Queensland Advocacy Incorporated
Systems and Legal Advocacy for vulnerable people with Disability

Our Mission: To promote, protect and defend, through advocacy, the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland.

SENATE STANDING COMMITTEE ON COMMUNITY AFFAIRS

SUBMISSION TO INQUIRY

The involuntary or coerced sterilisation of people with disabilities in Australia

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QAI endorses the objectives, and promotes the principles, of the Convention on the Rights of Persons with Disabilities.
Patron: Her Excellency, Ms Penelope Wensley, AC Governor of Queensland

Queensland Advocacy Incorporated (QAI) is a community-based advocacy organisation that has for the last twenty-five years campaigned for the rights of vulnerable people with disability in Queensland.

We acknowledge and support the joint submission made earlier to this enquiry by the Queensland Centre for Intellectual and Developmental Disabilty, Queenslanders with Disabilities Network and Queensland Advocacy Incorporated.

To further submit information to the inquiry we offer the following from our Policy and Procedures manual section 3.6 Sterlisaiton of People with disability (udne rthe section Systemic Abuse and Oppression. The following areoour key points:-

1. Sterilisation should never be performed for eugenic reasons1, for purely contraceptive reasons, to conceal sexual abuse, for control of menstruation or control of masturbation, sexual expression or "challenging behaviour", or on the basis of disability alone.

2. Sterilisation is a permanent, invasive and risky medical procedure – with lifelong consequences. Due to the serious consequences of this procedure, it is important that legal safeguards are in place in order to protect the fundamental right to bodily integrity for people with disability.

3. Sterilisation should never be performed on a discriminatory basis and should only be considered as a "last resort". Therefore, we suggest that a combination of tests should be satisfied, before a sterilisation can be authorised. These include: a test of "last resort", a test of "but for" (i.e. not discriminate on the basis of disability), a test that the procedure is "in the best interests of the person with disability" (rather than other stakeholders), and that decision-making is also guided by a principle of "least restrictive alternative".

4. The sterilisation of children raises particular alarm. It is unlikely to ever be an appropriate procedure to be performed on a child (except to preserve life) and most particularly on a child prior to puberty – in anticipation of difficulties. Any application to authorise sterilisation of a child should involve extremely rigorous examination of all evidence to ensure that all available alternatives have been trialled.

5. People with disability and their families have the right to adequate supports, and specialist information and resources to support their family member. Where families seek court/tribunal authorisation of sterilisation, the processes used must be respectful of family relationships.

6. Historically, the forced sterilisation of people with disability for eugenic reasons has constituted an unacceptable abuse of the human rights of people with disability. While sterilisation may in very rare circumstances be justified as an act of last resort, the potential for this to be abused and the fact that sterilisation overrides a woman's right to bodily integrity demands stringent safeguards.

7. Government and others must act to ensure that the rights of people with disability are adequately protected

The policy document is attached for more complete reading and to give context to this list of key points.

Yours sincerely,

BYRON ALBURY

PRESIDENT

QAI is an independent, community-based, systems and legal advocacy organisation for vulnerable people with disability in Queensland. Our mission is to promote and protect the fundamental rights of these people, and we have pursued this mission vigorously for 25 years.

> "The power to authorise sterilisation is so awesome, its exercise is so open to abuse, and the consequences of its exercise are generally so irreversible that guidelines if not rules should be prescribed to govern it" [Brennan J, Secretary Department of Health & Community Services v. JWB and SMB (1992) FLC 92 193
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> (Marion's Case)].
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> "Sterilisation in the absence of malfunction or disease may sometimes be the option of genuine last resort, but this too is a rare occurrence. There are almost always less invasive alternatives of both medical and non-medical kinds, and they work with few
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> exceptions. The sterilisations of the vast majority were unlawful because without any doubt alternative and less invasive options had not been exhausted … The law has failed to protect significant numbers of children from significant abuse of their fundamental right to bodily integrity" (Brady and Grover 1997:58-59).

