



Australian Government

Australian Government response to the Senate Community Affairs References Committee reports: Involuntary or coerced sterilisation of people with disabilities in Australia Involuntary or coerced sterilisation of intersex people in Australia

May 2015

Introduction

The Australian Government welcomes the Senate Community Affairs References Committee report on the involuntary or coerced sterilisation of people with disability and the report on the involuntary or coerced sterilisation of intersex people in Australia.

The Australian Government recognises people with disability have historically been subjected to sterilisation without their consent or against their wishes, the majority of whom have been women. The Committee's report includes the testimony of women who have been irreparably affected by these procedures.

Over the past two decades, the regulation of sterilisation of people with disability has been subject to a number of inquiries and reviews and state and territory law regulating sterilisation has been significantly reformed. These laws now provide better protection for people with disability than has historically been the case across Australia.

The majority of the recommendations in the report on the involuntary or coerced sterilisation of people with disability are directed to ensuring a more consistent approach to the regulation of sterilisation. The regulation of sterilisation of adults with disability is primarily a state and territory issue. The Commonwealth's jurisdiction in sterilisation cases exists only under the *Family Law Act 1975* and is confined to matters involving children. However, the Australian Government supports increased consistency across jurisdictions and will raise the Committee's recommendations regarding the legal framework regulating sterilisation for people with disability with state and territory governments.

As the Committee identified, the question of capacity is a threshold question in the regulation of sterilisation for people with disability. A report by the Australian Law Reform Commission on Equality, Capacity and Disability in Commonwealth Laws was tabled in November 2014. The report examined Commonwealth laws that deny or diminish the equal recognition of people with disability as persons before the law and their ability to exercise legal capacity, and made 55 recommendations for reform. The Government is currently considering the recommendations in the report.

The Senate Committee report also makes a number of recommendations to improve sexual health and family planning education for people with disability. The Australian Government encourages state and territory governments to review sexual and reproductive health education programs including specific funding or support for programs or materials for people with disability and the disability sector. The report also includes recommendations to improve medical workforce training and the Australian Government similarly encourages National Health Boards and specialist medical colleges to review the Senate Committee's findings as regards education for medical practitioners.

While available data suggests the numbers of sterilisations of people with disability is quite low, the inconsistency of data collection practices remains a cause of concern. For this reason, the Australian Government, through the Attorney-General's Department, has provided funding to the Office of the Public Advocate Victoria representing the Australian Guardianship and Administration Council to develop indicators to standardise the collection of data across jurisdictions.

The report on the involuntary or coerced sterilisation of intersex people outlines a broad range of views regarding the appropriate treatment of infants born with intersex variations. As with the

report on people with disability, it includes testimony from people whose adult lives have been shaped by the medical treatment that began when they were infants or children.

The Committee recommends the treatment of intersex infants is best managed by multidisciplinary teams and this is well supported by evidence from medical experts and advocates. In this regard, the Government understands a number of major hospitals have formed multidisciplinary teams to coordinate the treatment of intersex infants.

The Committee has recommended significant law reform so that the authorisation of civil and administrative tribunals or the Family Court of Australia would be required for all proposed intersex medical interventions for children and adults without the capacity to consent. A variety of views on the desirability or benefit of legal authorisation to medical treatment were submitted to the Committee during the Inquiry. The question of whether or not bringing the medical treatment of intersex variations into the jurisdictions of guardianship tribunals would lead to better outcomes for intersex people is one that would benefit from further research and consideration. However at this time the Government does not support amendment of the Family Law Act to expand the role of the Family Court of Australia.

There is increasing recognition of the needs of people who are intersex in Commonwealth law and policy. In 2013, the *Sex Discrimination Act 1984* was amended to introduce protections from discrimination on the grounds of intersex status. Australia is one of the first jurisdictions to provide specific protection from discrimination for people who are intersex. The *Australian Government Guidelines on the Recognition of Sex and Gender (2013)* clearly define intersex as a biological condition and provide an avenue for people who are intersex to establish or change their gender in Australian Government records. Over time, these reforms should support greater social acceptance of variations in gender identity and sex characteristics.

The Government thanks the Senate Committee for their reports.

1. Involuntary or coerced sterilisation of people with disability

Recommendation 1:

The committee recommends that, in education programs relating to disability and in sex education and family planning information targeted to the disability sector, education about relationships and sexuality for people with disability should be prioritised, with an emphasis on the reasonable and normal aspirations of people with a disability regarding their sexuality and relationships.

Response: Noted.

