Special Section: Bioethics Beyond Borders

Sex Definitions and Gender Practices

An Update from Australia

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Abstract: In recent years the Australian parliament has been considering the rights to protection from discrimination of intersex and gender identity disorder (GID) people. In 2013 such protections were made law in the amendment to the Sex Discrimination Act 1984, which in turn has influenced Senate inquiries into the medical treatment of intersex people. This year's Australian report describes the purview and the potential ramifications of the inquiry of the Senate Standing Committees on Community Affairs, published in October 2013, into the involuntary or coerced sterilization of intersex people in Australia.

Keywords: Australia; intersex; federal legislation; GID; discrimination; involuntary sterilization

Update from 2013

CQ readers may remember that my earlier article on Australian healthcare ethics¹ dealt with two ethical issues intimately involved with healthcare practices related to children and identity: the search for identity of children born of anonymous sperm donations and the efforts of parents seeking medical treatment for a minor with gender identity disorder (GID). I begin here by offering brief updates on each.

At the time of the 2013 review, a young Victorian woman, Narelle Grech, was a leading campaigner for the opening of sperm donor records to children, now adults, born prior to 1989 as a result of those donations. Up to that time, sperm donations had been anonymous. In March 2013, Grech succumbed to aggressive bowel cancer with a possible genetic link; this spurred her quest to identify her genetic siblings and to alert them to their potential risk of the disease. As her health rapidly declined, she was fortunate in the fact that the strength of her personal narrative and public advocacy led to the then premier of Victoria, Ted Baillieu, directing the Public Record Office to release further information. That action enabled Grech to identify and meet with her donor father, Ray Tonna, in the weeks before she died.²

Although the opening of anonymous sperm donor records to all affected remains unresolved throughout Australia, reform has moved one step closer in Victoria, at least in part due to Narelle Grech's activism. In August 2013, the state government tabled its response to the 2012 recommendations of the Victorian Parliament's Law Reform Committee,³ which included the opening of existing records of anonymous donors prior to 1989, the facilitation of contact between donor children and

With thanks (again) to Dr. John Waugh of the University of Melbourne for clarifying points about the legislation discussed in this report, any surviving misconstruction of this information is the responsibility of the author.

their biological fathers, and the counseling of donors and offspring prior to contact. The government's response offers qualified support for those recommendations, so it now seems likely that legislation will be introduced to allow donor identification in Victoria, subject to that information being "released with consent of donors," on the basis that "seeking consent would increase the likelihood that donor-conceived individuals could gain access to relevant contemporaneous information about their donors." It may still be some time before the legislation is framed, enacted, and repeated in other Australian jurisdictions. Nevertheless, the fact that vocal advocates, now including Ray Tonna, remain committed to Narelle Grech's goal and bipartisan, in-principle support for change is evidence of its achievement.⁵

Let us now turn to the case of the GID minor I reported on earlier,⁶ who was the subject of Re Jamie [2011] FamCA 248.7 Jamie is a genetically male but socially female minor seeking gender reassignment. Jamie's parents had successfully sought consent for the first stage of puberty-suppressing treatment from the Family Court but had their request to begin the second stage, estrogen therapy, rejected until the accepted age for beginning such treatment (at 15 or 16), at which time Jamie's views can be considered independently. One issue that remained unresolved at the time of my 2013 report was that, whether or not such treatment was in fact a "special medical procedure," the final decision on such treatment rests with a judge of the Family Court of Australia. Jamie's parents were appealing the status of the treatment, and that appeal has since been successful. The outcome obtained supports the parents' right to give informed consent, and they, rather than a judge, will be able to make the decision to begin stage 1 of the treatment regime (to suppress puberty), on the basis that it is a reversible treatment.8 Decisions about whether, when, and how to proceed with reversible hormone therapies for children with GID have, thus, reverted to the families and the doctors of the young persons concerned. Stage 2 of treatment, which is irreversible, remains an issue in which the competence of the child to consent (even with medical and parental consent) remains a matter to be determined by the courts.

Sex Discrimination, Gender Identity, and Intersex

Children like Jamie who seek such treatments and therapies are actively contesting the gender identity allied to the visible and genetic markers of sex that their growing bodies display, but from which they feel alienated. That exertion of agency may begin when the child is a toddler, as in Jamie's case, although this may not become a socially contentious issue until the child enters schooling and has to negotiate everyday gender practices (such as the use of gender-specific toilets). The child's dysphoria is most likely to become a pressing concern with the approach of puberty and the biological assertion of the mature physical traits of the rejected gender.

