

The ethics of surgically assigning sex for intersex infants

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Introduction

Intersex conditions raise profound ethical issues for the children born with these conditions, for their parents and for clinicians. ‘Intersex’ refers to conditions ‘in which chromosomal sex is inconsistent with phenotypic sex, or in which the phenotype is not classifiable as either male or female’.¹ This means that a child with an intersex condition may be genetically female with external genitalia which appear to be male or may be genetically male with external genitalia which appear to be female. In some rare cases the child has both male and female genitalia. The prevalence of these conditions is 1.8 in every 10,000 live births and the most common of the ‘classic intersex conditions’ are congenital adrenal hyperplasia (CAH) and complete androgen insensitivity syndrome (CAIS).² There is debate about the definition of ‘intersex’. Broader definitions, of course, will give a higher prevalence.³ In this chapter, our concern is with the contentious issue of early surgery – situations where the surgical assignment of sex or ‘corrective’ surgery is an option. In the literature and in practice guidelines, intersex conditions are variously referred to as ‘developmental anomalies of the external genitalia’,⁴ ‘atypical sexual differentiation’,⁵ and ‘ambiguous genitalia’,⁶ even though intersex children may or may not be born with external genitals that are ambiguous.’⁷ Some intersex conditions remain undetected until puberty or later.

Intersex conditions can be harmful in 3 ways. Firstly, the condition itself can be harmful. The range of intersex condition may include recurrent urinary tract infections,⁸ problems with infertility, precocious or delayed puberty, hormonal imbalance requiring medication, the risk of cancer, problems with sexual functioning and satisfaction and gender identity and relationship difficulties leading to social and psychological problems.⁹

¹ Leonard Sax. ‘How common is intersex? A response to Anne Fausto-Sterling. *The Journal of Sex Research*, 2002;39(3):174-78

² Sax. Op. cit. pp.174-75

³ Blackless M., Charuvastra A., Derryck A., Fausto-Sterling A., Lauzanne K., & Lee E. ‘How sexually dimorphic are we? Review and synthesis’ *American Journal of Human Biology*, 2000; 12:151-166

⁴ American Academy of Pediatrics. Committee on Genetics. Evaluation of the newborn with developmental anomalies of the external genitalia. *Pediatrics* July 2000; 106(1):138-142

⁵ Peggy T. Cohen-Kettenis and Friedemann Pfafflin. *Transgenderism and intersexuality in childhood and adolescence: Making choices*. Vol. 46 *Developmental clinical psychology and psychiatry*. California: Sage Publications. 2003.

⁶ Rangescroft, on behalf of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia. Surgical management of ambiguous genitalia. *Arch Dis Child* 2003;88:799-801; Low Y, Hutson J, and Murdoch Childrens Research Institute Sex Study Group. Rules for clinical diagnosis in babies with ambiguous genitalia. *J. Paediatr. Child Health* 2003; **39** (6):406-413.

⁷ Peggy T. Cohen-Kettenis and Friedemann Pfafflin. Op. cit. p.49

⁸ Garry Warne. Ethical issues in gender assignment. *The Endocrinologist* 2003;13 (3): 182-186.

⁹ Peggy T. Cohen-Kettenis and Friedemann Pfafflin. Op. cit. p.90-91

Secondly, openness about an infant's condition in an environment where people are not aware of, don't understand and don't accept genital ambiguity can lead to the child being stigmatised. Thirdly, not disclosing the child's condition creates 'an atmosphere of secrecy' suggesting that the child suffers from 'something shameful'.¹⁰ The attitude that ambiguous genitals are shameful is a 'primary source of harm' for people with intersex conditions.¹¹

Standard medical practice has been to make an early diagnosis and to perform early "corrective" genital surgery. The reasoning behind this is the need for a clear and unambiguous sex assignment to save intersex children from being ostracized and to enable parents to bond with their baby girl or baby boy.¹²

