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Third submission on the Involuntary or Coerced Sterilisation of People with Disabilities in Australia

3 June 2013

1. What is intersex?

Intersex is a term which relates to a range of natural biological traits or variations that lie between “male” and “female”. An intersex person may 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. Intersex is always congenital and can originate from genetic, chromosomal or hormonal variations.

2. OII Australia

Organisation Intersex International Australia Limited (OII Australia) is a national body by and for intersex people. We promote the human rights of intersex people in Australia, and provide information, education and peer support.

OII Australia is a not-for-profit company, recognised by the Australian Taxation Office as a charitable institution. OII Australia employs no staff and receives no public funding.

3. About this supplementary submission

This is our second supplementary submission, our third submission, in respect of the Senate’s inquiry into the involuntary or coerced sterilisation of people with disabilities. This submission is occasioned by two recent developments:

- The publication in May of a report on female genital mutilation by the Attorney General’s Department.
- The filing of a relevant court case in the US by the Southern Poverty Law Center, Advocates for Informed Choice, pro bono lawyers and the parents of child M.C.

In connection with these developments, we have taken the opportunity to table a 2005 Human Rights Investigation report on medical normalization.

4. Contents

5. Government inquiry into the legal framework around Female Genital Mutilation

The Attorney General's Department has just published a review of legal frameworks around Female Genital Mutilation. It is defined as follows:

> *5.1.33 Female genital mutilation—definition*
> *In this Division, female genital mutilation means:*
> *(a) a clitoridectomy; or*
> *(b) excision of any other part of the female genital organs; or (c) infibulation or any similar procedure; or*
> *(d) any other mutilation of the female genital organs.*

The report finds such surgeries abhorrent:

> *Female genital mutilation is an abhorrent practice. It intentionally alters and causes harm to female genital organs for no medical reason and can have serious and long-lasting consequences, including infertility, an increased risk of childbirth complications, and maternal and infant mortality during and shortly after childbirth.*[1]

However, there are two exemptions where such mutilation is permitted:

> *5.1.36 Exception—medical procedures for genuine therapeutic purposes*
> *(1) It is not an offence under this Division to perform a medical procedure that has a genuine therapeutic purpose or to take a person, or arrange for a person to be taken, from this jurisdiction with the intention of having such a medical procedure performed on the person.*
> *(2) The fact that a procedure is performed as, or as part of, a cultural, religious or other social custom is not to be regarded as a genuine therapeutic purpose.*
>
> *5.1.37 Exception—sexual reassignment procedures*
> *…*
> *(2) A sexual reassignment procedure means a surgical procedure to give a female, or a person whose sex is ambivalent, the genital appearance of a particular sex (whether male or female).*

These exemptions explicitly permit "therapeutic" surgeries on intersex infants, those with "ambivalent" sex, i.e. intersex children diagnosed during infancy.

In our second submission to this Inquiry we detail both the paucity of research on long term health outcomes relating to intersex people, but also the trauma revealed in the studies that exist.

To briefly recap the research on surgical outcomes, a Warne *et al.* study at the Royal Children's Hospital, Melbourne, reported in 2005. Schützmann reports the findings:

> *In the study by Warne et al. (2005), the persons with DSD [intersex] were similarly as distressed as a comparison group of chronic somatically [bodily] ill persons. Even though the rates of psychological distress are not directly comparable to our measures, the results similarly indicate markedly increased distress in persons with DSD. (For comparison, German prevalence rates of significant psychological distress in chronically somatic [bodily] ill persons range from 43% to 50%, see Harter, 2000).*[2]

[1] Attorney General of Australia, 24 May 2013, Review of Australia's Female Genital Mutilation legal framework – Final Report, http://www.ag.gov.au/Publications/Pages/ReviewofAustraliasFemaleGenitalMutilationlegalframework-FinalReportPublicationandforms.aspx, accessed 30 May 2013.
[2] Schützmann, K. et al, February 2009, *Psychological Distress, Self-Harming Behaviour, and Suicidal Tendencies in Adults with Disorders of Sex Development*, in *Archives of Sexual Behaviour* 38(1):16-

All but one of 37 adult participants in Schützmann's own pilot study had undergone surgeries, most including gonadectomies (sterilisation), but commonly also clitoris reduction, and also vaginoplasties and mastectomies. The study found clear evidence of psychological distress:

> *The prevalence rates of self-harming behavior and suicidal tendencies in the sample of persons with DSD were twice as high as in a community based comparison group of non-traumatized women, with rates comparable to traumatized women with a history of physical or sexual abuse.6*

Within the intersex cohort, the findings were significantly worse for people who had undergone sterilisation:

> *Within the total sample, the subgroup of persons with gonadectomy was significantly more distressed, with depression being particularly increased.*

We believe that the outcomes of infant genital surgeries on intersex infants are no different from the outcomes of genital mutilation on girls. Some of the surgeries are identical. The settings for such surgeries are irrelevant; female genital mutilation is considered no less abhorrent if it is carried out by a doctor.

Cultural practices and female genital mutilation

The exemptions from protection against female genital mutilation do not permit procedures for cultural purposes:

> *5.1.36 Exception—medical procedures for genuine therapeutic purposes …*
> *(2) The fact that a procedure is performed as, or as part of, a cultural, religious or other social custom is not to be regarded as a genuine therapeutic purpose.*

However, the 2006 Consensus Statement on the management of intersex conditions, which is the basis for the 2013 Victorian Health Department decision making framework on the treatment of intersex infants and children explicitly cites cultural, social ("psychosocial") rationales for surgery:

> *minimizing family concern and distress*
> *mitigating the risks of stigmatization and gender-identity confusion.*[3]

The Victorian Health Department also describes these social risks, in terms that might equally apply to women who have not undergone female genital mutilation in societies where that is the norm, such as marriageability, social and cultural disadvantage and social stigma:

- *risk of social or cultural disadvantage to the child, for example, reduced opportunities for marriage or intimate relationships, or reduced opportunity for meaningful employment and capacity to earn an income*
- *risk of social isolation, restrictions or difficulties, for example, caused by embarrassment or social stigma associated with having genitalia that does not match the gender in which the person lives.* [4]

33, http://link.springer.com/article/10.1007%2Fs10508-007-9241-9 accessed 7 February 2013

[3] Houk, Hughes, Ahmed, Lee, Writing Committee for the International Intersex Consensus Conference Participants, 2006, *Summary of Consensus Statement on Intersex Disorders and Their Management*, in Pediatrics, doi:10.1542.peds.2006-0737, http://www.pediatrics.org/cgi/doi/10.1542/peds.2006-0737 accessed 21 November 2012.

[4] Victoria Health Department, February 2013, *Decision-making principles for the care of infants, children and adolescents with intersex conditions,* http://docs.health.vic.gov.au/docs/doc/Decision-making-principles-for-the-care-of-infants-children-and-adolescents-with-intersex-conditions*, accessed 27 February 2013.*

Surgery to change the appearance of the genitals of intersex infants is not medically necessary, it's considered socially and culturally necessary.

Kuhnle and Krahl (2002) found, in research in Malaysia, that the sex assignment of intersex infants varied not simply based on their diagnosis but also the culture of their parents and the position of women in that culture.

> *…we would like to analyze briefly the cultural and ethnic differences of the three races living in Malaysia and present some data which in our opinion illustrates the different ways in which intersex patients are accepted.*
>
> *The ethnic Malay women are Muslims… the independence and the economic power of Malay women can be substantial… The condition of women is quite different in the ethnic Indian and Chinese communities… In neither culture or tradition were women able to inherit or control their own fortune… Among the Indian community girls usually mean a significant financial burden to the family, since depending on the social status of the family a significant dowry is expected, and to marry off several girls can be a financial disaster. In contrast, boys will increase the family's fortune*[5]

The outcome of such cultural norms for intersex infants is thus:

> *While we were working with different ethnic groups, it was never difficult to convince a Muslim family to assign a severely virilized girl or an undervirilized boy to the female gender. This was not the case for Chinese and Indian families, who on several occasions took off with their ambiguously born child when female sex assignment (or reassignment) was suggested.*

Kuhnle and Krahl go on to ask:

> *Is culture or society imposing a certain gender role, or do individuals shape their own gender roles? The few available case reports, including our own, seem to indicate that intersex individuals find their own gender independent and maybe even undisturbed by external factors*

The treatment of intersex infants in Malaysia, and also in Australia, is just as culturally-specific as the cases argued to support female genital mutilation. It is simply the case that it can be difficult to objectively observe our own cultural norms.