GID presupposes a stable, if rejected, biological sex. Where biological sex is neither straightforwardly male nor female—that is, when an individual is intersex—the dissonance between body and gender becomes much more complicated. In contrast to children like Jamie, children born with indeterminate, ambiguous, or incompletely formed genitalia as a result of a range of chromosomal and/or hormonal irregularities are far more likely to have decisions made for them long before they are able to express themselves verbally. Since at least the 1950s, in

developed countries with sophisticated health infrastructures, there has been considerable pressure on parents to accept the assignment of one gender to a child born intersex and, further, to consent to "normalizing" medical procedures (surgery, hormone treatment, etc.). This most often begins in infancy but has ongoing and lifelong medical, psychological, and social ramifications for the individual. It is increasingly acknowledged worldwide that it is incumbent on states to reassess prevailing sociopolitical attitudes toward intersex people within society, and medical ethical approaches to treating intersex people in healthcare settings. Australia's federal parliament has been considering these questions in recent years, and in 2013 two Senate committees made their findings public. The first committee considered amendments to antidiscriminatory legislation to explicitly include intersex people, and the second published reports in cross party support of the rights of intersex individuals.

The Inquiry into the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 20139 of the Australian Parliament's Senate Standing Committees on Legal and Constitutional Affairs¹⁰ sought to reconsider, make final recommendations, and further widen the scope of the Sex Discrimination Act 1984, in order to take into account the concerns of not only those with GID but also intersex people. The amended legislation, which came into force on August 1, 2013, includes the final principles coming out of the recommendations of the inquiry and reflects the shifts in public opinion and understanding of lesbian, gay, bisexual, transgender, and intersex (LGBTI) issues that have taken place over the past 30 years, both locally and in international human rights. In doing so it replaces the term "sexual preference" with "sexual orientation" and includes "gender identity" and "intersex." 11 With respect to the direct effects this amendment will have on healthcare professionals, there is explicit reference in Recommendation 1 (3.66) of the inquiry, a principle now part of the Sex Discrimination Act, to the point "that religious exemptions in section 37 of the Sex Discrimination Act 1984 do not apply in respect of sexual orientation, gender identity and intersex status in connection with the provision of Commonwealth-funded aged care services."12 In other words, places in nursing homes cannot be withheld on the basis of sexual orientation, gender identity, or intersex status, meaning that elderly LGBTI people may not be discriminated against in accessing care.

One of the most effective lobby groups to make submissions to the Senate inquiry—apart from institutions that wished to retain their restricted rights to discriminate (for example, religious organizations running single-sex schools and sporting associations)—was specifically concerned with supporting the rights of intersex people: the Organisation of Intersex International Australia (OII). The OII applauded the fact that the legislation encompasses the explicit recognition "that intersex is a biological characteristic. We agree that this is the correct approach to recognising intersex. The approach positions intersex as distinct from gender identity, as intersex is an innate biological phenomenon. It also positions intersex as distinct from sex, as intersex is not an arbitrary third sex."¹³ Whereas this amendment ensures protections for intersex people from discrimination in Australian society, it is also notable for its differentiation of intersex from gender identity, and for providing a definition of intersex that the OII supports:

intersex means the status of having physical, hormonal or genetic features that are:

- (a) neither wholly female nor wholly male; or
- (b) a combination of female and male; or
- (c) neither female nor male.14

The issues that were raised by the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill in relation to the rights of intersex individuals influenced the work and parameters of another Senate committee. The publications arising from that committee potentially have direct (and challenging) ramifications for healthcare professionals in Australia.

In the light of the Senate Standing Committees on Legal and Constitutional Affairs' report on the bill, the inquiry of the Senate Standing Committees on Community Affairs¹⁵ into the involuntary or coerced sterilization of people with disabilities in Australia (2013)¹⁶ noted that there were similarities and "overlap" between the issues at stake in the ethical and medical treatment of people with disabilities and those concerning intersex people (particularly infants) in relation to informed consent.¹⁷ On February 2, the Senate amended this inquiry's terms of reference to include the following:

- 2. Current practices and policies relating to the involuntary or coerced sterilisation of intersex people, including:
 - (a) sexual health and reproductive issues; and
 - (b) the impacts on intersex people. 18

Although it recognizes that a number of intersex conditions (such as cloacal extrophy or hypospadias) require immediate treatment to protect life, it also acknowledges that most intersex people are born both able and well. Despite this fact, many intersex people have been subject to involuntary or coerced sterilization or to procedures that have entailed sexual desensitization.