Types of early surgery include feminizing genitoplasty which involves the removal of tissue from what is either an enlarged clitoris or a small penis and surgery to enlarge or to create a vagina.¹³ Early gonadectomy (removal of testes) is sometimes carried out because malignant change is thought to be a possibility in infants who have testes which are intra-abdominal or contained in inguinal herniae.¹⁴

Box 1. Goals or objectives of early surgery

From various sources and perspectives the following have been identified as the goals or objectives of early surgery:

- Normal looking genitalia encourage stable gender identity, reduce stigma and psychological distress.¹⁵
- Pediatric urologists want to provide the patient with positive psychosocial and psychosexual adjustments throughout life.¹⁶
- Patients and parents want surgery that looks cosmetically authentic and provides good function.¹⁷
- The 'psychological benefit of the parents'.¹⁸
- To allow the child to avoid the psychological problems from being different from other children and the 'cruel discrimination' that that might bring about.¹⁹

¹⁰ Peggy T. Cohen-Kettenis and Friedemann Pfafflin, p.87-88

¹¹ Cheryl Chase. Surgical progress is not the answer to Intersexuality. *The Journal of Clinical Ethics*. 1998;9(4):385-392

¹² American Academy of Pediatrics, op. cit.: Joint Lawson Wilkins Pediatric Endocrine Society and The European society for Paediatric Endocrinology. Consensus Statement on 21-Hydroxylase Deficiency from the Lawson Wilkins Pediatric Endocrine Society and The European society for Paediatric Endocrinology. *J. Clin Endocrinol Metab* 2002;87(9):4048-4053

¹³ Warne G. op. cit..

¹⁴ L. Rangescroft, on behalf of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia. Surgical management of ambiguous genitalia. *Arch Dis Child* 2003;88:799-801

¹⁵ Appendix to Draft Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia, July 2001 – Available at <http://www.baps.org.uk/documents/Intersex%20statement.htm> (Accessed 17th October 2004) Referring to practice based on the work of John Money.

¹⁶ Justine M. Schober. Feminizing Genitoplasty: A Synopsis of Issues Relating to Genital Surgery in Intersex Individuals. *Journal of Pediatric Endocrinology & Metabolism*, 2004; 17:697-703. (p.698)

¹⁷ Schober, 2004, 697

¹⁸ Warne G. op cit.

¹⁹ Warne (2003), op. cit.

- To allow the child to grow up without medical problems caused by the anatomy.²⁰
- Early surgery confers some medical benefits.²¹
- To remove ‘anatomic or functional obstacles to the development of healthy and satisfactory sexuality.’²²

A growing number of objectors have argued against early genital surgery on the grounds that it is not necessary, it is not reversible and it can cause harm.²³ Some commentators argue that surgery to normalize the infant is based on parent’s fears and concerns rather than the best interests of the child and amounts to ‘the medical management of a psychological condition’ performed on the child for the sake of the parents:²⁴ ‘Cosmetic surgeries are performed without the subject’s consent because of adults’ discomfort with intersexuality’.²⁵

The central questions in the management of intersex infants are:

- When, if ever, should surgery be carried out?
- Who should decide?
- On what criteria should decisions be based?

The focus of the above issues for some seems to be the child’s future autonomy and the implications of parents or others making irrevocable decisions for young children. We will argue that the main ethical issue is not a question of autonomy but the question of whether surgery makes the child’s life go better or worse. We begin by outlining the criticisms of the traditional treatment model and early surgery and in what follows we address the central questions.

The challenge to the traditional treatment model and early surgery

Are medical professionals standing by with rulers and stamps of approval? To some extent they are, and we are all subject to their judgement ... We are not so quick to judge other parts of anatomy. We teach our children to respect diversity, yet adults create a 'state of emergency' over the size and shape of genitals. The real phenomenon is that the prevalence of genital and reproductive variation is kept such a secret. Intersex variations are so quickly 'disappeared' that we don't get a chance to know about them, or how they might mature.²⁶

²⁰ Warne (2003), op. cit.