Sex education programs in Australia are largely the responsibility of state and territory governments. The Australian Government encourages state and territory governments to ensure the funding of sexual and reproductive health education programs includes specific funding for programs or materials for people with disability and the disability sector.

Recommendation 2:

The committee recommends that medical workforce training with respect to sexual and reproductive health includes content on supporting sexual relationships and sexual and reproductive health needs for people with a disability.

Response: Noted.

The requirements for undergraduate education and training of health professionals in Australia, including medical practitioners, is determined by the relevant National Board for that profession.

The Australian Government understands that all accredited undergraduate health professional degrees include content on supporting sexual relationships and the sexual and reproductive health needs for people with a disability.

The Australian Government encourages National Health Boards and specialist medical colleges to review the Senate Committee's findings and to take action to support appropriate medical workforce training in relation to the sexual and reproductive health needs of people with disability.

Recommendation 3:

The committee recommends that medical workforce training include training with respect to the ethical and legal aspects of informed consent, substitute and supported decision making and fertility control.

Response: Noted.

As noted above, the requirements for undergraduate education and training of health professionals in Australia, including medical practitioners, is determined by the relevant National Board for that profession.

The Australian Government understands that all accredited undergraduate health professional degrees include the ethical and legal aspects of informed consent, substitute and supported decision making and fertility control. The Australian Medical Council accreditations standards for Primary Medical Education Providers notes as part of Domain 4 that Australian medical graduates must be able to demonstrate professional values including a commitment to high quality clinical standards, compassion, empathy and respect for all patients. Further information regarding the accreditation standards can be found at <www.medicalboard.gov.au/Accreditation/Medical-schools.aspx>.

The Australian Government encourages National Health Boards and specialist medical colleges to review the Senate Committee's findings and to take action to support appropriate medical workforce training in relation to informed consent and substituted and supported decision making for people with disability.

Recommendation 4:

The committee recommends that, in the development of participant plans (particularly for participants approaching puberty and in their teens), the participant work with any person assisting them with plan development, and with Disability Care Australia, to cover the need for understanding of sexuality and sexual relationships, support for relationships and sex education that meets the participants' needs, and covers appropriate support for menstrual management for girls and women with disabilities.

Response: Accepted in principle.

The Australian Government agrees with this recommendation in principle, but notes this is a matter for the National Disability Insurance Agency (the Agency). The Agency has informed the Australian Government that its current practices for developing individual plans with participants include discussion of the participant's goals and aspirations.

The Agency has also advised that it will ensure that future training for Agency planning staff includes a component on identifying where participants may need support to understand sexual relationships and menstrual management.

Governments have agreed the respective roles of the National Disability Insurance Scheme (NDIS) and other service systems, including the health system. In this agreement, the Agency can fund general capacity building and skills development for people with disability. The NDIS will not fund clinical services as these activities remain the responsibility of other parties within the health system.

Recommendation 5:

The committee abhors the suggestion that sterilisation ever be used as a means of managing the pregnancy risks associated with sexual abuse and strongly recommends that this must never be a factor in approval of sterilisation.

Response: Accepted.

The Australian Government has a zero tolerance approach to violence against all women and notes women with disability experience higher rates of sexual violence than the general population.

The National Plan to Reduce Violence against Women and their Children 2010-2022 (the National Plan) brings together the efforts of governments across the nation to make a real and sustained reduction in the levels of violence against women.

The Australian Government shares the Committee's view that sterilisation should never be viewed as a response to mitigate the risk of pregnancy as the result of sexual assault.

The Government will raise this issue with state and territory governments that do not explicitly proscribe sterilisation on these grounds. The Government recommends these jurisdictions consider amending relevant legislation to provide that sterilisation should not be approved by a Guardianship Tribunal or equivalent if the sterilisation is to remove the risk of pregnancy resulting from sexual abuse.

Recommendation 6:

The committee recommends that, for a person with a disability who has the capacity to consent, or to consent where provided with appropriate decision-making support, sterilisation should be banned unless undertaken with that consent.

Recommendation 28:

The committee recommends that each jurisdiction enact legislation prohibiting the performance or procurement of unauthorised sterilisation procedures. State and territory legislation should also make it an offence to take, attempt to take, or to knowingly assist a person to take, a child or an adult with a disability oversees for the purpose of obtaining a sterilisation procedure.

Response: Noted.

Almost all state and territory legislation regulating sterilisation creates an offence where a person carries out a sterilisation procedure without the consent of a Guardianship Board, Tribunal or Court.

The Australian Government will raise this issue with state and territory governments whose legislation does not create such an offence.

