrificed personal hopes and dreams, and time and resources. The financial cost alone of raising a disabled child is potentially three times higher than for bringing up non-disabled children.[9] The associated grief these sacrifices bring, together with the effect upon other family relationships[10] leaves most carers susceptible to depression and stress.

To reduce this stress, sterilisation of the IIP in their care may be sought to more simply manage behaviour and personal care. This also has the effect of reducing the carer's sense of social isolation caused by the socially inappropriate behaviours and consequential management of the IIP.[11] Economic and timesaving benefits as well as genetic containment may also be factors in considering sterilisation of the IIP.

What types of sterilisation are available and what risks are apparent?

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[8] The National Survey of Carer Health and Wellbeing (2005) found that 59% of carers suffered a decline in physical health, two-thirds reported a negative impact on mental and emotional health most commonly seen in increased stress levels and disturbed or lost sleep, and one-third noted that they had been physically injured in their role of caring. Thirty per cent of carers reported that they found it difficult to undertake or delayed seeking medical treatment for themselves because of their caring roles. Sharyn Lymer, Richard Percival and Ann Harding, "The cost of caring in Australia 2002 to 2005 – Who Cares", National Centre for Social and Economic Modelling Report (Australia: AMP, 2006), 17.

[9] Madeleine Brindley, "High cost for a family raising a disabled child", Western Mail, 7/7/2005.

[10] Care-giving and the decision making process within this role can lead to competing caring roles and conflict amongst other family members.
Cathy Hales, "Crisis or Commotion? An objective look at evidence on caregiving in families" Family Matters, Australian Institute of Family Studies, 76 (2007), 21.

[11] For example, hormone-driven fluctuations in IIP behaviour can result in inappropriate, awkward or dangerous behaviour that prevents the carer from usual public contact.

"The most common forms of [permanent] sterilisations are tubal ligation[12], endometrial ablation with tubal ligation, endometrial ablation[13], hysterectomy[14] and ovariectomy[15] for women; and orchidectomy[16] and vasectomy for men."[17] Only hysterectomy, ovariectomy and orchidectomy remove sexual organs and are not medically considered "day" procedures.

More complicated medical procedures obviously have additional risks often due to the greater time required under anaesthesia. Removal of sexual organs (ovaries or testes) incurs greater side effects through the reduction of hormones produced in the patient. Consequently, these surgeries are not appropriate except in selected patients in whom there is a clear indication for them over and beyond the desire for sterilisation. The risk of complications following hysterectomy, for example, is greater than the risk of complications following tubal ligation, and therefore "hysterectomy should not be chosen as the most acceptable method of surgical sterilisation unless significant gynaecological disease or symptoms are present."[18]

There are many non-permanent contraceptive options for the intellectually impaired. These range from daily medication, quarterly injections, skin patches, male and female condoms, hormone implants and an array of devices needing to be fitted internally by a medical practitioner.[19] It must be

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[12] Tying or cauterising the fallopian tubes.

[13] Scraping the lining of the uterine wall to prevent monthly bleeding.

[14] Removing the uterus, and often ovaries.

[15] Removing the ovaries.

[16] Removing both testes.

[17] M. Jones and L. A. B. Marks, "Female and Disabled: A Human Rights Perspective on Law and Medicine", Intersections: Women on Law, Medicine and Technology, K. Peterson ed., (Dartmouth, 1997).

[18] J. Thompson & H. Birch, "Indications for Hysterectomy", Clinical Obstetrics and Gynaecology, 24:4 (1981), 1254.

[19] "Pros and Cons of Different Contraceptive Methods", Centre for Young Women's Health, retrieved

noted that the carer would be responsible for administering or arranging for these items to be applied to an IIP. If sterilisation for reasons other than contraception is required, the alternatives are greatly reduced.

Permanent versus non-permanent sterilisation

Whilst there are many non-permanent alternatives to prevent unwanted pregnancy, many of these are unsuitable for the IIP for a myriad of reasons. The scope of this document does not permit an extensive analysis of the pros and cons of each alternative. However, some obvious issues arise with non-permanent sterilisation:

Firstly, these are non-permanent measures. This means that for the life of the individual, a carer must ensure that the dose, injection or device is never missed. Depending on the alternative used, this may be a daily burden or a regular medical appointment requiring sedation. This responsibility adds to the strain upon carers.

Secondly, many of these methods are equally, or more invasive, than one-off surgery, over the course of the individual's lifetime. For those with a needle phobia, tactile intolerance (to skin patches), inability to swallow, or general negative behaviour expressed toward medical officers, (all of which are not uncommon amongst the disabled) a one-off procedure will result in reduced fear and interference. This is turn reduces ongoing behaviour challenges for the parent/carer to manage.

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via Internet at http://www.youngwomenshealth.org/prosandcons.html, accessed 30/7/10.

Thirdly, permanent solutions address concerns for the future care of the IIP when the parent/carer is no longer in a capacity to care – that is, succession caring. The increasing life expectancy of disabled family members arising from advances in medical and other services has had an impact upon aging parents. A permanent procedure reduces the worry associated in depending upon a future carer who may not be so vigilant in addressing sexual management.

Fourthly, the financial burden and time sacrificed for a lifetime of filling and administering prescriptions, in addition to the cost and time of doctor's appointments, is far greater than a once-in-a-lifetime surgical procedure.[20]

Fifthly, there are some things which permanent sterilisation can achieve more effectively than non-permanent sterilisation. For example, if pain and discomfort, or a blood-phobia, is a monthly routine for a female, many non-permanent contraceptive methods will not eliminate this.

Who has rights?

