AIS SUPPORT GROUP AUSTRALIA
Support for people and families affected by AIS and similar conditions.
P.O. Box 1089, Altona Meadows, Victoria Australia. 3028
Telephone/facsimile: 03 9315 8809
Website: http://www.vicnet.net.au/~aissg
Email: aissg@iprimus.com.au

5 July 2008

Committee Secretary
Senate Legal and Constitutional Affairs Committee
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Phone: +61 2 6277 3560
Fax: +61 2 6277 5794
Email: legcon.sen@aph.gov.au

To whom it may concern,

INQUIRY INTO THE EFFECTIVENESS OF THE COMMONWEALTH SEX DISCRIMINATION ACT 1984 IN ELIMINATING DISCRIMINATION

Thank you for the opportunity to provide the Senate Legal and Constitutional Affairs Committee with details about the ongoing discrimination faced by people with genetic intersex conditions (also known medically as "disorders of sex development").

The AIS Support Group

The Androgen Insensitivity Syndrome Support Group Australia (AISSGA), formed by the Director of Endocrinology at the Royal Children's Hospital in Melbourne in 1986, is without doubt the preeminent group for families affected by intersex conditions in Australia. Since being founded over 20 years ago, our group has assisted many families affected by intersex conditions across Australia and beyond, provided submissions to the Commonwealth and State Law Reform Commissions, participated in a number of Ministerial Advisory Committees (predominently in Health and Justice), and has delivered speeches and presentations at many conferences and fora including the NSW Anti-Discrimination Board's 'Neglected Community Forum' at NSW Parliament House in 2003. Importantly, although the group became independent from hospitals some 10 years ago when it became an Incorporated Association, it remains committed to working with the medical community to improve the treatment of people affected by intersex conditions. Moreover, although the AIS Support Group was founded for families affected by Androgen Insensitivity Syndrome and similar intersex conditions, it's incorporated status and membership grew almost 10 years ago to the point that we became the main advocacy group for people affected by all intersex conditions in Australia.

Intersex Conditions – Definitions, Identity and Representations

The Australian Medical Association Position Statement on ‘Sexual Diversity and Gender Identity’ defines a person with an intersex condition as a person ‘born with sex chromosomes, external genitalia, or an internal reproductive system that is not exclusively either male or female. This word replaces hermaphrodite.’ The AIS Support Group agrees with this definition. Having an intersex condition is a matter of biological fact. It is not sufficient for someone who doesn’t have an intersex condition to merely “identify” as an intersex person and therefore be classified as such. This is offensive to people with intersex conditions and their families because it doesn’t respect our experiences and adversely impacts our ability to come together as a community. There is so much shame and stigma involved in having an intersex condition, misrepresntations about what intersex is confuses parents of children with intersex conditions and spreads misinformation leading to erroneous stereotypes. Thus, the only people that should be called intersex – either as a sex or as an identity – are people with intersex conditions. Not doing so would be akin to recognising someone as an indigenous Australian or Aboriginal just because they identify as such, irrespective of whether they are Indigenous Australian or Aboriginal.

The Royal Children’s Hospital in Melbourne report intersex conditions occur in approximately 1 in 1000 live births in Australia, with about 25% of them also being born atypical genitalia. The AIS Support Group’s brochure for families of infants with ambiguous genitalia is enclosed for your information.

Although people with intersex conditions cleary fit into the category of “sex diverse”, where sex means the category of being biologically male or female, people with intersex conditions are rarely “gender diverse”. The vast majority of people with intersex conditions identify as male OR female, and in accordance with the gender they were raised. This is a significant difference between the intersex community and the transgender, transsexual, pansexual and crossdresser communities.

There are, however, a small percentage of people with intersex conditions who identify as having a gender that is both male and female. In this sense, they have a sex that is intersex, and a gender that is also intersex. The AIS Support Group estimates this is true of about 5% of people with intersex conditions, but is likely to increase as society’s awareness and acceptance of intersex conditions grow.

The AIS Support Group has an excellent and proud history of working collaboratively with the gay, lesbian and transgender community. Regretably however, there are a small number of groups for the transgender and gender variant community that have misrepresented people with intersex conditions in the past, and some continue to do so. Consequently, the AIS Support Group respectfully asks the Commission to be mindful of what information and sources it uses to progress with its Sex and Gender Diversity Project. The intersex community are the people best placed to understand our issues and, although the intersex community has increasingly been finding its own voice, it is still not as loud as that of other sex and gender groups and runs the risk of being ignored.

Marriage in Australia

Marriage in Australia is only permitted between a man and a woman.[1] Although the decision in Kevin [2] has made the situation arguably clearer for people with intersex conditions who identify as

---

[1] Marriage Act 1961 (Cth) s 5.

male or female and are accepted in the community as such, the situation for people with intersex conditions who also identify and live in an intersex gender role remains unclear. People with intersex conditions are, by definition, not exclusively male or female in terms of biological sex; they are biologically both. Denying them the right to marriage is tantamount to discrimination on the basis of an impairment, sex and/or physical features, and breaches Article 23 of the International Covenant on Civil and Political Rights.[3] One can only imagine what would happen if the Marriage Act prevented people from getting married due to any other genetic condition (diabetes, thalaseamia, haemophilia, and cyctic fibrosis).

Rights to Self Determination and Physical Integrity

A child's right to self determination and protection from irreversible, non-therapeutic surgical intervention was upheld by the High Court of Australia in Marion [4], which also held that the scope of parental authority did not extend to special medical procedures like sterlisation.[5] These special medical procedures also include the hormonal and surgical intervention of children with intersex conditions [6] and transsexualism. However, the medical community and governments in Australia (excluding the ACT government) still conduct these procedures on children with intersex conditions, denying children with intersex conditions their rights and arguably committing asault and gross medical negligence.

Interestingly, this is not the case with children with gender dysphoria (transsexualism). In those cases the doctors rightly seek the permission of the Family Court of Australia to provide irreversible, non-therapeutic intervention. [7] In the case of Re Alex, the Family Court determined a transsexual adolescent could not provide consent for his own hysterectomy and genital surgeries until he reached the age of majority. Further, hormone treatment could not commence until he reached the age of 16. This is in stark contrast with children with intersex conditions, whose fate relies solely on the doctors and whose irreversible treatment commenses shortly after birth. There is no Family Court arbitor in the process. No review. The High Court judgement of Marion is

---

[2] *Re Kevin (validity of marriage of transsexual)* [2001] FamCA 1074.

[3] *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976).

[4] Department of Health & Community Services v JWB and SMB, (1992) 175 CLR 218.

[5] Brady, Susan, Briton, John and Grover, Sonia, 'The Sterilisation of Girls and Young Women in Australia: Issues and Progress' (2001).

[6] See Merle Spriggs & Julian Savulescu, 'The ethics of surgically assigning sex for intersex infants' (2006) *Cutting to the Core: Exploring the Ethics of Contested Surgeries* 79-96. Professor Savulescu was Director of the Ethics of Genetics Unit at the Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne, Australia. He was also the Director of the Bioethics Program at the Centre for the Study of Health and Society at the University of Melbourne and the Chair of the Department of Human Services, Victoria, Ethics Committee. His opinion that surgeries on children with intersex conditions constitutes "special medical procedures" as defined by the High Court in Marion is especially significant as Professor Savulescu has previously worked with the team at the Royal Children's Hospital responsible for the clinical management of children with intersex conditions, and co-authored a paper reporting the outcomes of the Royal Childrens Hospital long-term follow-up study with that team. Also see Warne GL, S Grover, J Hutson, AH Sinclair, S Metcalfe, E Northam, J Freeman, E Loughlin, M Rillstone, P Anderson, E Hughes, J Hooper, S Todd, JD Zajac, and J Savulescu (2005) A long-term outcome study of intersex conditions. *Journal of Pediatric Endocrinology & Metabolism* 2005 Jun;18(6):555-6.