Recommendation 7:

The committee recommends that, for a person with a disability for whom it may reasonably be held that they may develop the future capacity to consent, irreversible sterilisation should be banned until either the capacity to consent exists, or it becomes reasonably held that the capacity to consent will never develop.

Response: Noted.

A number of state and territories prevent Guardianship Boards or their equivalent from consenting to a sterilisation procedure for a person unless they are satisfied it is unlikely the person will acquire the capacity to give an effective consent at any time, or anytime in the foreseeable future.

The Australian Government will raise this issue with those state and territory governments that do not provide this protection and encourage these jurisdictions to consider introducing such provisions as appropriate.

The Government is of the view that the Family Law Rules, which require the Family Court to consider the future capacity to consent in sterilisation cases (see rule 4.09(1)(h)), provide adequate protection to allow the Court to defer sterilisation where appropriate.

Recommendation 8:

The committee recommends that state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that it is presumed that persons with disabilities have the capacity to make their own decisions unless objectively assessed otherwise. The legislation should be amended to specify that it cannot be presumed that persons are without legal capacity in relation to the proposed special medical procedure, including a sterilisation procedure, even where there is an existing guardianship order in place.

Response: Noted.

This is a matter for state and territory governments. The Australian Government encourages state and territory governments to ensure guardianship law evolves to ensure the highest possible standard of support for people with disability.

Recommendation 9:

The committee recommends that Commonwealth, state and territory legislation regulating the sterilisation of adults with disabilities be amended to explicitly state that a court or tribunal does not have authority to hear an application for an order approving a proposed special medical procedure, including a sterilisation procedure, where the person with a disability has legal capacity.

Response: Noted.

This is a matter for state and territory governments. The Family Court's jurisdiction in sterilisation cases under the Family Law Act is limited to matters involving children.

Recommendation 10:

The committee recommends that each Australian jurisdiction use the same definition of capacity, to ensure that a person's rights to autonomy and bodily integrity do not vary according to, and are not dependent on, the jurisdiction in which they live.

Response: Noted.

This is a matter for state and territory governments.

Recommendation 11:

The committee recommends that all jurisdictions adopt in law a uniform 'best protection of rights' test, replacing current 'best interests' tests, that makes explicit reference to the protection of the individual's rights; and the maintenance of future options and choices.

Recommendation 12:

The committee recommends that, in those cases where the need for supports has a bearing on the assessment of interests, regard should be had to best support services available, rather than the deficit in services provided in the past.

Response: Noted.

The Australian Government is of the view that the 'best interests' tests as articulated and applied in Australia in relation to children is consistent with Australia's international obligations. A key principle underlying decision-making in relation to children, including in courts, administrative authorities and legislative bodies under the Convention on the Rights of the Child is that a child's best interests be a primary consideration.

The principle of 'best interests' is well established in the context of family law. The best interest test allows the court to make an objective decision about what is best for a child in the particular circumstances of each case. This could include, but is not limited to, the consideration of the rights of the child. It could also include the availability of support services. The Australian Government believes a shift away from this principle is not desirable, or necessary.

However, the Australian Government encourages state and territory governments to review the articulation of the test in relevant legislation to ensure a person's rights are considered in determining their best interests. This may also include an assessment of the best support services available.

Recommendation 13:

The committee recommends that the states and territories ensure that independent representation is provided for people with disabilities. Representation should be independent; while family or guardians should have a right to be involved, an independent representative should not be a member of the person's family or a caregiver.

Response: Noted.

This is a matter for state and territory governments.

Recommendation 14:

The committee recommends that the costs of legal representation for adults should be covered by the relevant legal aid commission. State and territory governments should review legal aid funding arrangements to ensure that there are adequate funds to meet the costs of providing a legal representative for persons with disabilities in special medical procedure cases, including sterilisation cases.

Response: Noted.

This is a matter for state and territory governments.

The Australian Government encourages state and territory governments to consider the level of assistance available for people with disability requiring legal representation in special medical procedure matters.

Recommendation 15:

The committee recommends that a legal representative be appointed in each child sterilisation case regardless of the jurisdiction in which the matter is heard. Commonwealth, state and territory legislation should be amended as necessary to ensure that the appointment of a legal representative of the child is mandatory in each sterilisation case.

Response: Not supported.

Under the Family Law Act, the Family Court of Australia has the power to appoint an independent children's lawyer in particularly complex cases.¹ Independent children's lawyers act as a 'best interests' advocate for children on behalf of the Court.