The question of who has rights is fundamental to any authority granted to one person over another. As the severely intellectually impaired cannot advocate for themselves, they are reliant upon the integrity of the parent/carer to act in their best interests. In the matter of permanent sterilisation should the IIP have rights to decide their sexual management, even if they don't understand them or can't express them? Or, should the parent/carer, as the approved

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[20] Consider a single monthly prescription (assuming a Health Care Card enables Government subsidised scripts) is $64.80 per annum. Over the course of even only forty years, the expense is in excess of $2500 (in 2010 values), before any doctor's fees, travel or time expenses are taken into account.

advocate, have the right to make such decisions for the IIP? Or thirdly, should the community of "experts" have greater rights over the IIP's sexual management?

Clearly, an individual assessed as II5 or II6 will not have the ability to offer the informed consent necessary for surgical procedures. Hence, this discussion then diverts to the extent of the parent/carer's authority over the IIP as compared with community "experts". At present, in Australia, parental or carer authority does not extend to special medical procedures like sterilisation, for only a court has that authority.[21]

For minors, the Family Court in Australia exercises its welfare jurisdiction under the Family Law Act. A single judge, who is appointed to the Family Court for life, hears the application for sterilisation.[22] For those with adult children, Guardianship Tribunal authority is required. The tribunals are not constitutionally protected like the Family Court. They comprise people from multi-disciplinary backgrounds with experience in disability issues. The State Government appoints members to the Tribunal for a fixed term, usually three years.[23]

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[21] Susan Brady, John Briton and Sonia Grover, The Sterilisation of Young Women, retrieved via Internet access, http://www.hreoc.gov.au/disability_rights/sterilisation/sterilisation_report.pdf, accessed 3/8/10.

[22] Ibid.

[23] It is a requirement that applications for sterilisation are heard by a minimum of three people at least one being a woman. Each panel comprises a chair person who is a lawyer versed in human rights law, a professional member, usually a doctor, and a 'community' member with a social science background or direct disability experience as person with disability or as an advocate or carer. Some board members have both a professional background and personal experience.
Ibid.

The Judge or Tribunal hears arguments on the benefits or detriments of a sterilisation procedure. The underlying rationale is always the welfare of the IIP and their right to bodily integrity.[24] This is not the case in all western nations.[25] As an indicator, courts and tribunals in Australia authorised seventeen female sterilisations in a nine-year period. In this same period, the Health Insurance Commission reported 1045 girls had been sterilised with Medicare rebates claimed.[26] The most recent approval in Queensland this year was interestingly received with mixed reactions from disability groups, contending an abuse of human rights.[27] Apart from the legal and political issues arising from these statistics, this indicates that the need for medical sterilisation is certainly a social concern that requires further discussion.

Ultimately, when the medical and legal "experts" make a decision for the IIP, they are inadvertently having a profound influence in the parent's/carer's lives. As two marginalised groups then, the question is raised then whether the right of the carer to have a certain quality of life is equal to, or greater than, the right of the IIP to retain bodily integrity. Further, do the Courts and Tribunals have the right to determine this? A discussion of rights often asserts selfishness. Yet with rights also comes duty and responsibility. It is often in duty and responsibility that the carer's world is out of equilibrium.

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[24] Ibid.

[25] For example, in 1991, the New Zealand case, Re X11, 2 NZLR 365, authorised sterilisation of a prepubescent girl with severe, multiple disabilities, based principally on her carer's capacity to cope with her menstruation.
Jones & Marks.

[26] S. M. Brady and S. Grover, The Sterilisation of Girls and Young Women in Australia (Australia: HREOC, 1997).

[27] Caroline Overington, "Family court lets couple sterilise disabled daughter", The Australian, 9/3/10, retrieved via Internet at http://www.news.com.au/national/family-court-lets-couple-sterilise-disabled-daughter/story-e6frfkvr-1225838469430, accessed 9/3/10.

To remove the involvement of the judicial system and solely enable the parent/carer to authorise permanent sterilisation of their charge is potentially to subject IIPs to abuse. For if a parent/carer does not have the best interests of their IIP at the heart of any decision, the IIP is powerless to defend themselves. Furthermore, if permanent sterilisation is parentally authorised, how might this contribute to the legislative and social equality of disabled persons in other issues?

The greater impact of such authority must be considered, for if something should go wrong or power is abused, what are the consequences and who will be accountable? Clearly, some involvement of medical and social experts is necessary to regulate the usage of permanent sterilisation. However, the issues pertaining to the wellbeing of the parent/carer must be given more consideration in the Australian court system than is currently held.

Conclusions

There is extensive recognition of the valuable role parents/carers have to both an IIP and the broader community.[28] Government-funded support to assist the parent/carer in their role is often available in the form of pensions, limited respite services and access to medical assistance. The area of managing sexuality amongst the disabled, however, has very little support or clarity.

Clearly, the rights of the IIP must be safeguarded. Yet, insufficient support and counselling to carers in this area may result in forfeiture of their role. The

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[28] For example, National Carer's Week, and numerous Government and Private Sector reports acknowledging the economic and social impact of carers: See the Australian Institute of Families resources on caring at http://www.aifs.gov.au/afrc/bibs/carers.html.

consequence of this would be broken familial relationships as well as increased economic burden on the Government. Ultimately, a careful balance of supports is essential to enable the parent/carer to manage well.

Sterilisation of the disabled has attracted great public outcry in the past, and continues to do so. There is presently, however, no clear pathway forward to permanently address the dilemmas of sexual management in the severely intellectually impaired. Further research needs to be conducted on suitable options for addressing the needs of both the carer and the intellectually impaired person in their care. Any change to policy must bear compassion toward both parties of greater significance than legal simplicity.

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