[7] *Re Alex: Hormonal Treatment for Gender Identity Dysphoria* [2004] FamCA 297.

completely ignored. Doctors decide what is in the best interests of the child and seek consent from the parents. This is despite the parents often not knowing all treatment options available, or that the High Court has determined parents don't have the right to consent to these surgeries. Worst still, governments continue to blindly ignore the advice of intersex activists informing them that these serious breaches continue.

It should also be noted that the same doctors that sought approval from the Family Court of Australia in Re Alex clinically manage children and adolescents with intersex conditions. Why then, don't they also seek permission for the treatment of children with intersex conditions? In other words, why do they discriminate against children with intersex conditions? Why does this genetic condition (i.e. intersex conditions) treated so differently to other conditions in terms of recognition of the right to physical integrity? If children with intersex conditions had another condition, or even transsexualism, the decision to have irreversible, nontherapeutic medical intervention would be reviewed by the Family Court of Australia and a Child Advocate appointed to act in their interests.

The High Court decision in Marion must be upheld. Failing this is clearly a breach of the fundamental rights of children with intersex conditions.

There are two international treaties that also recognise the rights of children with intersex conditions and protect them from irreversible, non-therapeutic treatment. Article 1 of the *International Covenant on Civil and Political Rights* recognises the right of an individual to self-determination.[8] Conducting irreversible, non-therapeutic surgeries on children removes this right. It is imposible for one to determine their future and development when irreversible decisions of severe consequence are made on your behalf, and without an independent arbiter like the Family Court.

The *United Nations Convention on the Rights of the Child* [9] states:

> **Article 2**
> 1. States Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's … sex, … disability … or other status.
>
> **Article 3**
> 1. In all actions concerning children, whether undertaken by public or private … administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration. [This includes hospitals and the doctors treating children with intersex conditions.]

---

[8] *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976).

[9] *United Nations Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 20 November 1989).

> 2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being … and, to this end, shall take all appropriate legislative and administrative measures.
>
> **Article 19**
> 1. States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.
>
> **Article 24**
> 1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.

Consequently, Australia also has international obligations to enforce the High Court's decision in Marion, to require medical professionals to seek the prior approval of the Family Court of Australia proir to conducting any irrreversible, non-therapuetic intervention on children with intersex conditions, and to provide children with intersex conditions the best treatment possible. The Australian government should no longer allow these treatments to continue, and should educate doctors, paediatric hospitals and medical insurers of their obligations in these circumstances.

Recommendations
People with intersex conditions continue to face legal discrimination in marriage and the application of fundamental protections to physical integrity provided by the High Court. The AIS Support Group respectfully requests the Senate Legal and Constitutional Affairs Committee look into these matters to ensure discrimination against people with intersex conditions is eliminated.

Thank you for the opportunity to make this submission. I look forward to the outcomes of your inquiry and invite you to contact me should you require any additional information.

Sincerely,

Tony Briffa JP
President, AIS Support Group Australia

Encl.

1. AIS Support Group Australia Inc., ‘A Guide for Parents of Children with Ambiguous Genitalia’ (2007).
2. AIS Support Group Australia Inc., ‘Comparison between Intersex Conditions and Transsexualism’ (2005).
3. Dreger, Alice Domurat, ‘Intersex and Human Rights – The Long View’ (2006) *Ethics and Intersex* 73-86.

Recommended treatment paradigm

1 *Obtain an accurate diagnosis.*

2 *Raise the child as a girl or a boy – expert medical advice will help you decide.*

3 *Obtain complete information about your child's condition.*

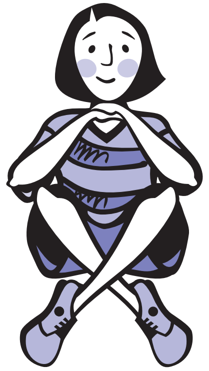
4 *Contact peer support groups that deal with your child's specific condition.*

5 *Seek appropriate counselling to help you (and your family) deal with your child's condition.*

6 *If surgery is medically required, discuss all treatment options and seek a second opinion. Do not rush into making a decision.*

7 *Inform your child about their condition in stages as they become old enough to understand certain concepts (such as people are different, not everyone is able to have children, etc).*

8 *Ensure your child is fully informed of their condition by the time they are around 16 years old, and allow them to make decisions about their treatment (such as hormone therapy and any surgeries).*



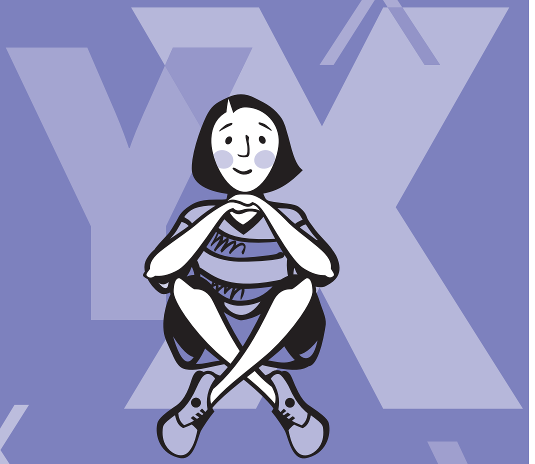
Contact us for support.
We've been through this too.

There are a number of support groups available for people affected by ambiguous genitalia and various intersex conditions. Your doctor can put you in touch with a group in your area, but you are also able to contact the following group for advice and referrals:

AIS Support Group Australia Inc.
PO Box 1089, Altona Meadows
Victoria 3028 Australia
Telephone/fax: +61 3 9315 8809
Email: aissg@iprimus.com.au
Website: www.vicnet.net.au/~aissg

Design ERC, RCH 051271

A guide for parents of children with ambiguous genitalia



Introduction

The birth of any child is an exciting time for parents and family. There are always many questions and concerns, but in this day and age most prospective parents are sufficiently aware of any potential issues arising from the birth of their child that they are ready to cope with most eventualities. The medical profession and support groups are working together to ensure parents are better equipped to deal with a growing number of situations that may follow the birth of a child.

One such situation where communication between parents, the medical profession and support groups is very important, is the birth of a child with genitals that are a variation of what most people consider 'normal' male or female. There are immediate and long-term matters that need to be considered, but most importantly to start with is the fact that ambiguous genitalia are not a threat to the life of your child. The medical profession has an excellent understanding of any underlying health problems that may be present with such a birth and are well placed to manage any of these. So that you may better understand the situation that you and your child face, this guide has been prepared to explain some potential issues to you.

How did this happen?

All children's sexual reproductive organs (including genitals) start out exactly the same way and have the potential to develop before birth anywhere along a spectrum with male at one end and female at the other. Children that are born somewhere along this spectrum have what are called 'intersex' conditions. Some children with intersex conditions are born looking as any other boy or girl but many are born somewhere "in between". This is sometimes referred to as ambiguous genitalia. This is simply a natural biological variation and in all but a few very rare cases does not indicate anything life threatening. A specialist will have taken immediate steps and advised you if your child has an underlying medical problem, so even in these cases health is not an immediate concern.

Will my child have a normal life?