We believe that genital surgeries on intersex infants to give them the appearance of a specific sex are just as mutilating as identical surgeries on girls. In our view, the different language used to describe such surgeries reflects a degree of cultural relativism and double standards.

Intersex infants should receive the same protection from mutilation that girls receive. Surgical intervention should conform to the principles established in the Swiss National Advisory Commission on Biomedical Ethics report[6], discussed in our first[7] and second[8] submissions.

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[5] Kuhnle and Krahl, 2002, *The Impact of Culture on Sex Assignment and Gender Development in Intersex Patients*, in *Perspectives in Biology and Medicine*, volume 45, number 1 (winter 2002):85–103, The Johns Hopkins University Press.

[6] Swiss National Advisory Commission on Biomedical Ethics, November 2012, *On the management of differences of sex development, Ethical issues relating to "intersexuality, Opinion No. 20/2012"*, available in English via http://www.bag.admin.ch/nek-cne/04229/04232/index.html?lang=en accessed 21 November 2012.

[7] OII Australia, 2013, Submission to the Senate Inquiry on involuntary or coerced sterilization, https://senate.aph.gov.au/submissions/comittees/viewdocument.aspx?id=a13a3d26-2288-41b8-9555-1e5ffdf2d6a1

That is, treatment to modify the appearance of genitals should wait until the patient can personally give fully informed consent.

6. The M.C. Case

Advocates for Informed Choice (AIC), the Southern Poverty Law Center, pro bono lawyers and parents Pam and Mark Crawford filed, in May 2013, "the first ever impact litigation lawsuit" against the state of South Carolina Department of Social Services, the Greenville Hospital System, Medical University of South Carolina and individual employees for, AIC state, "performing an irreversible and medically unnecessary surgery on an infant who was in the state's care at the time of the surgery".

The Southern Poverty Law Center comment:

> *In M.C.'s condition, there is no way to tell whether the child will ultimately identify as a boy or a girl. Instead, the doctors decided to assign M.C. female and change his body to fit their stereotype of how a girl should look.*[9]

M.C. was born with an intersex variation known as ovotestis. The future gender identity of all intersex people cannot be predicted with accuracy, and between 8 and 40% of intersex people have issues with their sex classification, depending upon the diagnosis[10].

AIC state:

> *Despite not knowing whether M.C. would grow up to be a man or woman, or whether he would elect to have any surgery at all, the defendants performed sex-assignment surgery on a 16-month-old child, removing his healthy phallus in an attempt to make M.C. a girl. M.C. has shown signs of developing a male gender and now, at age 8, has clearly identified himself as a boy.*[11]

Professor Elizabeth Reis wrote about the M.C case at Nursing Clio. Reis says:

> *M.C. had been identified male at birth, but his genitals were sufficiently indeterminate that surgeons removed his ambiguous phallus, a testis, and testicular tissue on one gonad, and surgically created an ostensible approximation of female genitals. The suit asserts that there was no medical need for this surgery, which was meant to permanently "fix" this child and turn him into an unequivocal girl, but it did him more harm than good. M.C., now eight years old, feels more like a boy, lives as a boy, and heartbreakingly has asked his mother, "When will I get my penis?"*[12]

Anne Tamar-Mattis, director of AIC, comments:

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[8] OII Australia, 2013, Second submission to the Senate Inquiry on involuntary or coerced sterilization, https://senate.aph.gov.au/submissions/comittees/viewdocument.aspx?id=d3758d86-a7cb-483c-a8fa-a6515ee5ff8f

[9] Southern Poverty Law Center, 14 May 2013, *Groundbreaking SPLC lawsuit accuses South Carolina, doctors and hospitals of unnecessary surgery on infant,* http://www.splcenter.org/get-informed/news/groundbreaking-splc-lawsuit-accuses-south-carolina-doctors-and-hospitals-of-unnece#.UZKsSEmhS1I accessed 15 May 2013.

[10] See Furtado, 2012, reference in OII Australia's second submission to this inquiry.