Queensland Advocacy Incorporated (QAI) believes that the continuing sterilisation of people with disability – often without legal authorization – is a matter of grave public concern and a practice which potentially threatens the rights and equal standing of people with disability.

The following position statement relates to children with disability and adults with decision-making incapacity who are unable to give consent. It addresses situations where sterilisation is requested or performed for reasons other than genuine life-threatening disease, illness or medical emergency. Many of the principles suggested in this policy are also relevant to people with disability that have capacity to give consent. Our policy position in these circumstances is that the decision to have a sterilisation procedure should be a fully informed one and not subject to any coercion, pressure or discriminatory assumptions.

QAI Believes

People with disability are people first – fully human, with the same fundamental rights, needs, and desires as other human beings. For this reason, sterilisation without consent of the individual needs to be understood as a very grave undertaking.

Sterilisation should never be performed for eugenic reasons1, for purely contraceptive reasons, to conceal sexual abuse, for control of menstruation or control of masturbation, sexual expression or "challenging behaviour", or on the basis of disability alone.

People with disability deserve support and legal protection in order to live full lives, fulfil their potential and access the goods of society – including equal rights. People with disability have the right to express themselves sexually, to live free from abuse and exploitation, to have support to become good parents, to assistance with menstrual management, to access contraception appropriate to their circumstances, to supports to live in the community, and to access quality medical care.

Sterilisation is a permanent, invasive and risky medical procedure – with lifelong consequences. Due to the serious consequences of this procedure, it is important that legal safeguards are in place in order to protect the fundamental right to bodily integrity for people with disability.

(QAI)

1 *Eugenics was coined in the late 1800s by Galton and means to be "well born". The eugenics movement was directed towards the 'improvement' of human 'stock' by preventing breeding by undesirables, such as people with disability. Historically eugenics involved control of human mating, through restrictive marriage and reproductive laws, sterilisation, incarceration and, during World-War II, extermination of people with disability.*

Bodily integrity is a concept which enshrines the individual's legal right to protection from assault or other bodily interference which occurs without appropriate consent. Where sterilisation is performed without informed consent or appropriate authorisation, sterilisation violates the individual's right to personal bodily integrity. In relation to sterilisation, the permanent removal of a person's fertility means the impact of any breach of bodily integrity has a particularly serious impact. Because of sterilisation's irreversible effects and the significant vulnerability of many people with disability (particularly children and people with decision-making incapacity) the practice of sterilisation must be carefully circumscribed and subject to legal restrictions. Because sterilisation involves a loss of fertility and healthy bodily organs and frequently cessation of menstruation, the procedure involves significant psychological and

identity impacts. These cannot be assumed to be insignificant purely on the basis of the individual's disability or on a subjective and untested view that sterilisation is in the "best interests" of the person with disability because it removes the "burdens" of fertility and menstruation.

Sterilisation should never be performed on a discriminatory basis and should only be considered as a "last resort". Therefore, we suggest that a combination of tests should be satisfied, before a sterilisation can be authorised. These include: a test of "last resort", a test of "but for" (i.e. not discriminate on the basis of disability), a test that the procedure is "in the best interests of the person with disability" (rather than other stakeholders), and that decision-making is also guided by a principle of "least restrictive alternative".

Sterilisation of people with disability

The Test of "Last Resort" and "But For"

Sterilisation is currently performed on a discriminatory basis, in particular being performed on very young women and girls, men and boys, where the culturally valued norm is for young people never to be sterilised. Thus, it is important to ask whether sterilisation would be proposed "but for" the disability. While both men and women with disability have historically been sterilised, sterilisation of young women and girls with disability has been most common. Even when performed on mature women who have had the advantage of processes of adequate informed consent, sterilisation procedures are commonly not without significant immediate risks or risks of long-term health consequences. Therefore, sterilisation should always be seen as a drastic measure and as an option of last resort. It should be considered only after all other options have been carefully investigated, trialled and evaluated.