²¹ Warne (2003), op. cit.

²² Warne (2003), op. cit.

²³ Intersex Society of North America, [<http://www.isna.org/drupal/>] Amicus Brief on Intersex Genital Surgery, 1997, Accessed October 10, 2004

²⁴ Purves, Brooke Sanders. “Parental consent and the surgical management of intersexed newborns.” In: *Monash Bioethics Review* 2000;9(1):23-42 (pages 30-37)

²⁵ Alice Domurat Dreger. *Intersex in the Age of Ethics*, Hagerstown: University Publishing Group, 1999: 17

²⁶ Esther Morris. The self I will never know: *New Internationalist*, Jan-Feb 2004;364:25-27

Since the 1990s the traditional treatment model has been challenged. Opposition to ‘normalizing’ surgery for people with intersex conditions has been expressed by patient advocacy groups and through the following kind of personal testimony of patients who are not happy with the way their condition has been managed:

At the age of 13, I was scheduled for surgery ... My body was altered to meet social values, but my values were never discussed. My puberty was focused on vaginal function before I had a chance to care.²⁷

One of the criticisms of the traditional treatment model is that it fails to recognize the experience of intersexed people and to recognize that they are experts in terms of their experience of intersex conditions.²⁸

Another factor in the opposition to early genital surgery is the failed sex reassignment of an infant whose penis was completely burned off in a circumcision accident – the much publicised John-Joan case.²⁹ The biologically unambiguous male infant was reassigned to the female sex on the recommendation of psychologist John Money who claimed that infants are sexually neutral, that nurture trumps nature and that gender identity is determined by the prenatal environment.³⁰ In a series of publications, Money reported that the surgically reassigned male infant had been successfully reared as a girl – resulting in the wide dissemination of the view that gender is malleable. He wrote that “no one” would “ever conjecture” that the child was born a boy.³¹ Ultimately, however, gender reassignment in this case proved unsuccessful. The child ‘never became a normal girl’ and from the age of 14 lived as a male.³² He underwent four rounds of reconstructive surgery and in 2004, at the age of 38 he committed suicide.³³ Many have taken this case as evidence that the claim that gender is socially constructed is wrong.³⁴

In relation to the surgical assignment of sex, Kipnis and Diamond make three recommendations which have wide support amongst those who oppose early surgery. The recommendations are as follows:³⁵

²⁷ Morris (2004), . Op. cit.

²⁸ Alice Domurat Dreger. *Intersex in the Age of Ethics*, Hagerstown: University Publishing Group, 1999:19

²⁹ Ian Aaronson, [Editorial Comments], *The Journal of Urology*, 2004;171:1619.

³⁰ Jorge Daaboul and Joel Frader. Ethics and the management of the patient with intersex: A middle way. *Journal of Pediatric Endocrinology & Metabolism*, 2001;14:1575-1583

³¹ Kenneth Kipnis and Milton Diamond. Pediatric Ethics and the surgical assignment of sex. *The Journal of Clinical Ethics*, 1998;9(4). Reprinted in Alice Domurat Dreger ed. *Intersex in the Age of Ethics*. Maryland: University Publishing Group. 1999: 173-193 p.176

³² Kenneth Kipnis and Milton Diamond. Pediatric Ethics and the surgical assignment of sex. *The Journal of Clinical Ethics*, 1998;9(4). Reprinted in Alice Domurat Dreger ed. *Intersex in the Age of Ethics*. Maryland: University Publishing Group. 1999: 173-193 p.180

³³ It is difficult to interpret this case as this individual had a twin brother whose death from an overdose of medication was a suspected suicide. Katie Chalmers. ‘Sad end to boy/girl life: Subject of gender experiment’ *The Winnipeg Sun*, May 10, 2004, Available at

<http://www.canoe.ca/NewsStand/WinnipegSun/News/2004/05/10/453481.html> (Accessed 26 April, 2005); ‘David Reimer: the boy who lived as a girl’ *CBC News Online*, May 10, 2004

<http://www.cbc.ca/news/background/reimer/> (Accessed April 26, 2005)

³⁴ Ian Aaronson, [Editorial Comments], *The Journal of Urology*, 2004;171:1619.