[11] Advocates for Informed Choice, May 2013, http://aiclegal.org/wordpress/wp-content/uploads/2012/10/050714_Crawford_Complaint_Release_FINAL_FINAL.pdf?utm_source=AIC+mailing+list&utm_campaign=7e1f32960f-&utm_medium=email&utm_term=0_e174173e96-7e1f32960f-412569761, accessed 15 May 2013.

[12] Professor Elizabeth Reis, 17 May 2013, *Do No Harm: Intersex Surgeries and the Limits of Certainty*, at Nursing Clio, http://nursingclio.org/2013/05/17/do-no-harm-intersex-surgeries-and-the-limits-of-certainty/, accessed 18 May 2013.

> *No one advocated for M.C.'s rights when this decision was made at a time when the state was entrusted with his safety and well-being.*

The lawsuit, filed in both state and federal courts, describes the surgery as a violation of the Constitution. The Southern Poverty Law Center say:

> *The lawsuit describes how the defendants violated M.C.'s substantive and procedural due process rights, outlined in the 14th Amendment, by subjecting M.C. to the unnecessary surgery "without notice or a hearing to determine whether the procedure was in M.C.'s best interest."*
>
> *It also charges that the doctors committed medical malpractice by failing to obtain adequate informed consent before proceeding. The defendants told M.C.'s guardians to allow the sex assignment surgery but did not provide information regarding the surgery's catastrophic risks… Most important, they did not tell them that the procedure was medically unnecessary.*

There are several unique characteristics of this case – including M.C.'s status as a ward of the state at the time of surgery and the limited time elapsed since surgery.

Like the Southern Poverty Law Center, Advocates for Informed Choice, we believe that the risks associated with infant genital surgery as serious, and not limited to a choice of the wrong sex and associated psychological harm, but also include damage to sexual function, sterility, and a need for multiple corrective surgeries as his body grows and matures, and lifelong medical treatment. Similar risks are acknowledged by the Australian government in relation to female genital mutilation.

Hida Viloria, global chair of OII, comments to the BBC World Service[13] that doctors have known for years that non-consensual cosmetic surgery on infants can have devastating consequences – even when the child's developing gender identity conforms to the surgical outcome. Professor and bioethicist Alice Dreger, writing in The Atlantic, concurs:

> *M.C. should certainly be supported in his self-identification as a boy, but one would hope that the courts might understand his rights to have been violated even if he had grown to be a girl…*
>
> *Many intersex women who had their clitorises surgically shortened in infancy are legitimately angry about having had tissue (and thus sensation) taken from them.*
>
> *…Doctors have believed for many years, based on little to no evidence (and in some cases, faked evidence), that children require male-typical or female-typical genitals, matched to their gender assignments, in order to grow up psychologically healthy.*[14]

In her comment about "faked evidence", Dreger is referring to the case of David Reimer. Described by biographer John Colapinto as "one of the most famous patients in the annals of medicine"[15], Reimer was an infant boy who lost his penis in a failed circumcision, and was then raised as a girl. The "classic" case study was described by Professor John Money as a success, and it directly led to the existing protocols for the treatment of intersex infants. The failure of the case was exposed in 1997 by Professor Milton Diamond and Dr H. Keith Sigmundson in *Archives of Pediatrics and Adolescent Medicine*, No. 151. In that paper they say:

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[13] Hida Viloria interview with the BBC World Service, http://www.bbc.co.uk/programmes/p0188d3z, accessed 19 May 2013.
[14] Professor Alice Dreger, When to Do Surgery on a Child With 'Both' Genitalia, http://m.theatlantic.com/health/archive/2013/05/when-to-do-surgery-on-a-child-with-both-genitalia/275884/, accessed 18 May 2013.