The appointment of an independent children's lawyer is not mandatory, but made by a court depending on the circumstances of the case. Independent representation may be ordered on the

¹ Family Law Act, s 68L

courts' own initiative, on the application of a party, the child themselves, or an organisation concerned with the welfare of children (Family Law Act, section 68L).

Independent children's lawyers are primarily funded by the Australian Government through Legal Aid Commissions. Legal Aid Commissions are responsible for appointing independent children's lawyers following an order from the Court.

The Australian Government considers the appointment of a legal representative for children in sterilisation cases should remain a matter for the Court, rather than establishing a mandatory legislative requirement. This allows the Court to decide whether the appointment of an independent children's lawyer is appropriate in the individual circumstances of each case.

Guidance for the appointment of an independent children's lawyer is set out by the Full Court of the Family Court of Australia in the case of *Re: K* (1994) FLC 92-46. This Guidance provides that an independent children's lawyer should normally be appointed where applications are made to the Court's welfare jurisdiction relating to the medical treatment of children where the child's interests are not adequately represented by one of the parties.

If an independent children's lawyer is appointed by the Court, their role includes representing the child's best interests, ensuring all relevant information is provided to the Court about the child's welfare, and informing the Court about any views expressed by the child (section 68LA Family Law Act).

A number of states already require or allow the appointment of an independent legal representative for children. The Australian Government will raise this issue with those state and territory governments that do not include any provision for the appointment of an independent children's lawyer and encourage these jurisdictions to consider whether their legislation should be amended to allow for their appointment.

Recommendation 16:

The committee recommends that legal aid be provided to cover the costs incurred by the child's legal representative. The committee recognises that governments may need to revise current legal aid funding arrangements to ensure that there are sufficient funds to meet the costs of children's representatives in sterilisation cases.

Response: Noted.

The Australian Government believes the Commonwealth's current legal aid funding arrangements are adequate to meet the costs of child sterilisation matters heard by a federal court because of the small number of cases and the priority they are afforded.

The National Partnership Agreement on Legal Assistance Services is the agreement between the Commonwealth Government and each state and territory government to fund legal aid commissions for Commonwealth service priorities. Under the Agreement, family law matters involving children,

including the appointment of a court appointed independent children's lawyer, are listed as a Commonwealth legal aid service priority. The agreement expires on 30 June 2015.

Legal assistance funding for sterilisation matters in state jurisdictions is an issue for state and territory governments. The Australian Government encourages state and territory governments to consider the level of assistance available for representing children in proceedings regarding sterilisation procedures.

Recommendation 17:

The committee recommends that Commonwealth, state and territory governments work with legal aid commissions and relevant law societies to develop training courses for legal practitioners about children's legal capacity, techniques to communicate, and the varying effects and nature of disability. Successful completion of such courses should be mandatory before being appointed to represent a child.

Response: Supported in principle.

Independent children's lawyers are managed by state and territory legal aid commissions. It is a national prerequisite that all lawyers who conduct independent children's matters must have completed the Independent Children's Lawyer Training Program.

In 2013, the Australian Institute of Family Studies released a report examining the use and efficacy of independent children's lawyers in the family law system. This report was commissioned by the Commonwealth Attorney-General's Department. The report noted some concerns about the adequacy of accreditation, training and ongoing professional development arrangements in equipping independent children's lawyers to deal directly with children and perform optimally in matters involving family violence and child abuse.

The Australian Government has been working with the Law Council of Australia and National Legal Aid to address the Institute's findings so that training and professional development can be improved to better equip independent children's lawyers to deal directly with children, especially in matters involving family violence and child abuse.

The Australian Government also encourages the Law Council of Australia to review the Independent Children's Lawyer Training Program to ensure it provides adequate guidance on the legal capacity of children with disability.

Recommendation 18:

The committee recommends that Commonwealth, state and territory legislation be amended to provide the right to public advocates, such as the Office of the Public Advocate, to be a party to child or adult sterilisation cases.

Response: Not accepted.

The Australian Government believes a public advocate or equivalent can make an important contribution in proceedings related to sterilisation.

Under the Commonwealth's jurisdiction, a public advocate is able to request the Family Court of Australia allow them to join proceedings.² The Australian Government considers the decision to allow a public advocate to join sterilisation cases in the Family Court of Australia should remain a matter for the Court, rather than establish a right for public advocates to be a party. This allows the Court to decide whether the appointment of a public advocate is appropriate in the individual circumstances of each case.

The Australian Government notes the Family Court of Australia has a range of mechanisms available to it to ensure it has sufficient evidence before it to make decisions which are in the best interests of children in sterilisation cases, in addition to allowing a public advocate to join proceedings. The evidence must include evidence from a medical, psychological or other relevant expert witness.