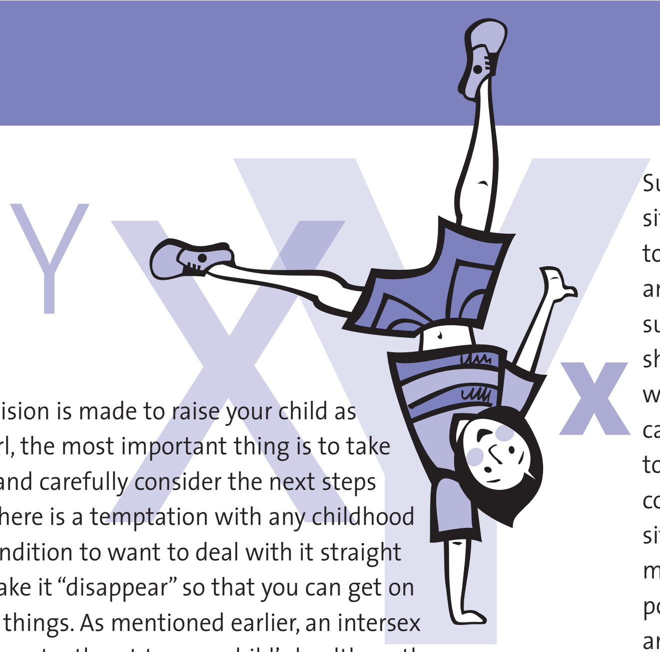
Many children a year are born with intersex conditions; it is not as rare as you might think. You may not have heard of these conditions because in the past anything that concerned sexual development was considered a taboo subject and not spoken about, but now more and more people are aware of these conditions so it is easier to talk about. This is not to say it will not initially be a shock to learn of your child's condition, however, you will find if you talk to specialists, other parents who have dealt with these issues or members of a support group that your child will be just fine. People with intersex conditions live happy and productive lives and many have successful careers as engineers, lawyers, medical practitioners, law enforcers, serve in the armed services, are married, have families and do all the things you hope any child will one day achieve.

What should I do?

Like any medical condition there are going to be some situations early on that you will have to deal with. The first thing is what to tell other family members or friends as they will want to know if your child is a boy or a girl. With family, it may be easier to tell them that doctors are not completely sure, so they just want to do some tests to make absolutely certain. With friends, it is probably better initially to tell them that you have had a boy or girl, specialists will be able to give you some initial guidance with this. Don't worry if it turns out that this initial judgment is not later the case, there are ways of explaining this as having been a mistake that will not draw too much attention. You can also provide close family and friends with a brochure about the condition if you feel that's appropriate.

Is my child a boy or a girl?

Undoubtably the hardest decision you will have to make at this early stage is whether you should raise your child as a boy or a girl. It is important to make a decision to raise your child as either a boy or girl, but remember, only your child will really know if they identify as male or female (this is called their "self identified gender"). It used to be widely believed, that a child's self identified gender could be created by simply raising a child as either a boy or girl and that they did not have a gender identity when they were born. There is ever increasing evidence available that shows children already have a self identified gender when they are born and although this can be influenced by upbringing, it cannot be completely erased. Specialists can perform tests that will assist determining if your child is likely to identify as male or female. This is accurate in most but not all cases. Even in cases where your child rejects the sex he or she is being raised as, there are specialists and support group members that can help you should this situation arise.



Once a decision is made to raise your child as a boy or girl, the most important thing is to take your time and carefully consider the next steps you take. There is a temptation with any childhood medical condition to want to deal with it straight away or make it "disappear" so that you can get on with other things. As mentioned earlier, an intersex condition is not a threat to your child's health, so there is time to consider what you think is best for your child and for you as parents.

Surgery – clearly thinking through the alternatives

After a decision is reached to raise your child as a boy or girl, you will have to decide what treatment your child should undergo early in life and what treatment to leave until your child can decide for themselves. There are advantages to both early and late treatment and it is very important to weigh these up very carefully before making a decision on behalf of your child as some treatments are irreversible. Some people born with intersex conditions and born with ambiguous genitalia have surgery to 'cosmetically' alter the appearance of their genitalia when children, some choose to have this as teenagers or adults, and some choose not to have surgery at all.

The legal position about whether parents can or cannot consent to irreversible, non-therapeutic surgeries on children and adolescents is currently uncertain, but **consideration should always be given to all possible treatment options**, including the benefits gained from not performing surgeries at all.

Surgery early in your child's life may avoid certain social situations that you and your child would rather not have to face. There is also evidence that children heal quicker and more successfully than adults who undergo similar surgery. The negative side to the early approach is that should the child decide later this is not what they wanted, it is impossible to undo some surgeries and this can make it very difficult for both the child and parents to deal with. Support groups and specialists will of course help in whatever way they can should this situation arise, but there is a limit to what can be done medically in such circumstances. Surgery also has the potential to adversely effect sensitivity of the genital area and whilst improvements in surgical procedures have reduced the effect of this, there will always be some nerve damage.

The other choice is to leave any decision about surgery to your child once they are old enough to understand and make a decision for themselves. This will mean that if they decide to have surgery they are making the decision they feel is best for them. This is especially important if their self identified gender is different to the gender it was decided as a child they should be raised as they are not trying to undo something they feel was inappropriate. The negative side to waiting until your child can make their own decision about surgery, is that there are some social situations your child and your family may be faced with that might be difficult. These might be questions about what to tell baby-sitters, how to avoid a child being teased in change rooms at school or what to tell the child themselves about their condition.

Specialists and support groups all recommend telling the truth to a child about their condition, in stages that the child can understand.

Comparison between Intersex Conditions and Transsexualism

This documents seeks to clarify the confusion surrounding the differences between intersex conditions and transsexualism. Please contact the AIS Support Group Australia on aissg@iprimus.com.au if you would like more information.

Intersex	Transsexualism
One of the many long-established biological conditions where a child is **born with reproductive organs, genitalia and/or sex chromosomes that are not exclusively male or female**.	A condition where people are born with a **completely male or female sexual reproductive organs and sex chromosomes,** but with a gender identity of the opposite sex.
The previous word for intersex is **hermaphrodite**.	Transsexualism is also referred to as gender dysphoria’ or ‘**gender identity disorder**’.
Medically determined by simple diagnostic tests.	**Self-identified** condition
Approx 5 to 10% of people with intersex conditions have some question about their gender identity, usually as a result of earlier inappropriate medical treatment.	People with transsexualism **reject their chromosomal and reproductive sex as a result of having a gender identity of the opposite sex.**
People with intersex conditions are preliminarily assigned a sex of rearing at birth if there is an obvious ambiguity as to the child’s sex. **A decision is made for them.** Others with intersex conditions are diagnosed later when they fail to menstruate etc.	People with transsexualism are raised in the sex that matches their unambiguous reproductive sex.
People with intersex conditions **cannot reproduce** without medical intervention except in very rare circumstances. Most are sterile.	Most people with transsexualism are **able to reproduce** naturally. (Many do prior to rejecting their birth sex).
Children and infants with intersex conditions endure repeated examinations and medical procedures including orchidectomies, vaginoplasties and hormone **treatment without their consent**. A standard of care does not exist, but treatment is generally based on invalidated research from the 1960s.	People with transsexualism receive treatment under internationally approved Standards of Care and **give full disclosure and consent to any medical intervention**. Care is specifically taken to ensure mistakes are not made.
Long established biological condition.	History of being a psychological condition, with **“brain sex” still an unproven theory**.
Main issues of concern for intersex groups are: • Humane treatment of children with intersex conditions, • Support for parents, • Accurate and timely diagnosis, • Access to appropriate medical specialists, • Infertility, • Osteoporosis, and • Management of hormone imbalances. Note: People with intersex conditions have always been able to have their birth certificates corrected if raised in the wrong sex. They can also marry and adopt children.	Main issues of concern for transsexual groups are: • Legal status of their self-identified gender, • Relationship recognition, • Transitioning issues, • Access to sex reassignment surgeries, • Employment and • Discrimination.

For more information contact the AISSGA on aissg@iprimus.com.au or visit our website at www.vicnet.net.au/~aissg

ALICE DOMURAT DREGER

INTERSEX AND HUMAN RIGHTS:

The Long View

1. INTRODUCTION

This is an essay about how an article I published in 1998 was wrong. I hope the reader will bear with me and see this is not an exercise in narcissism or self-flagellation. It is, rather, an attempt to explain why changing the treatment of intersex has turned out to be a much harder job than those of us in the early intersex reform movement imagined it would be.