> *This report is a long term follow-up to a "classic" case in the pediatric, psychiatry, and sexology literature. In this case an XY individual had his penis accidentally ablated and was subsequently raised as a female. The initial reports were that this individual was developing into a normally functioning female. The present findings show the individual did not accept this sex of rearing. At puberty this individual switched to living as a male and has successfully lived as such from that time to the present. The significant factors in this switch are presented. In instances of extensive penile damage to infants it is standard to recommend rearing the male as a female. Subsequent cases should, however, be managed in light of this new evidence.*
>
> *Long term follow-ups of case reports are unusual but often crucial. This up-date to a case originally accepted as a "classic" in fields ranging from medicine to the humanities completely reverses the conclusions and theory behind the original reports.*

The paper shows how the case established clinical norms which persist today:

> *Among the more difficult decisions physicians have to make involve cases of ambiguous genitalia or significantly traumatized genitalia. The decision as to how to proceed typically follows the following contemporary advice: "The decision to raise the child as a male centers around the potential for the phallus to function adequately in later sexual relations (pp. 580)." and "Because it is simpler to construct a vagina than a satisfactory penis, only the infant with a phallus of adequate size should be considered for a male gender assignment (pp. 1955)" These management proposals depend upon a theory which basically says: "It is easier to make a good vagina than a good penis and since the identity of the child will reflect upbringing, and the absence of an adequate penis would be psychosexually devastating, fashion the perineum into a normal looking vulva and vagina and raise the individual as a girl." Such clinical advice, concerned primarily with surgical potentials, is relatively standard in medical texts and reflects the current thinking of many pediatricians.*
>
> *This management philosophy is based on two pediatric beliefs held strongly enough that they might be considered postulates: 1) individuals are psychosexually neutral at birth, and 2) healthy psychosexual development is dependent upon the appearance of the genitals. These ideas arise most strongly from the original work of Money and colleagues. The following are typical pronouncements from that research: "… erotic outlook and orientation is an autonomous psychological phenomenon independent of genes and hormones, and moreover, a permanent and ineradicable one as well (pp. 1397)."; "It is more reasonable to suppose simply that, like hermaphrodites, all the human race follow the same pattern, namely, of psychological undifferentiation at birth." The first postulate was derived, not from normal individuals but from hermaphrodites and pseudohermaphrodites and the second postulate had only anecdotal support.*
>
> *Money no longer holds such extreme views but his involvement in one particular case was significant enough that it became a totem in the lay press and a classic for the academic and medical community. And, as quoted above, the textbooks have not kept abreast of the new thinking.*

A copy of the full paper can be found at http://www.hawaii.edu/PCSS/biblio/articles/1961to1999/1997-sex-reassignment.html and the case was later detailed in the book *As Nature Made Him: The Boy Who Was Raised as A Girl* by John Colapinto.

David Reimer took his own life in 2004[15].

[15] John Colapinto, 3 June 2004, *Gender Gap: What were the real reasons behind David Reimer's suicide?,* at *Slate*, http://www.slate.com/articles/health_and_science/medical_examiner/2004/06/gender_gap.single.html, accessed 1 June 2013.

Professor Elizabeth Reis also reflects on the culturally-specific history of these "therapeutic" protocols. While she refers to the US, the same cultural norms equally apply to Australia:

> *Many of the news sources surrounding the recent case of M.C. have reported that damaging surgeries such as these have been happening since the 1950s. While it is true that during the 1950s infant surgeries became standard protocol, interventionist surgeries to "repair" ambiguous genitals and to change people into the supposed "correct" gender began long before the 1950s… Throughout American history, fears of homosexuality have motivated intersex surgeries, as some physicians wanted to make sure that patients were certain of their sex so that they wouldn't be attracted to the "wrong" sex.*

The case has received press attention, including in the New York Times and the Washington Times. From the latter:

> *[this case] brings attention to a condition that gets very little attention aside from the sensationalism surrounding the occasional celebrity rumors or the misunderstanding of intersex athletes like South African Olympic runner Caster Semenya…*
>
> *Moreover, this case questions who gets to decide what kind of procedures can be performed on intersex children before they are old enough to consent to a life-altering procedure that is not medically necessary… this case differentiates between a life-saving or medically necessary procedure and one that is cosmetic and could have catastrophic physical, psychological and emotional implications for the individual in the future.*[16]

The Washington Times quoted Claudia Astorino of OII-USA, who talks about the M.C. case and broader media coverage of intersex, at the blog Autostraddle:

> *This case is important for a lot of reasons. First off, it's always a big deal when intersex is mentioned in the news at all in a way that doesn't stigmatize, fetishize, or sensationalize intersex. There are a lot of great articles and TV specials that have focused on intersex over the years, but when intersex is covered on the small screen or in column inches, it's oftentimes handled in a less-than-sensitive way that belies a misunderstanding of what intersex is in the first place…*
>
> *These are not storylines that serve to accurately define what intersex is, discuss why intersex is such a highly-charged issue, and help people to understand that we're neither unrelatable weirdos, nor objects of fascination whose bodies and identities are available for public consumption. We're just people, who happen to be intersex. There are a lot of messed-up things that are happening to us right now, but we are just people…*
>
> *This case is also important because it illustrates a radical shift in perspective about who gets to consent to what is done to intersex bodies. Doctors and parents have traditionally made decisions as to whether surgery and other medical procedures should be performed on intersex children. In part, this is because we conceive of intersex as a medical problem. There are actual health problems that are associated with some forms of intersex [but] this doesn't mean that intersex in and of itself is a medical problem.*[17]

In the context of the Australian government's report on female genital mutilation, analysis by Erica Landau in the Huffington Post is pertinent:

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[16] Washington Times, *Adoptive parents sue over son's sex-assignment surgery,* http://communities.washingtontimes.com/neighborhood/world-our-backyard/2013/may/18/adoptive-parents-sue-over-sons-sex-assignment-surg/, accessed 19 May 2013.

[17] Claudia Astorino, *South Carolina Intersex Lawsuit A Major Step In Ending Nonconsensual Surgery to "Fix" Intersex Kids,* http://www.autostraddle.com/south-carolina-intersex-lawsuit-a-major-step-in-ending-nonconsensual-surgery-to-fix-intersex-kids-177169/, accessed 18 May 2013.

> *…to see this simply as an instance of medical malfeasance and negligence is to miss the larger cultural point. Doctors didn't just treat a condition or a disease incorrectly or too hastily. They didn't treat a medical disease at all. The procedure was done without any medical justification whatsoever, as is historically the case with most intersex infants who undergo such operations.*
>
> *Instead, they treated a social illness, for which the remedy is making bodies deemed "abnormal" conform to society's strict sex and gender guidelines, and in the process they mutilated a child in their care…*
>
> *There is nothing wrong with a body that defies social expectations, but there is something abhorrent and ghastly about a compulsion for and obsession with clear gender and sex distinctions that shortchange us all and result in victimizing and mutilating people like M.C.*[18]

Here in Australia, we have had our own M.C. case, in the sense that an infant who underwent clitoridectomy as an infant has appeared before the Family Court. This case, *In the Matter of the Welfare of a child A* (1993) FLC 92-402 (per Mushin J) saw a mother blamed for the gender identity of her suicidal child, who was to be sterilized on reassignment to male with Family Court approval. We discuss this case in our second submission to the Inquiry[8].

We note that adrenal insufficiency is also a characteristic of CAH, but this was not an issue in the matters before the Court. The current medical protocols for Congenital Adrenal Hyperplasia (CAH) continue to permit the same treatment as in *In the Matter of the Welfare of a child A*. The same situation, analogous to the case of M.C., has the potential to arise again in future.

We believe that the Australian government should not need to wait until the outcome of the US case of M.C. before making a determination to cease unnecessary surgeries to modify the genital appearance of intersex infants.

7. San Francisco Human Rights Investigation, 2005

Many commentators, including Alice Dreger and Claudia Astorino comment on the intentions behind the surgery in the M.C. case – but as Hida Viloria said, the problems associated with infant cosmetic genital surgeries have been understood for many years.

On 3 June we took the opportunity to table a 2005 Human Rights Investigation into the Medical “Normalization: of Intersex People, by the Human Rights Commission of the City and County of San Francisco. This is likely to be the first human rights report into the treatment of intersex people, certainly in the English language. It shows that the issues described in this and our previous submissions, and the submissions of the AIS Support Group Australia and the National LGBTI Health Alliance are not new issues. The San Francisco inquiry began in 2003.

[18] Erica Landau, 31 May 2013, *Carolina Infant's Mistaken Sex Assignment Surgery More Than a Case of Malpractice,* http://www.huffingtonpost.com/erica-k-landau/carolina-infants-mistaken-sex-assignment-surgery-more-than-a-case-of-malpractice_b_3369340.html, accessed 1 June 2013.

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