As a result of this widening of its terms, two reports were forthcoming from the committees, the first debating ethical issues related to the medical treatment of people with disabilities (hereafter the First Report)¹⁹ and the second specifically directed at the involuntary or coerced sterilization of intersex people in Australia (hereafter the Second Report).²⁰ The Second Report, in combination with the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013, directly challenges the ethical and medical practices of healthcare practitioners, both past and present. It lists fifteen recommendations, all of which affect healthcare professionals treating intersex individuals, and which will lead to significant reform in practices if accepted.

The recommendations fall into five broad categories of concern that address the following issues: the terminology used in relation to intersex, the guidance and oversight of treatment, the decisionmaking regarding treatment, the management of treatment and research related to intersex, and the cessation and regulation of dexamethasone in the prenatal treatment for one form of intersex, congenital adrenal hyperplasia (CAH). The overall intention of the Second Report is to ensure that valid consent is obtained, that any proposed treatment has merit, and that neither the parents nor intersex individuals are coerced into treatment. This, of course, further entails all the issues of central concern to healthcare professionals as set out in the *National Statement on Ethical Conduct in Human Research* (2007, rev. 2013),²¹ such as dignity, respect, justice, beneficence, and nonmaleficence.

Each of these categories will be briefly outlined. First, the Second Report recommends the revision of the terminology in use both in government and in other organizations, and its review among health professionals and in health organizations, in order to move away from classifying individuals as having "disorders of sexual development"; this terminology is to be replaced with either the term "intersex" or "differences of sexual development" when addressing "genetic or phenotypic variations that do not necessarily require medical intervention in order to prevent harm to physical health."²² The intention here is to recognize that while intersex involves physical differences in the sex organs of the individual—to varying degrees, dependent on cause—where there is no danger to the health of the individual, those differences should be respected.

Relatedly, the second category of interventions seeks to minimize the former (and still current) tendency toward physical "normalization" of the individual toward an assigned sex in infancy, through surgical and/or hormonal treatment (generally on the basis of psychosocial motivations). To that end, the report recommends a set of guidelines administered and managed by an interdisciplinary team within a "human rights framework," and it is further recommended that such dedicated teams should be established in treating organizations that encompass the range of expertise available from both medical and nonmedical specialisms, to which "all intersex people should have access." ²³

The third category of recommendations has connections to the issues discussed in 2013 in relation to who has the jurisdiction to make decisions for those who cannot do so themselves. The First Report of the committees found that responsibility should continue to rest with the Family Court regarding decisions on irreversible procedures for people with disabilities, although with improved criteria. ²⁴ This was the distinguishing criterion described previously in the case of Jamie's parents, who could make decisions on Jamie's behalf about medical treatments that were reversible but not about those that were irreversible. The accepted medical treatment for intersex infants involves similarly irreversible hormonal treatments and surgical procedures, but they are most often performed in infancy or early childhood. To date, the treatment of intersex children has not fallen within the Family Court's bounds of duty of care to uphold the "best interests of the child"; instead, it has remained in the power of medical specialists in consultation with parents or, as the OII submitted, has been "managed according to standard therapeutic protocols." ²⁵

The Second Report thus recommends that there be "oversight" of the "complex and contentious" treatments performed on "intersex people who are unable to make decisions on their own treatment." It nominates the bodies to have that oversight as the Family Court or "a civil and administrative tribunal." To facilitate the practical implementation of that responsibility, it further recommends that the Senate Standing Committees 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" and that all such tribunals be adequately funded for the purpose. ²⁶

The better management of treatment and research related to intersex, the fourth category of concerns, encompasses five recommendations. It is recommended that guidelines be drafted for the "treatment of common intersex conditions based on medical management, ethical, human rights and legal principles," to be conducted by "the special medical procedures advisory committee." It is further

recommended that the special medical procedures advisory committee should be referred to for decisions regarding "complex medical interventions" and that the committee report its findings to "whichever body is considering the case." Further suggestions for appropriate management go to supporting (through the mandatory provision of information about) and facilitating interaction with intersex support groups (through adequate funding of such organizations). Furthermore, the Commonwealth government is urged to support the establishment "of an intersex patient registry" and the funding of prospective and longitudinal research on "clinical outcomes for intersex patients."²⁷

The final two recommendations of the Second Report relate to the use of dexamethasone in the prenatal treatment of CAH infants. In the context of a discussion of the contentious nature of the clinical use of dexamethasone for this purpose, the Second Report recommends that the appropriate regulation of the drug's use be investigated and, finally, that, "effective immediately," its use for this purpose "only take place as part of research projects that have ethics approval and patient follow-up protocols." What remains to be said is that the Second Report is notable for the depth of and the unusual level of recourse to original, peer-reviewed research, and for the efforts that have been made to address the complex technical nature of the inquiry and the "differences of view between stakeholders regarding the published research." ²⁸

The Second Report was released on October 25, 2013, and in the short time that has intervened since the finalization of this article, there has been little time for the impact of the recommendations to be felt or to be debated. If the recommendations are accepted and implemented, the practical implications for the clinical practices of healthcare professionals are evident. Not least, medical teams would need to make recourse to the Family Court or tribunals before commencing irreversible "normalizing" procedures and treatments. However, it should also be clear from the breadth of the recommendations included in it that Australia is moving toward the world's best practice.