Probably because we had so few allied doctors back then, in 1998 those of us agitating for intersex treatment reform were naïve about the way medical practice works.[1] Today we know that the standard of care for intersex wasn't the simple anomaly we thought it was. As a consequence, though we started out thinking that to improve the care of people with intersex conditions we would just need to move the care of intersex into line with the rest of medicine, we now know there are some basic problems generalized in the institution of medical practice that contribute to the poor treatment of families dealing with intersex. Fixing the treatment of intersex isn't, therefore, like trying to get one surly elephant to line up in a parade of otherwise well-behaved elephants. It's like trying to push a whole parade of stubborn elephants—and trying to do this with soap on your feet.

I want to suggest, though, that this heavy lifting—or heavy pushing—is worth it. That yes, it is very hard to change intersex practice, because it's very hard to change any entrenched practice that continues to run on the energy of its own inertia. But changing the practice of intersex is going to have (and indeed already has started to have) critically useful effects for many other realms of medical care—for example, the care of gay and lesbian patients, and of children born with various anomalies and disabilities.

This is because—though until recently this has not been well articulated—the intersex reform movement has been essentially a human rights movement.[2] That is—like the civil rights movement against racism, and the women's rights movement against sexism—it has been and is founded on the assumption that people with intersex should not be oppressed simply because their bodies do not rank at the top of the social hierarchy.[3] As a consequence, doctors who have "gotten" intersex as a human rights issue find themselves realizing what it could mean to get beyond the

S.E. Sytsma (Ed.), Ethics and Intersex, 73–86.

presumption that Western healthcare "standards of care" are necessarily respectful of human rights. In other words, the intersex reform movement is helping to push the question of what humane healthcare really means.

2. CONCEALING INTERSEX

The theoretical basis for the standard of care for intersex as it existed in the early 1990s grew, historically speaking, out of an interdisciplinary team operating at Johns Hopkins. That group developed what came to be known as the "optimum gender of rearing" model of care, a model that centered on the belief that you could (and should) try to make intersex children as convincing boys or girls as possible, though surgical and medical technologies, and through counseling. The Hopkins team favored the idea that, in terms of gender identity and sexual orientation, children are born as blank slates; they develop a gender identity and a sexual orientation based upon social interactions with the people around them. If you made a child *look* like a girl, and made others *believe* that she was a girl, then she would also *think* she was a girl, and thus would *become* a girl—preferably a straight girl. Because the team believed genitals were the most important aspect of sex and gender identity, and because they believed it was easier to construct good-looking girl genitals than good-looking boy genitals, most intersex patients were made into girls.

Though, in their early writings, members of the team (including the famous John Money) said that patients should be informed of their medical histories in age-appropriate ways, in practice few were.[4] Indeed, many were actively deceived by medical practitioners who thought that the truth would be counter-productive. As a consequence, my colleague Cheryl Chase and I have termed the late-twentieth-century standard of care, as it came to be, the "concealment approach."[5] The goal of this model was, after all, to make intersex disappear—to obscure any appearance of intersex and also most personal and social knowledge of intersex.[6]

I was not at all the first person to criticize the concealment approach. In fact, by 1998 several clinicians had implicitly questioned it through peer-reviewed research articles that showed, for example, the successful rearing of micropenis boys as boys[7], the high frequency of penises fitting the American urological establishment's definition of penile "abnormality,"[8] and the persistence of male gender identity in a boy who had been surgically sex re-assigned in infancy.[9] Meanwhile, criticisms had also started coming from science studies scholars[10] and were flowing like water from an open main from many people with intersex, especially those who had experienced at first-hand the concealment model.[11]

So there was a disparate but clear groundswell already in place when, in 1998, I published in the *Hastings Center Report* an article exploring in detail the concealment model's many ethical problems.[12] As was probably clear to readers of the article, by then I thought it was obvious that the standard treatment of intersex was so morally outrageous that, once exposed, it would quickly change. I was particular struck by three components of intersex treatment that seemed extraordinary for medicine:

In cases of intersex clinicians were intentionally *withholding and misrepresenting critical medical information*. This prevented parents of minors and major patients from making informed choices, from doing their own research on their situations, and from finding others in the same position.

Otherwise healthy children were being subjected to procedures that risked or sometimes negated sexual sensation, fertility, continence, health, and life *simply because their bodies did not fit social norms*. Not only were these children being treated differently from non-intersex children, within intersex clinics they were also being treated in a literally sexist way: "for example, physicians appear[ed] to do far more to preserve the reproductive potential of children born with ovaries than that of children born with testes…Similarly, surgeons seem[ed] to demand far more for a penis to count as 'successful' than for a vagina to count as such."[13] Doctors were equating—or at least conflating—statistical difference and disease, treating healthy-but-funny-looking genitals as surgical emergencies.[14] And, although nearly all clinicians agreed that intersex was primarily a *psychosocial* problem (a problem of norms), very few provided professional or peer psycho-social support to parents and patients.

The final ethical problem was the *near total lack of evidence*—indeed, a near-total lack of *interest* in evidence—that the concealment system was producing the good results intended. The goal of all this work was supposed to be psychosocial health, but the few follow-up studies that existed looked instead at what the surgeon thought of the cosmetic outcome. Not only did clinicians ignore evidence that gender identity was less plastic than Money claimed, not only did they ignore evidence that micropenis boys could do well as boys, not only did they ignore well-known sexological studies that showed how important the shaft of the clitoris is to men and women's sexual pleasure, they used clinical standards for phallic appearance that were so arbitrary as to sound like a bad joke to outsiders.[15] Parents, though, were not told the experimental nature of this treatment system.

Given all this, I ended that 1998 article by arguing that the treatment of intersex was unlike anything else in modern-day medicine. In fact, I said that doctors seemed to be employing for intersex what ethicist George Annas had termed "the monster approach".[16] In other words, children with intersex were being treated as "so grotesque, so pathetic, any medical procedure aimed at normalizing them would be morally justified."[17] In short, they were being treated as non-humans—or at least not fully human—in the sense that they were being subjected to a system of treatment that would have been considered inhumane had it been applied to others.

After I published this article and the related book, many academic ethicists, journalists, and activists readily agreed that the concealment model of intersex treatment was fundamentally flawed and needed changing.[18] But the reaction among the medical establishment (at least the elites at the top of their fields) has been notably slower. And I think that the reason for that must be because, in spite of what we in the intersex reform movement thought in 1998, the treatment of intersex actually looks a lot like other realms of modern medicine. Those three enumerated core components of the treatment of intersex didn't—and don't—shock most of the folks treating intersex because they are in fact pretty familiar to them and their colleagues from other realms of care.

3. SEX, LIES, AND PEDIATRICIANS

Dig a little into the experiences of intersex clinicians and patients, and you soon find that intersex is a hotbed of deception. And in a weird sort of way, the medical profession has been rather honest about that deception. In other words, they talk openly about it—while at the same time lying to individual patients. For instance, in 1995 the Canadian Medical Association awarded a medical student a prize for an article arguing that practitioners had an ethical *duty* to deceive patients with Androgen Insensitivity Syndrome (AIS—an intersex condition) about the nature of their conditions.[19] The logic was that the patients would needlessly suffer from knowing the truth. More recently, the North American Task Force on Intersex (NATFI) found its quest for follow-up data stymied by clinicians who insisted they couldn't possibly tell their patients the truth about what had happened and been done to them. And in a 2000 issue of Discover magazine, in an article entitled "The Curse of the Garcias," a physician wrote—*for popular entertainment purposes*—about how he has been lying for years to one of his patients, a woman with AIS.[20]

In most of medicine today practitioners would never think it their ethical duty to consistently and repeatedly lie and withhold critical medical information; indeed most would see their duty as the opposite. But I've come to realize that, at least in pediatric care of serious medical conditions, it is still often the case that practitioners do withhold critical information from patients and parents under the guise of bearing the burden of knowledge for them.[21] In other words, what happens in intersex treatment is different in degree, but not different in kind, from what happens elsewhere in medicine, especially tertiary pediatric medicine.