The Court is also able to:

- invite the Attorney-General or a state and territory child protection authority to intervene in proceedings³
- order an independent children's lawyer to represent the best interests of the child⁴ (section 68L), or
- order a family consultant's report.⁵

In most states and territories, the public advocate has standing to appear before the Tribunal or Board. The Australian Government encourages state and territory governments to review relevant legislation and consider inserting provisions to ensure, at a minimum, a public advocate is able to seek leave of a court to join sterilisation cases.

Recommendation 19:

The committee recommends courts and tribunals develop information packs and questionnaires to provide guidance for medical experts in sterilisation cases. The information packs should specify the factors that courts and tribunals consider under the relevant legislation, and should also note issues that the courts and tribunals are not authorised to consider such as outdated and paternalistic attitudes to disability, eugenic arguments or assessments of the person's current or hypothetical capacity to care for children. Questionnaires should seek the medical expert's advice about the procedures that could usefully be adopted in the particular case to facilitate both a robust medical assessment and the person's participation in proceedings.

² see Family Law Rules 6.05

³ see Part IX of the Family Law Act

⁴ Section 68L of the Family Law Act.

⁵ See part III of the Family Law Act

Response: Supported in principle.

The development of supporting or guiding material for experts appearing before courts or tribunals is a matter for consideration by the individual courts and tribunals. Federal courts and tribunals are independent of government and each responsible for their own operation and management, including what guidance they provide to court and tribunal users.

Recommendation 20:

The committee recommends that the Family Court of Australia gives strong consideration to the evidence gathered by this inquiry about the absolute necessity of ensuring that judicial officers participating in special medical procedure cases have appropriate skills and expertise in disability matters. The committee urges the Family Court of Australia to develop training courses about disability matters and to ensure that such courses are completed by any judicial officer who may hear cases concerning special medical procedures.

Response: Supported in principle.

Participation by federal judges in professional development and training opportunities is voluntary. However, ongoing professional development of the judiciary is encouraged and supported through the courts' own programmes, the National Judiciary College of Australia and the Australasian Institute of Judicial Administration.

The Family Court of Australia has published resources, available on its website <www.familycourt.gov.au>, to assist court users to understand processes of the Court and facilitate the resolution of special medical procedure matters.

The Australian Government notes the federal family law courts (the Family Court of Australia and the Federal Circuit Court of Australia (Family Division)) are specialised courts that deal with family law matters. Paragraph 22(2)(b) of the *Family Law Act 1975* also provides a person shall not be appointed as a Judge of the Family Court of Australia unless, by reason of training, experience and personality, the person is a suitable person to deal with matters of family law.

Recommendation 21:

The committee recommends that the Commonwealth government establish a special medical procedures advisory committee, to provide expert opinion to the Family Court upon request in relation to specific cases, and to other statutory decision-makers and government as appropriate on best practice in relation to sterilisation and related procedures for people with disability; and that the committee must include non-medical disability expertise as well as medical expertise.

Response: Not supported.

Current evidentiary requirements for sterilisation cases and the ability of the Family Court of Australia to receive or request information means the Court is well placed to make informed decisions in these cases.

In all special medical procedure cases, the Court must be satisfied that the proposed medical procedure is in the best interests of the child. Evidence in support of a procedure must include evidence from a medical, psychological or other relevant expert witness.

As noted above, the Family Court of Australia also has a range of mechanisms available to it to ensure that it has sufficient evidence before it. The Court is able to:

- invite the Attorney-General or a state and territory child protection authority to intervene in proceedings (see Part IX of the Family Law Act)
- grant an application for a non-party to intervene, for example the Australian Human Rights Commission or the Office of the Public Advocate, or allow interested parties to join proceedings as friends of the court (*amicus curiae*) (see rule 6.05 Family Law Rules)
- order an independent children’s lawyer to represent the best interests of the child (section 68L), or
- order a family consultant’s report (see Part III of the FLA).

It is the Australian Government’s view that these mechanisms ensure the Court has access to expert opinion to assist in sterilisation cases and does not support the creation of a special medical procedures advisory committee.

Recommendation 22:

The committee recommends that legal aid should be provided to cover the costs incurred by the parents or guardians in child sterilisation cases. The legal aid grant should not be subject to capping or to a means or merits test

Response: Not supported.

All grants of legal aid are means and merit tested and may be subject to a cap. These measures ensure that available legal aid resources are targeted at the most disadvantaged Australians and the most meritorious matters.