As an option of last resort, it should not be offered on a discriminatory basis. Therefore, it is crucial to consider whether sterilisation would be offered to a person without disability in the same circumstances or given the same medical indications. For this reason, we are reluctant to say that sterilisation should never be authorised for someone with decision making incapacity (given that such an option would be available to someone with capacity who was able to give informed consent). We concede that it may be possible that in rare circumstances, the complex health needs of a person with a disability and lack of other appropriate alternatives may make sterilisation a legitimate option. At the same time, we consider that the practice should be extremely rare, subject to rigorous examination of all alternatives, and be subject to a combination of tests which would safeguard the rights of the person with disability.

The test of “last resort” encapsulates that a sterilisation could only be authorized after all other possible procedures, medications, and education or training programs have been considered, and found to be inappropriate or more restrictive.

Best Interests

Many discriminatory, prejudicial and paternalistic assumptions about people with disability persist. Therefore, the test of “best interests” requires careful consideration and analysis. Frequently, there is a tendency to give substantial weight to the “best interests” of other parties, particularly family members and services. While QAI is sympathetic to the demands placed on families to manage many challenging issues without adequate supports, we are also deeply concerned that families may be driven to seek sterilisation to ensure their child’s entry or continued placement in services. This in effect justifies inadequate supports and the neglect of people with disability. Support with menstrual management should not be seen as “extraordinary” but as a reasonable and necessary part of providing personal supports to women with disability. Similarly independence in menstrual management should not be seen as a pre-requisite for community inclusion and community living.

Least Restrictive Alternative

This principle of “least restrictive alternative” reflects both that the sterilisation option must be considered the least restrictive option (among other alternatives) and also that the form of procedure should be the “least restrictive alternative”. It is deeply concerning that hysterectomy continues to be the predominant surgical procedure performed and this appears to result from inadequate consideration of adverse effects and alternative procedures.

While QAI is mindful of the needs and sincere feelings of families who are often left to cope without adequate supports, QAI rejects the use of the “least restrictive option” test to support sterilisation when it is for the prime benefit of people other than the person with disability – particularly for the convenience of services.

The sterilisation of children raises particular alarm. It is unlikely to ever be an appropriate procedure to be performed on a child (except to preserve life) and most particularly on a child prior to puberty – in anticipation of difficulties. Any application to authorise sterilisation of a child should involve extremely rigorous examination of all evidence to ensure that all available alternatives have been trialled.

Queensland Advocacy Inc. has particularly serious concerns about the sterilisation of minors because it is likely that sterilisation of a very young person does not meet a test of “last resort” but rather is being considered because too much weight is being given to immediate circumstances, and because there is too little investigation or optimism about the potential for other interventions, development, trials etc. to meet the same ends while being less restrictive for the individual. A hysterectomy may take away a young girl’s right to development, not allowing adequate time for the developmental challenges of puberty and early menstruation to resolve themselves positively.

People with disability and their families have the right to adequate supports, and specialist information and resources to support their family member. Where families seek court/tribunal authorisation of sterilisation, the processes used must be respectful of family relationships.

QAI acknowledges that many families form a genuine belief that sterilisation is in the best interests of their family member. We believe that the circumstances cited as justification for sterilisation usually arise from a failure to provide assistance with menstrual preparation and management and where the family is not provided with adequate supports. Without in any way attributing ill intent to those family members, there is substantial evidence that when families have access to adequate supports and information about alternatives, requests for sterilisation drop dramatically.

Families must have adequate and appropriate supports which promote the inclusion of their family member with disability in their own home and which allows the whole family to enjoy a quality of life equal to that enjoyed by other families in the community.

It is also crucial that the medical, psychological and social consequences of sterilisation are acknowledged and discussed with families/guardians prior to, and when making, an application for sterilisation. I

Families need to be acknowledged for their central and continuing role in the life of their family member. Thus, their perspectives deserve respectful consideration in the decision-making processes of the Family Court and the Queensland Civil and Administrative Tribunal. They must be able to access adequate information about the tribunal/court processes and the principles underlying the relevant legislation. It is also important that evidence and findings are reported, as clearly as possible and in “ordinary” language.