Now, because they are experts, doctors almost always know a lot more about a particular condition than they tell their patients. But sometimes doctors choose to reveal *much* less than any reasonable outsider would think they ought, either because they are made uncomfortable by discussing issues or are worried about undermining their authority and heroic images. This seems to be especially true in pediatrics, where parents and patients are often patronized (ex., called "Mom" and "Dad" by team members) and treated with greater than the usual amount of paternalism.[22] The excuse I've heard for this is that there is no point in making the parents or patients "unnecessarily" feel uncertain, but uncertainty about one's life (or one's child's life) is part of the prognosis of that life, and so should be shared, not withheld or glossed over. Yet too often uncertainty becomes an excuse for medical paternalism when it ought to function as a critique of it.

In intersex, as is other situations, sometimes the information withheld by doctors is about well-established and well-respected patient advocacy groups who would provide an alternative perspective on treatment options (often available at rival institutions), sometimes the information is about how little is known about outcomes for recommended options, and sometimes it is about how much difference it makes which surgeon you engage for a particular procedure.[23] Many physicians feel this sort of information is either not relevant or too political to reveal. Yet it seems to me—from conversations I've had with parents and with persons born with atypical anatomies—that this information is exquisitely relevant to making informed decisions.

One response to the observation that intersex isn't the only realm of medicine where information is misrepresented or withheld is to throw up one's hands and say deception is "normal" medical practice in certain arenas—that there's nothing you can do about it. But I think this is the wrong approach. Paul Farmer, a Harvard-based international infectious-disease specialist, suggests that when we see two groups of people being treated differently in medicine for social (and not metabolic) reasons, we should not make that observation the end of the conversation.[24] It should rather begin a conversation that inquires into what would happen if you treat both groups as equally human.

If we decline the "monster approach" and consider persons with intersex as fully enfranchised human beings—as I think we should—we realize that they and their parents have the right to know at least as much as their doctor is willing to tell his or her colleagues, no less the one million readers of *Discover* magazine. Indeed, all over medicine physicians need to realize that informed consent means more than giving the usual disclaimers about, say, anesthetic risks; it ought to mean educating patients (and parents, if applicable) about the specific medical condition at issue, handing over without reservation copies of everything in the chart, explaining what is known and unknown and what is under serious debate.

What I'm suggesting is that we reject the idea that (a) intersex is so freakish it calls for extraordinary behavior on the part of clinicians, or (b) clinicians' treatment of intersex is appropriate because it looks like behaviors we find in other realms of medicine, and instead adopt the notion that (c) the treatment of families with intersex has often been very poor indeed—so poor that, like a lens, it helps us see what other parts of medicine might also need immediate revision to effect humane care.

3. NORMAL MEDICINE?

What, then, about this issue of changing otherwise-healthy children to fit social norms? Isn't that unusual in medicine?

Hardly. It happens during most circumcisions, during non-emergent conjoined twin separation surgeries, and when children who are just short are put on growth hormones.[25] Increasingly, all over medicine, children are subject to drugs, surgeries, and intensive behavioural therapies specifically aimed at making them fall into the boundaries of an idealized norm.

But whereas I used to think that this push to "normalize" signaled a rejection of the "abnormal" child, I am now more inclined to think that those pushing see it (paradoxically) as loving acceptance of the child. Since becoming a parent in 2000, I've realized how much I underestimated the parental (and sometimes pediatric-paternalist) desire to "normalize" children, a desire that is clearly a manifestation of the visceral—almost savage—desire to protect children. The parent (and pediatric surgeon) sees the child as essentially perfect, and wants the often-cloddish and boorish world to see the same, so she "reconstructs" the child to "normality." In

1998, when, thanks to sociologist Arthur Frank's work,[26] I recognized the mythology of calling intersex surgeries "reconstructive" I think I failed to understand how much parents and surgeons *believed* in the restitution narrative they spoke. They really think they are *restoring* the child to the normality they've come to see within that child.

In that sense, I think I failed also to see what social scientist Adrienne Asch does in "Distracted by Disability,"[27] namely the conflicted position of the physician approaching the congenitally or chronically "disabled" patient. How is it the surgeon can truly accept the whole child born with an unusual anatomy—including the supposedly "deformed" anatomy which will very likely form a critical aspect of that person's identity—and also seek to "rescue" her from it? In 1998 I thought doctors treating intersex had put themselves in an awkward position—wanting to help patients while unintentionally hurting them. Now I realize what I am calling them to is a much more awkward position. I'm asking them to put down their tools of "correction" when in their minds that would signal abandoning the child, rather than accepting her.

More generally put, I think I misunderstood to what extent medical and surgical intervention is the primary means of demonstrating *caring* for many clinicians, patients, and family members. This is especially true as non-intervention gets represented almost always as cheapskate HMO-type behavior, or as racist, sexist, or classist (which it sometimes is). Doctors see something as abnormal—anatomically or behaviourally—and think the way to help is to change what they see as the primary problem. The child is subjected to procedures aimed at changing their body or behaviour, and no one questions whether the norm itself might need correction.

But again, what I want to suggest here is that we reject the idea that (a) intersex is so freakish it calls for extraordinary behaviour on the part of clinicians, or (b) clinicians' treatment of intersex is appropriate because it looks like behaviours we find in other realms of medicine, and instead adopt the notion that (c) the treatment of people with intersex has been problematic enough that it helps us see what other parts of medicine might also need immediate revision to effect truly humane care.

In this case, I think what we can learn from the history of intersex experience is that there are other ways to care for people (especially children) who are "abnormal"—i.e., different from the social norms—than to throw medicines and surgeries at them. In fact—aside from the underlying metabolic dangers such as salt imbalance, adrenal crisis, or cancers that sometimes attend intersex conditions, all of which everyone agrees you should treat thoughtfully—the challenges families with intersex face are *social* challenges. Like racism and sexism, they are social challenges, even if they do arise—as some sociobiologists and surgeons will claim—from "hardwired" fear of difference.[28] When doctors see a clash between a child's body and the social body and they choose to address that clash by changing the child, they are in effect saying the social body cannot, will not, or should not be changed. But to consider this as a matter of human rights—that is, to consider people with intersex as we would other humans—means considering the possibility that the child is not the wound that needs healing. It is, for example, to consider that the correct response to oppressive racism is to work against racism, not to eliminate racial differences in infancy (or during gestation). And the correct response to the derision of people with intersex is to change the people doing the deriding. What to do about bullies? Fix *them*.

So far as re-thinking infant genital cosmetic surgeries as a human (rights) issue, I have two illustrative anecdotes. The first involves a conversation I had with a prominent intersex clinician, an experienced and thoughtful man—thoughtful enough to find himself now tortured over the question of how to handle intersex. This clinician was telling me that you have to do what parents want, that if a parent of a child with intersex wants to have a surgeon "normalize" the child's genitals, that's what you have to do. Indeed, he told me this is what it means to be culturally sensitive. In response, I asked this clinician, "If a set of parents came from Africa and wanted to have their non-intersex daughter's genitals changed according to their culture's customs of female genital cutting, you wouldn't do it, right?" His answer was, "Of course we wouldn't do it. It would be wrong to cut her for this reason." I then asked him why he thinks it is OK to cut the genitals of an intersex girl at her parents' request. His answer was that "they're abnormal. It isn't the same."