The Australian Government does not support the removal of eligibility requirements for parents or guardians seeking legal aid in child sterilisation cases. It is the view of the Government that it would not be appropriate for a separate set of rules to apply only to the provision of legal aid for child sterilisation cases.

Recommendation 23:

The committee recommends that the matter of the scope and operation of the relevant courts and tribunals be placed on the agenda of the Standing Council on Law and Justice for ongoing review.

Response: Noted.

In December 2013, the Council of Australian Governments agreed to streamline the Council system. The Standing Council on Law and Justice has been amalgamated with a number of councils to form the Law, Crime and Community Safety Council. The new Council will promote best practice in law, criminal justice and community safety, including in policy, operations and service provision.

The Australian Government supports increased consistency in the regulation of sterilisation across jurisdictions and will work with state and territory governments to support the implementation of recommendations regarding the legal framework regulating sterilisation for people with disability.

Recommendation 24:

The committee recommends that the Standing Council on Law and Justice obtain information about the frequency and nature of 'therapeutic' sterilisation cases being conducted, and compare the circumstances of those cases with 'non-therapeutic' cases that have been authorised by courts or tribunals.

Recommendation 25:

The committee recommends that data about adult and child sterilisation cases be recorded, and reported, in the same way in each jurisdiction. Data records should include the number of applications made for a special medical procedure, the kind of special medical procedures specified in the application, the categories of parties to the proceedings (for example, parents, medical experts, public advocates), and the outcome of the case.

Response: Supported in principle.

While available data suggests the numbers of sterilisations of people with disability is quite low, the inconsistency of data collection practices is cause for concern. For this reason, the Australian Government will work with the Australian Guardianship and Administration Council to standardise the collection of data across jurisdictions.

Recommendation 26:

The committee recommends that the Department of Human Services investigate the pattern of vasectomy in young males, including the apparently high number occurring in Queensland, and provide information to the Standing Council on Law and Justice if it has reason to believe the figures include sterilisations of men with disability.

Response: Noted.

Policy responsibility for health matters, the *Health Insurance Act 1973* and the Medicare Benefits Schedule rest with the Department of Health. The Department of Human Services provides Medicare payment data to the Department of Health.

Neither the Department of Human Services nor the Department of Health currently have the required information to undertake the requested analysis of this recommendation.

There are two sterilisation procedures for males in the Medicare Benefits Schedule – item 37622 and 37623 – the first performed by a General Practitioner, the second by a specialist. Medicare benefits are only payable for services listed in the Medicare Benefits Schedule where the procedure meets the item descriptor and is clinically relevant. Medicare data shows that there were no Medicare benefits paid to males aged less than 19 years of age for these items in the 2013-14 financial year, and no such benefits have been paid for 2014-15 to date.

The Department of Human Services is able to confirm the publically available information on its website concerns men in the 15-24 age range who have had relevant sterilisation services. However, under the *Privacy Act 1988*, the National Privacy Principles relating to the use and disclosure of personal information would preclude the release of a breakdown of this information for individual ages. In addition, at present, there is no requirement in the Health Insurance Act (which underpins the Medicare programme), to include information about patient disability when registering for Medicare or claiming benefits under the programme and therefore this information is not collected. Furthermore, as it is unlawful to carry out sterilisation of a minor without appropriate authority, Medicare would be prevented from paying Medicare Benefits for these services without sighting appropriate authority, noting that authorities of this type are not required to include information about patient disability.

Recommendation 27:

The committee recommends that the Council of Australian Governments oversee the development of uniform model legislation to regulate the sterilisation of persons with disabilities. Based on this model, a new division of the *Family Law Act 1975* (Cth) should be created.

Response: Not accepted.

The Australian Government believes the Law, Crime and Community Safety Council is the most appropriate body to consider the regulation of sterilisation of people with disability.

Developing uniform provisions regarding sterilisation of minors was on the agenda of the Standing Committee of Attorneys-General between 2003 and 2008. The issue was removed from the agenda when the Committee found the number of reported sterilisations that were occurring appeared to be significantly less than originally reported, and that existing procedures for approval of sterilisation procedures appeared to be working adequately in light of treatment options and education initiatives.

Given the recent consideration of this issue, the Australian Government is of the view that uniform model legislation is unlikely to be successful. However, as noted above, the Australian Government supports a more a consistent approach to the regulation of sterilisation between jurisdictions and will work with individual state and territory governments to encourage a consistent, principles-based approach to this issue.