Historically, the forced sterilisation of people with disability for eugenic reasons has constituted an unacceptable abuse of the human rights of people with disability. While sterilisation may in very rare circumstances be justified as an act of last resort, the potential for this to be abused and the fact that sterilisation overrides a woman's right to bodily integrity demands stringent safeguards.

- Tribunals hearing applications should consist of three member panels. Panel members must have particular knowledge and training specific to this contentious issue. Such knowledge and training should include familiarity with alternatives to sterilisation, knowledge of menstrual management techniques, knowledge of successful supports available to individuals and families and demonstrated knowledge of human rights frameworks in relation to sterilisation of people with disability.

- Disability Services should act to establish a centralized contact point for information about alternatives to sterilisation and to ensure that all individuals, family members and service providers have access to the most up-to-date information about available training programs, medical aids/equipment, and alternatives to sterilisation in order to ensure that the "least restrictive" option can be chosen.

  2 *The notion of bodily integrity forms the basis of the laws of assault, whereby protection from the insult of bodily interference is upheld by the fundamental common law principle that every person has a right to bodily integrity. Any intervention that interferes with bodily integrity may be seen to constitute trespass upon the person.*

- Prior to setting down hearings, the tribunal should ensure that all applicants have received counselling about available training, aids/equipment and medical information about alternative treatments.

- Decision-making authorities (whether courts or tribunals) must take account of the likelihood of conflicts of interests between families and individuals with disability. While families have a legitimate continuing role in the lives of their family members, competing rights and interests exist. Where conflict between these rights and interests cannot be resolved, the interests of the person with disability must remain paramount.

- Sterilisation can never be justified as a result of the inadequate resources available to individuals and families. Currently families may be placed under pressure to consider sterilisation because of service system failures, inflexible service provision and lack of supports. This is unacceptable.

- No sterilisation can be authorized without development of a comprehensive health plan being undertaken.
- Families and medical practitioners should be encouraged to seek authorisation for sterilisation procedures in order to comply with the current law.

Government and others must act to ensure that the rights of people with disability are adequately protected

- The decisions made by the Queensland Civil and Administrative Tribunal should be subject to monitoring, review and public reporting.
- State and Federal Governments must liaise in order to assess the actual extent of sterilisation of people with disability – including the numbers undergoing unauthorized sterilisations. State and Federal Governments must act to ensure that systems and specialist services are in place to ensure the health needs of people with disability are met.
- Disability Services, as lead agency for disability services, must act to ensure that information and menstrual management resources are publicly available and widely known. This would involve ensuring that corporate knowledge about menstrual management strategies and alternatives to sterilisation is maintained and through liaison with other organisations (including Family Planning Queensland and the Queensland Centre for Intellectual and Developmental Disability) that Queenslanders with disability have access to quality, up-to-date information and supports. DS should also liaise with other relevant departments, such as the Department of Education Training and Employment to ensure access to and knowledge of these supports. They should act to ensure that this information is available to their staff, in medical training courses and to the disability service sector generally.
- Continuing research and monitoring of the Queensland context should be undertaken. This would include the level of demand for sterilisation, the basis for tribunal decision-making and the adequacy of counselling/supports to families. Ideally such monitoring should involve the Office of the Public Advocate, Office of Adult Guardian and community based advocacy organisations.
- The Australian Medical Association and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists must ensure that their membership is well aware of the legal framework in which sterilisations may be authorised, the existence of community based services and supports, and

those alternatives to sterilisation that exist. Where members are found to have been performing unauthorized sterilisations, the AMA and RANZCOG should act to ensure that appropriate action is taken and that membership is reviewed.

- Services and family support organisation should be made aware of the current legislation requiring authorisation for sterilisations of minors and people with a decision-making incapacity. Relevant departments, including Disability Services, Department of Justice and Attorney-General, and others should ensure wide knowledge of the legislation, the necessity and benefits of seeking court authorisation etc., in order to encourage compliance.