But I think that if we are to consider the African girl's genital integrity as a matter of human (universal) rights, then the only way to cut the intersex girl's genitals for social reasons is to exempt her from human rights—i.e., to declare her non-human, sub-human, or pre-human.[29]

The second anecdote is this: I found myself at a major surgical conference speaking about intersex on a panel with several distinguished and experienced clinicians. One of them, a man who had become an ally in intersex reform work early on, met informally with me before the panel. Over coffee, he said to me, "It's clear to me now intersex treatment is a matter of human rights." As I recall, I spontaneously planted a kiss on his cheek—or at least wanted to. But he then went on to delineate for me what he would do in various cases of intersex. And when he got to 46,XX children with CAH and very virilized genitals, he noted to me that that was the one case he could not abide foregoing early "normalizing" genital surgery. He explained that that was one that just made him too uncomfortable. I was so confused, I'm afraid I sounded cruel in my response: "Tell me, what are you going to say to that woman in 25 years when she comes back to you and asks why *she* wasn't human enough to be entitled to what you otherwise call a *human* right?"

Do we really need to change some children to make them human enough to get human rights?

4. JUST THE PRINCIPLES, MA'AM

So here's where I used to wish the evidence would save us. Here's where I thought, in 1998, that we could all look at the concealment treatment of intersex and say, "My word, they're cutting down phalluses and withholding information and building vaginas out of colons in infants with no evidence that it produces the desired results of a healthy patient! Now, that's outrageous medicine." I thought the exposed lack of evidence would cause a moratorium, and in its vacuum would come honesty and "first do no harm"—a general cessation of irreversible procedures while outcome data was collected.

But then finally I heard what clinicians around me—most frequently my own husband, an internist—were saying to me: we don't have evidence for *most* of what happens in medicine. The treatment of intersex isn't the exception; it's the rule. Tradition and storytelling trump evidence—they trump even the *desire* for evidence much of the time in medical practice.

But again, let's reject the idea that (a) intersex is so freakish it calls for extraordinary behavior on the part of clinicians (in this case, practicing without scientific evidence), or (b) clinicians' treatment of intersex is appropriate because it looks like behaviors we find in other realms of medicine, and instead adopt the notion that (c) the treatment of people with intersex has been problematic enough that it helps us see what other parts of medicine might also need immediate revision to effect humane care.

For example, what ever happened to "first, do no harm"? Is throwing more medicine and surgery at a non-emergent (even non-pathological) condition like "ambiguous genitals", without controls or evidence or data collection—really a good idea, morally speaking?

Now, I know some intersex clinicians—surgeons, generally—claim that *not* doing early surgery in cases of intersex is as morally problematic as *doing* early surgery. But this is patently false—I want to say patently *stupid*. Doing an irreversible surgery for cosmetic reasons on a child's sexual anatomy clearly eliminates important options—it takes away tissue that *can't be put back*. Granted, there are psychological challenges to being allowed to grow up with unusual genitals until you can decide what they mean to you, until you can decide whether they work well in your life, and until you can decide whether you might want to make some (risky) cosmetic changes to them. But to treat a psycho-social challenge with irreversible surgery cannot be seen as practicing reduction of risk of harm by any stretch of the imagination. There's a *reason* people cross their legs and wince when you tell them about infant genital cosmetic surgeries. And there's a *reason* they don't have the same reaction when you talk about psychological services and social workers.

Moreover, look at what we know: After more than 12 years of loud activism, after hundreds of investigations by national and international journalists, *not a single person with intersex has come forward publicly to say she or he thinks her or his infant genital surgeries were a good idea.* Meanwhile, hundreds of people have publicly denounced the surgeries to which they were subject. This is an important point: Listen and you find that adults with intersex are *not* actively debating the use of unconsented cosmetic genital surgeries, the way, say, some women with breast cancer have actively debated the use of prophylactic mastectomies and post-mastectomy reconstructive surgeries.[30] Listen and you find that adults with intersex are *not* actively debating whether they should be told the truth and given their medical records, the way, say, some people with dwarfism are debating limb-lengthening surgeries.[31]

Undoubtedly, the question of evidence in favor of (or against) certain procedures *is* one place where there's been progress in the treatment of intersex since 1998. Some clinicians are finally trying to get good data on what's happened to people who were treated with the "concealment" model.[32] But still too often they're asking the wrong question—for example: Do you think intersex children should be raised in a "third" gender or should they get early cosmetic genital surgery? (no other option allowed)—and coming up with the wrong conclusions based on the answers—for example, that if a simple majority of patients stayed in the gender role assigned, the doctors did well for the population.[33] Moreover, in my experience, most clinicians treating intersex continue to believe whatever evidence we have doesn't apply to them, because their surgeries are better, their gender assignments more sensible, their patients obviously happy. They don't think the evidence will matter that much to them.

And part of me thinks they're right, but for the wrong reason. They think their surgeries are better than the ones now being evidenced to have resulted in poor outcomes, so the evidence doesn't matter. I think the evidence about which kind of clitoroplasty leaves more sensation won't matter much because, in the end, *it's just wrong to cut healthy tissue off a girl's clitoris unless she herself wants it cut off and she knows the risks.* I think the evidence about which kind of vaginoplasty works better on a one-year-old doesn't matter because *there's no reason to do a vaginoplasty on a one-year-old.* About this, my mind hasn't changed. I *do* think new follow-up studies will be useful for doing best-guess gender assignments in cases of intersex—they may help us understand which gender to assign preliminarily in various cases of partial AIS, for example—but all the evidence in the world in favor of the "effectiveness" of a treatment doesn't make it ethical.

5. INTERSEX AS A HUMAN RIGHTS ISSUE

Here's the most important thing I've learned, ten years into the intersex scene: What you think intersex is determines how you think you're supposed to treat it, and what you think the ethical issues are. If you think intersex is mostly about gender, then you're going to focus on that—and if you get a gender assignment "right" (i.e., if the child turns out to identify with the gender you picked), you'll think you did well. If you think intersex is mostly about genital appearance, then you're going to focus on that—and if you get the genital appearance to look "normal" (i.e., good to you), you'll think you did well.

I hope it is clear that I am suggesting in this article is that intersex is about being a human being, and that therefore ethical analyses of intersex should focus on what it means to treat the patient as a full-fledged member of the human race. What it means to do well in a case of intersex is to wind up with a person who feels she or he was treated as fully human—as humanely as the next person. If you wouldn't slice into the genitals of a non-intersex child because her parents wanted it—even if her daycare workers, her grandparents, her babysitter, and her peers wanted it—then you ought not to do it to an intersex child. If you would not obfuscate the medical history of a person who was born without intersex, then you ought not to do so when dealing with a person born intersex. If you would not attempt risky, unconsented medical procedures in a non-intersex population without proof that there is anything really wrong,[34] then you ought not attempt it in the intersex population.

Moreover, I'm arguing that, when we look hard and notice reflections of the uglier sides of intersex treatment in other realms of medicine, the right thing to do is to use those insights to push for even *broader* change. I hate it when people talk about "what people with intersex have to teach us"—it makes them sound like a bunch of cute little lab rats—but I will say this: If we treat people with intersex like human beings, and listen to what they have to say, there's a possibility we'll see that a lot of other people, too, are suffering more than they have to at the hands of well-meaning doctors and not-so-well-meaning "society." We can choose to ignore that, to be overwhelmed by it, or to be motivated by it to effect change. I vote for the last.