Recommendation 28:

The committee recommends that each jurisdiction enact legislation prohibiting the performance or procurement of unauthorised sterilisation procedures. State and territory legislation should also make it an offence to take, attempt to take, or to knowingly assist a person to take, a child or an adult with a disability overseas for the purpose of obtaining a sterilisation procedure.

Response: See response to recommendation 6

2. Involuntary or coerced sterilisation of intersex people

Recommendation 1:

The committee recommends that governments and other organisations use the term 'intersex' and not use the term 'disorders of sexual development'

Response: Supported in principle.

The *Australian Government Guidelines on the Recognition of Sex and Gender* standardise the gender classification system and the evidence required for a person to establish or change their sex or gender in personal records held by the Australian Government. These Guidelines use the term intersex to describe people with genetic variations that mean they have the biological attributes of both sexes or lack some of the biological attributes considered necessary to be defined as one or the other sex. Australian Government departments and agencies have until July 2016 to align their practice to the new standards.

The Guidelines apply only to Australian Government departments and agencies. However, the Australian Government encourages other organisations to adopt the terminology used in the Guidelines as appropriate.

Recommendation 2:

The committee recommends that health professionals and health organisations review their use of the term 'disorders of sexual development', seeking to confine it to appropriate clinical contexts, and should use the terms 'intersex' or 'differences of sexual development' where it is intended to encompass genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health.

Response: Noted.

The Australian Government cannot mandate the language used by health professionals and organisations. Health organisations are largely managed by state and territory governments and the private sector.

Recommendation 3:

The committee recommends that all medical treatment of intersex people take place under guidelines that ensure treatment is managed by multidisciplinary teams within a human rights framework. The guidelines should favour deferral of normalising treatment until the person can give fully informed consent, and seek to minimise surgical intervention on infants undertaken for primarily psychosocial reasons.

Response: Noted.

This is a matter for state and territory governments.

The Australian Government encourages all state and territory governments to review the Victorian *Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions*, and consider adopting or developing specific principles for their jurisdiction in consultation with intersex support groups and medical experts as appropriate.

Recommendation 4:

The committee recommends that the Commonwealth government provide funding to ensure that multidisciplinary teams are established for intersex medical care that have dedicated coordination, record-keeping and research support capacity, and comprehensive membership from the various medical and non-medical specialisms. All intersex people should have access to a multidisciplinary team.

Response: Not supported.

The Australian Government supports the principle of multidisciplinary and coordinated care for people who are intersex. However, service provision is generally a state and territory responsibility.

Recommendation 5:

In light of the complex and contentious nature of the medical treatment of intersex people who are unable to make decisions for their own treatment, the committee recommends that oversight of these decisions is required.

Recommendation 6:

The committee recommends that all proposed intersex medical interventions for children and adults without the capacity to consent require authorisation from a civil and administrative tribunal or the Family Court.

Recommendation 7:

The committee recommends that the Standing Committee on Law and Justice consider the most expedient way to give all civil and administrative tribunals in all States and Territories concurrent jurisdiction with the Family Court to determine authorisation for intersex medical interventions proposed for a child.

Recommendation 8:

The committee recommends that civil and administrative tribunals be adequately funded and resourced to consider every intersex medical intervention proposed for a child.

Response: Noted.

A variety of views on the desirability or benefit of legal authorisation to medical treatment were submitted to the Committee during the Inquiry. The question of whether or not bringing the medical treatment of intersex variations into the jurisdictions of guardianship tribunals would lead to better outcomes for intersex people is one that would benefit from further research and consideration. However at this time the Government does not support amendment of the Family Law Act to expand the role of the Family Court of Australia. The Australian Government considers that substantive regulation of medical treatment is a matter for state and territory governments.

The issue of resourcing for civil and administrative tribunals to consider applications for medical treatment of intersex children or people unable to consent to treatment would be a matter for consideration if or when these tribunals were to be granted jurisdiction to hear such cases.

Recommendation 9:

The committee recommends that the special medical procedures advisory committee draft guidelines for the treatment of common intersex conditions based on medical management, ethical, human rights and legal principles. These guidelines should be reviewed on an annual basis.

Response: Not supported.

Recommendation 21 of the Senate Committee's report on the involuntary or coerced sterilisation of people with disability recommends the Commonwealth government establish a special medical procedures advisory committee to provide expert opinion to the Family Court. This recommendation is not supported by the Australian Government for the reasons outlined above.

However, the Australian Government commends the Victorian *Decision-Making Principles for the Care of Infants, Children and Adolescents with Intersex Conditions* and notes other jurisdictions are not precluded from adopting or developing their own principles in consultation with intersex support groups and medical experts as appropriate.