Notes

- Cregan K. Who do you think you are? Childhood and identity in Australian healthcare ethics. Cambridge Quarterly of Healthcare Ethics 2013;22(3):232–7.
- 2. Tomazin F. "Suddenly she's there": Daughter and donor dad united. *The Age* 2013 Mar 17; available at http://www.theage.com.au/victoria/suddenly-shes-there-daughter-and-donor-dad-united-20130316-2g7mv.html (last accessed 9 June 2013).
- 3. Law Reform Committee. *Inquiry into Access by Donor-Conceived People to Information about Donors*. Melbourne: Victorian Government Printer; 2012.
- 4. Parliament of Victoria. *Inquiry into Access by Donor-Conceived People to Information about Donors: Victorian Government Response, August 2013.* Melbourne: Parliament of Victoria; 2013, at 7.
- 5. See note 1, Cregan 2013.
- Tomazin F. Push to give "donor babies" right to know. The Age 2013 June 9; available at www.theage. com.au/Victoria/push-to-give-donor-babies-right-to-know-20120608-2nwxt.html (last accessed 9 June 2013).
- 7. Family Court of Australia. *Re Jamie* [2011] FamCA 248; 2012; available at http://www.familycourt.gov.au/wps/wcm/connect/FCOA/home/ (last accessed 13 Oct 2013).
- 8. Family Court of Australia. *Re Jamie* [2013] FamCAFC 110; 2013; available at http://www.familycourt.gov.au/wps/wcm/connect/FCOA/home/ (last accessed 13 Oct 2013).
- Legal and Constitutional Affairs Legislation Committee. Inquiry Report on the Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 [Provisions]. Canberra: Senate Legal and Constitutional Affairs Committee Secretariat; 2013.

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- The Senate has two such committees, and the report was by the Senate's Legal and Constitutional Affairs Legislation Committee.
- 11. See note 9, Legal and Constitutional Affairs Legislation Committee 2013, at 3.73.
- 12. See note 9, Legal and Constitutional Affairs Legislation Committee 2013, at 3.66.
- 13. See note 9, Legal and Constitutional Affairs Legislation Committee 2013, submission 8, page 3, cited at 3.5.
- 14. See note 9, Legal and Constitutional Affairs Legislation Committee 2013, at 1.11.
- 15. In this case, the Senate's Community Affairs Reference Committee.
- 16. Community Affairs References Committee. *Involuntary or Coerced Sterilisation of Intersex People in Australia*; 2013; available at http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Involuntary_Sterilisation (last accessed 1 Dec 2013).
- 17. See note 16, Community Affairs References Committee 2013, report 2, at 1.2.
- 18. See note 16, Community Affairs References Committee 2013, report 2, at 1.1.
- 19. Commonwealth of Australia. First Report: Involuntary or Coerced Sterilisation of People with Disabilities in Australia. Canberra: Senate Community Affairs Committee Secretariat; 2013.
- 20. Commonwealth of Australia. Second Report: Involuntary or Coerced Sterilisation of Intersex People in Australia. Canberra: Senate Community Affairs Committee Secretariat; 2013.
- Cregan K. Regulating ethics in Australian healthcare research. Cambridge Quarterly of Healthcare Ethics 2012;21(3):384–90.
- 22. See note 20, Commonwealth of Australia 2013, Second Report, at 2.20, 2.21.
- 23. See note 20, Commonwealth of Australia 2013, Second Report, at 3.130, 3.133.
- 24. See note 20, Commonwealth of Australia 2013, Second Report, at 5.2.
- 25. See note 20, Commonwealth of Australia 2013, Second Report, at 5.7.
- 26. See note 20, Commonwealth of Australia 2013, Second Report, at 4.43, 5.30, 5.31, 5.32.
- 27. See note 20, Commonwealth of Australia 2013, Second Report, at 5.38, 5.41, 5.70, 5.72, 6.11.
- 28. See note 20, Commonwealth of Australia 2013, Second Report, at 6.25, 6.27, 1.5.