I started with a bit of history, and I'd like to end with some. The collection of events now known as the Tuskegee Syphilis Study ran from 1932 to 1972, and was aimed at finding out what happened to untreated syphilis in the black man. Though the originating study may have been scientifically legitimate—and there is some historical evidence that it may have been—the medical professionals running the Tuskegee Syphilis Study kept it going long after penicillin became known as an effective treatment for syphilis. Moreover, as time went on, the researchers worked hard to make sure the men in the study wouldn't "accidentally" get penicillin. They intentionally misled the men, denying them the very name of their disease as much as denying them the cure. Tests like blood draws and spinal taps were represented as "treatments" in order to make the men enrolled in the study think they were really getting medical care, so the study could continue uninterrupted by actual treatment.[35]

Most people who have heard about the Tuskegee Syphilis Study subscribe to a myth that the researchers were rogue, bad doctors who carried on the experiment in secret out of pure racist hatred. In fact, though the subjects in the study were individually deceived, time and again the researchers published their interim findings in journals like *Public Health Reports* and the *Journal of Chronic Disease.* In other words, the researchers' colleagues knew what was going on, and indeed approved the papers through peer review. Historical records show only one clinician ever raising an objection, in a 1965 private letter, to the persistent withholding of penicillin from the subjects. (The letter was filed without response, and the study didn't end until a journalist exposed it to the general public in 1972.)[36] And the researchers were not generally contemptuous of their black male subjects; indeed, one key member of the team was nurse Eunice Rivers, an African-American woman who aided in the deception and obfuscation. Rivers believed, against all reason, that she and the study were helping the subjects. The initial funding agency for what became a long-term study came from the Julius Rosenwald Fund, a *liberal* foundation that wanted to see the extension of good medical care to the usually-neglected African-American population in the U.S. south. The Tuskegee Institute, a proud, African-American medical institution, participated in the study.[37]

In short, the Tuskegee Syphilis Study wasn't hidden, and it wasn't carried out by bad, overtly racist people. It just went all wrong—it went on much too long, long after penicillin became available, long after it was clear the study was founded on a disproven racial theory, and long after it became clear that untreated syphilis is really, really bad. What kept it going? Institutional inertia. Continued funding and publication opportunities. The assumption that good doctors and nurses couldn't do bad things to patients. And what Martha Solomon Watson has called "the rhetoric of dehumanization" within the study's internals records and its published reports—that is, language that made the researchers sound like passive tools of medical science, language that made the subjects sound like mere sites of disease, and language that "highlight[ed] a relatively minor difference (skin color) between groups of subjects as it obscure[d] their more numerous and significant resemblances."[38] Language that made it sound like the subjects were something other than humans.

It seems to me, given how things are going socially and clinically, that most people a few decades from now will view today's treatment of intersex like people today view the Tuskegee Syphilis Study. There will be a myth that the people who carried on, for decades, with the concealment approach and its derivatives were bad, hateful, overtly sexist people. There will be a myth that the whole thing happened because it was hidden from view. But as in the case of the Tuskegee Syphilis Study, none of that will be true. The truth will be that what kept the unethical intersex system going was institutional inertia, the desire to maintain professional reputations and careers, the use of language and pictures that dehumanized patients and posed them as if they were mere sites of localized disease, and the subsequent harm that arose from accidentally treating subjects as exempt from the rights accorded others. The lesson of the Tuskegee Syphilis Study and the treatment of intersex ought to be the same: Being well-meaning is not enough.

Is it hard to change practice? Yes. Especially when insurance companies and government agencies don't want to pay for long-term psycho-social services, when there doesn't seem to be anyone to provide those services, when parents seem more grateful for confident assurances than honest uncertainty, and when changing means admitting your field's heroes or your mentors (or you) were wrong. But you know what I would tell those practicing today? The old-time clinicians have learned the hard way that kids with intersex do grow up, and become quite obviously human. Whether they end up as men or women, straight or gay, they end up as quite obviously human. And they become quite articulate about how they wish they had always been treated that way. Start assuming that outcome now.

Alice Domurat Dreger, Visiting Professor, Medical Humanities and Bioethics Program, Northwestern University Feinberg School of Medicine, Chicago, Illinois, U.S.A.

NOTES

[1] On early intersex reform work and relations with the medical profession, see Cheryl Chase, "Hermaphrodites with Attitude: Mapping the Emergence of Intersex Political Activism," GLQ: A Journal of Gay and Lesbian Studies, 4(2)(1998):189-211; and see Alice Domurat Dreger, "Cultural History and Social Activism: Scholarship, Identities, and the Intersex Rights Movement," in *Locating Medical History: The Stories and Their Meanings*, ed Frank Huisman and John Harley Warner (Baltimore: Johns Hopkins University Press, 2004), pp. 390-409.

---

[2] The San Francisco Human Rights Commission and the South African Human Rights Commission are the leaders in this realm. See Marcus de Maria Arana, *A Human Rights Investigation into the Medical "Normalization" of Intersex People: A Report of a Public Hearing by the Human Rights Commission* (City and County of San Francisco, 2005); Wendell Roelf, "Intersex Children Must Be Protected from Temptation of Parents to 'Fix' Them Socially," Cape Times, December 1, 2004, available at http://www.capetimes.co.za/index.php?fSectionId=271&fArticleId=2329017.

[3] Alice Domurat Dreger, *One of Us: Conjoined Twins and the Future of Normal* (Harvard University Press, 2004), chap. 5.

[4] See, for example, John Money, Joan G. Hampson, and John L. Hampson, "Hermaphroditism: Recommendations Concerning Assignment of Sex, Chang of Sex, and Psychologic Management," *Bulletin of Johns Hopkins Hospital*, vol. 97, no. 4 (1955): 284-300.

[5] Alice Dreger, "Shifting the Paradigm of Intersex Treatment," available at www.isna.org/drupal/compare.

[6] Cheryl Chase, "Affronting Reason," in *Looking Queer: Body Image and Identity in Lesbian, Bisexual, Gay, and Transgender Communities*, edited by Dawn Atkins (Haworth Press, 1998), pp. 205-220.

[7] Justine M. Reilly and C. R. J. Woodhouse, "Small Penis and the Male Sexual Role," *Journal of Urology*, vol. 142 (1989): 569-571.

[8] Jan Fichtner et al., "Analysis of Meatal Location in 500 Men: Wide Variation Questions Need for Meatal Advancement in All Pediatric Anterior Hypospadias Cases," *Journal of Urology*, vol. 154 (1995): 833-834.

[9] See Milton Diamond and H. K. Sigmundson, "Sex Reassignment at Birth: A Long Term Review and Clinical Implications," *Archives of Pediatrics and Adolescent Medicine*, vol. 150 (1997): 298-304; Natalie Angier, "Sexual Identity Not Pliable After All, Report Says," *New York Times*, 14 March 1997, p. 1; John Colapinto, "The True Story of John/Joan," *Rolling Stone*, 11 December 1997, pp. 54-73, 92-97.

[10] See Suzanne Kessler, "The Medical Construction of Gender: Case Management of Intersex Infants," *Signs: Journal of Women in Culture*, vol. 16, no. 1 (1990): 3-26; Anne Fausto-Sterling, "The Five Sexes: Why Male and Female Are Not Enough," 1993, *The Sciences* 33 (2): 20-25.

[11] See, for example, Cheryl Chase, Letters from Readers, *The Sciences*, July/August 1993, p. 3; Cheryl Chase, "'Corrective' Surgery Unnecessary" (letter), Johns Hopkins Magazine (February 1994), pp. 6-7; Cheryl Chase, "Intersex Society of North America: Intersexuals Advocate for Change," *American Medical Student Association Task Force Quarterly*, Fall 1994, pp. 30-31; Cheryl Chase, "Re: Measurement of Evoked Potentials during Feminizing Genitoplasty: Techniques and Applications" (letter), *Journal of Urology*, vol. 156, no. 3 (1996):1139-1140; Cheryl Chase, "Stop Medically Unnecessary Surgery" (letter), San Francisco Bay Times, 28 November 1996, p. 17; Cheryl Chase, "Re: Measurement of Pudendal Evoked Potentials during Feminizing Genitoplasty: Techniques and Applications" (letter), *Journal of Urology*, vol. 156, no. 3 (1996):1139-1140; Cheryl Chase and Martha Coventry, Special Issue on Intersexuality, *Chrysalis*: *The Journal of Transgressive Gender Identities, Fall*/Winter 1997; Cheryl Chase, "Phallocentric Criteria" (letter), *Clinical Psychiatry News*, September 1997; Cheryl Chase, "Spare the Knife, Study the Child" (letter), *Ob.Gyn. News*, 1 October 1997, pp. 14-15; Cheryl Chase, director, *Hermaphrodites Speak! San Francisco: Intersex Society of North America*, video tape (30 minutes), 1997, available from www.isna.org; Anonymous, "Be Open and Honest with Sufferers," *BMJ*, vol. 308 (1994): 1041-1042; B. Diane Kemp, letter to the editor, *Canadian Medical Association Journal*, vol. 154 (1996), p. 1829; Sherri A. Groveman, letter to the editor, *Canadian Medical Association Journal*, vol. 154 (1996): 1829 and 1832. By 1998 there were also many autobiographical accounts and first-hand former-patient critiques available on the web through, for example, the now-defunct "Intersex Voices" website created by Kiira Triea.