Recommendation 10:

The committee recommends that complex intersex medical interventions be referred to the special medical procedures advisory committee for consideration and report to whichever body is considering the case.

Response: Not supported.

Recommendation 21 of the Senate Committee's report on the involuntary or coerced sterilisation of people with disability recommends the Commonwealth government establish a special medical

procedures advisory committee to provide expert opinion to the Family Court. This recommendation is not supported by the Australian Government for the reasons outlined above.

The Australian Government notes the Family Court of Australia has a range of mechanism available to it to ensure it has sufficient evidence before it to make decisions which are in the best interests of children in special medical procedure cases. In particular, in all special medical procedure cases evidence must be given to satisfy the Court that the proposed medical procedure is in the best interests of the child. The evidence must include evidence from a medical, psychological or other relevant expert witness.

The Court is also able to:

- invite the Attorney-General or a state and territory child protection authority to intervene in proceedings⁶
- grant an application for a non-party to intervene, for example the Australian Human Rights Commission or the Office of the Public Advocate, or allow interested parties to join proceedings as friends of the court (*amicus curiae*) (see rule 6.05 Family Law Rules)
- order an independent children’s lawyer to represent the best interests of the child⁷ (section 68L), or
- order a family consultant’s report.⁸

It is the Australian Government’s view that these mechanisms ensure the Court has access to expert opinion to assist in special medical procedure cases.

Recommendation 11:

The committee recommends that the provision of information about intersex support groups to both parents/families and the patient be a mandatory part of the health care management of intersex cases.

Response: Noted.

Health care management in Australia is largely the responsibility of state and territory governments and the private sector. The Australian Government encourages state and territory governments and health care providers to facilitate patients and families accessing support and information available from intersex support groups.

⁶ See Part IX of the Family Law Act

⁷ Section 68L of the Family Law Act.

⁸ See part III of the Family Law Act

Recommendation 12:

The committee recommends that intersex support groups be core funded to provide support and information to patients, parents, families and health professionals in all intersex cases.

Response: Noted.

Health care management in Australia is largely the responsibility of state and territory governments. The Australian Government encourages state and territory governments to support intersex support groups to provide support and information to patients, parents, families and health professionals in intersex cases.

Recommendation 13:

The committee recommends that the Commonwealth Government support the establishment of an intersex patient registry and directly fund research that includes a long-term prospective study of clinical outcomes for intersex patients.

Response: Not supported.

The Australian Government considers preliminary investigations regarding the possibility of adding an indicator to Australian Institute of Health and Welfare data sets or other existing data sets to capture intersex data a more appropriate response to the lack of data and research on long-term outcomes for people who are intersex. The Australian Government will raise this recommendation with the Institute.

Recommendation 14:

The committee recommends that the Commonwealth government investigate the appropriate regulation of the use of dexamethasone for prenatal treatment of CAH.

Response: Noted.

The Therapeutic Goods Administration is responsible for ensuring therapeutic goods, including prescription medicines, available for supply in Australia are safe and fit for their intended purpose.

Dexamethasone is in Schedule 4 of the Standard for Uniform Scheduling of Medicines and Poisons and is, therefore, a prescription only medicine. Dexamethasone has a wide range of clinical uses, including treatment of adults and children with adrenal hyperplasia. It is not specifically approved for use in the prenatal management of congenital adrenal hyperplasia and its use for this purpose has been at the discretion of the prescribing physician in consultation with the patient.

Recommendation 15:

The committee recommends that, effective immediately, the administration of dexamethasone for prenatal treatment of CAH only take place as part of research projects that have ethics approval and patient follow-up protocols.

Response: Noted.

As above, dexamethasone is not specifically approved for use in the prenatal management of congenital adrenal hyperplasia (CAH) and its use for this purpose could be considered "off-label".

Where a clinical trial is undertaken for an unapproved indication, the investigator is required to notify the Therapeutic Goods Administration of the trial under the Clinical Trial Notification Scheme. The purpose of the Scheme is to enable supply of the therapeutic good for the trial. The Therapeutic Goods Administration would have a limited monitoring role in any clinical trials undertaken, however the outcomes of any trials may inform any potential regulatory action that the Therapeutic Goods Administration may or may not need to take.

In the absence of good data from long-term clinical trials that dexamethasone is safe and effective for the prenatal management of congenital adrenal hyperplasia, a recommendation that the administration of dexamethasone for prenatal treatment of congenital adrenal hyperplasia only take place as part of research projects that have ethics approval and follow up protocols has merit.