[12] Alice Domurat Dreger, "'Ambiguous Sex' – or Ambivalent Medicine? Ethical Problems in the Treatment of Intersexuality," *The Hastings Center Report*, vol. 28, no. 3, May/June 1998, pp. 24-35.

[13] Ibid., pp. 28-29.

[14] See, for example, the discussion of to what extent "ambiguous genitalia" constitute a "medical and social emergency," in Richard H. Hurwitz, H. Applebaum, and S. Muenchow, *Surgical Reconstruction of Ambiguous Genitalia in Female Children*, videotape, 1990; available from Cine-Med at www.cine-med.com. In this training film, Dr. Hurwitz claims that, "In most cases it is better to wait until the child is six months old when the anesthetic risks are minimized. If the clitoris is very large, however, it may need to be taken care of earlier for social reasons." In other words, social

---

distress on the part of surrounding adults is sufficient reason to risk a child's life in a "normalization" procedure.

[15] ISNA found it useful to lampoon clinical standards for phallus length by producing and distributing "phall-o-meters"—little plastic measuring sticks that showed who was a good girl and who was a bad boy according to leading American pediatric urologists. These trinkets proved very popular—I'm still asked for them, years after ISNA stopped producing them—but they didn't accomplish much in terms of changing clinical practice. A point relevant to this article's thesis: the Smithsonian Institution now possesses an ISNA phall-o-meter as part of a special collection on the intersex rights movement.

[16] George J. Annas, "Siamese Twins: Killing One to Save the Other," *Hastings Center Report* 17 (April, 1987): 27-29. Annas used the term in relation to the treatment of conjoined twinning; he did not advocate the approach.

[17] Dreger, "'Ambiguous Sex'," p. 33.

[18] Alice Domurat Dreger*, Hermaphrodites and the Medical Invention of Sex* (Harvard University Press, 1998).

[19] Anita Natarajan, "Medical Ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome," *Canadian Medical Association Journal*, vol. 154 (1996): 568-570. For responses to this article from women with AIS, *see Canadian Medical Association Journal*, vol. 154 (1996): 1829-1833. Dr. Natarajan retracted her remarks to some extent in an online follow-up statement, available at http://www.happinessonline.org/CommonSenseMoralCode/p3.htm.

[20] Robert Marion, "The Curse of the Garcias," Discover, December 2000, 42. See also response to this from Sherri A. Groveman, "Lifting the Curse," *Discover*, March 2001.

[21] On this point, see Dreger, *One of Us*, chap. 2.

[22] This is developed more fully in Alice Domurat Dreger, "What to Expect When You Have the Child You Weren't Expecting," in *Surgically Shaping Children*, edited by Erik Parens (Washington, Georgetown University Press, 2005).

[23] See Dreger, One of Us, pp. 80-81.

[24] Paul Farmer, "Pathologies of Power: Rethinking Health and Human Rights in the Global Era," public lecture delivered at Calvin College, Grand Rapids, Michigan, January 10, 2005.

[25] Alice Dreger, "When Medicine Goes Too Far in Pursuit of Normality," New York Times, July 28, 1998, p. B-10; reprinted in *Health Ethics Today*, vol. 10, no. 1, August, 1999, pp. 2-5.

[26] Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (University of Chicago Press, 1995), chap. 4.

[27] Adrienne Asch, "Distracted by Disability," *Cambridge Quarterly of Healthcare Ethics*, 7 (1998): 77- 87.

[28] I discuss this attitude—that discrimination and bullying is hardwired and therefore inevitable—in Alice Domurat Dreger, "Etiologies of Revulsion" (essay review of Margrit Shildrick's *Embodying the Monster: Encounters with the Vulnerable Self*), in *Health: An Interdisciplinary Journal for the Social Study of Health, Illness, and Medicine*, vol. 9, no. 1 (2005): 113-116.

[29] This point is more fully developed in Alice Dreger and Bruce Wilson, Commentary on "Culture Clash Involving Intersex," *The Hastings Center Report*, vol. 33, no. 4 (July/August 2003), pp. 12-14.

[30] For a history of debates surrounding mastectomies and reconstructive surgeries, see Barron H. Lerner, *The Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* (Oxford University Press, 2001).

[31] For references to this issue, see http://www.lpaonline.org/resources_faq.html, website resource of *Little People of America*.

[32] See, for example, Catherine Minto, Lih-Mei Liao, Christopher R. J. Woodhouse, Philip G. Ramsley, and Sarah M. Creighton, "The Effects of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross Sectional Study," *Lancet*, vol. 361, no. 9365 (April 2003): 1252-1257; Thomas Mazur, David E. Sandberg, M.A. Perrin, J. A. Gallagher, and M. H. MacGillivray, "Male Pseudohermaphroditism: Long-Term Quality of Life Outcome in Five 46,XY Individuals Reared Female," *Journal of Pediatric Endocrinology and Metabolism*, vol. 17, no. 6 (June 2004): 809-823.

[33] H. F. L. Meyer-Bahlburg, C. J. Migeon, G. D. Berkovitz, J. P. Gearhart, C. Dolezal, and A. B. Wisniewski, "Attitudes of Adult 46,XY Intersex Persons to Clinical Management Policies," *Journal of Urology*, vol. 171 (April 2004): 1615-1619.

---

[34] For evidence people with intersex have survived psychologically and socially without early surgical "correction," see John Money, *Hermaphroditism: An Inquiry into the Nature of a Human Paradox* (Doctoral Dissertation, Harvard University, 1952); Dreger, *Hermaphrodites and the Medical Invention of Sex*; Hida Viloria in Chase, *Hermaphrodites Speak*!; Alice Domurat Dreger and Cheryl Chase, "A Mother's Care" (interview with woman with intersex and her mother), in *Intersex in the Age of Ethics,* edited by Alice Domurat Dreger (Hagerstown, Maryland: University Publishing Group, 1999): 83-89; Hale Hawbecker, "Who Did This to You?," ibid., 111-113; Intersex Society of North America, "What evidence is there that you can grow up psychologically healthy with intersex genitals (without 'normalizing' surgeries?", http://www.isna.org/faq/healthy.

[35] Allan M. Brandt, "Racism and Research: The Case of the Tuskegee Syphilis Experiment," *Hastings Center Report*, vol. 8, Dec. 1978, pp. 21-29.

[36] See the letter of Irwin J. Schatz to Donald H. Rockwell, 11 June 1965, and the annotation accompanying it ("This is the first letter of this type we have received. I do not plan to answer this letter") reprinted on pp. 103-104 in Susan M. Reverby, editor, *Tuskegee's Truths: Rethinking the Tuskegee Syphilis Study* (Chapel Hill: University of North Carolina Press, 2000).

[37] See Brandt, "Racism and Research," for a historical overview of the study.

[38] Martha Solomon Watson, "The Rhetoric of Dehumanization: An Analysis of Medical Reports of the Tuskegee Syphilis Project," in Reverby, ed., *Tuskegee's Truths*, pp. 251-265, quote on p. 260.