³⁵ Kenneth Kipnis and Milton Diamond. Pediatric Ethics and the surgical assignment of sex. *The Journal of Clinical Ethics*, 1998;9(4). Reprinted in Alice Domurat Dreger ed. *Intersex in the Age of Ethics*. Maryland: University Publishing Group. 1999: 173-193

1. 'That there be a general moratorium on such surgery when it is done without the consent of the patient'. Kipnis and Diamond argue that doctors should not perform the surgery without the knowledge that 'comparable patients generally do badly without the surgery'.³⁶ They also argue that the lack of evidence about benefits means that surgical assignment of sex is an 'experimental procedure.' Their objection is to the '*surgical* assignment of sex, not to gender assignment per se.'³⁷
2. 'That this moratorium not be lifted unless and until the medical profession completes comprehensive look-back studies and finds that the outcomes of past interventions have been positive'. Kipnis and Diamond claim that retrospective outcome studies can be done with the thousands of grown intersexuals who have and have not had surgical and hormonal treatment.³⁸
3. 'That efforts be made to undo the effects of past deception by physicians'.³⁹

Who should decide?

One of the controversies about early genital surgery focuses on the question of who should decide or who should have the authority to consent to surgery on behalf of children with intersex conditions. Should parents, doctors, or the courts decide, or should the decision be left to children themselves when they become old enough?

Parents are usually the best placed to judge what is in their children's best interests and ordinarily have authority to make medical decisions for them. However, there are some medical procedures for which parental consent is considered insufficient. These include interventions which are grave and irreversible, involve significant risk, involve difficult ethical issues and procedures that are not for the purpose of treating an illness. Such interventions sometimes require court authorization.⁴⁰

In Australia there is a legal category of "Special Medical Procedures", which require authorization. These special procedures include non-therapeutic sterilisation and hysterectomy, gender reassignment and organ donation.⁴¹ The Australian High Court decided⁴² that some grave and irreversible medical procedures which may permanently affect a child's quality of life are not within the scope of parents' or guardians' powers and should be made by 'an objective, independent umpire' such as the Family Court.⁴³

³⁶ Kipnis and Diamond 1999: 186-7

³⁷ Kipnis and Diamond 1999: 187

³⁸ Kipnis and Diamond 1999: 187-188

³⁹ Kipnis and Diamond 1999: 188

⁴⁰ Family Court of Australia. A Question of Right Treatment: The Family Court and Special Medical Procedures for Children – An introductory guide for use in Victoria. 1998, p.vii. Available at <http://www.familycourt.gov.au/papers/pdf/vicmedical.pdf> (Accessed Sept. 2004)

⁴¹ Ibid

⁴² Secretary, Department of Health and Community Services v. J.W.B. and S.M.B. (Marion's Case) [1992] HCA 15; (1992) 175 CLR 218 F.C. 92/010 (6 May 1992) Marion's case involved an application for the sterilisation of a 14-year-old teenager with a severe intellectual disability for the purpose of "preventing pregnancy and menstruation with its psychological and behavioural consequences".

⁴³ Family Court of Australia. A Question of Right Treatment, 1998, p.vii.

The High Court thought that special medical procedures require special consideration because there is a significant risk of making a wrong decision and grave consequences for the child would follow if a wrong decision were made.⁴⁴ Consideration of the child's best interests was one of the key issues identified by the court.

Box 2. Factors taken into account in assessing a child's best interests.⁴⁵

- The difficulties facing the child and family which led to the treatment being proposed
- The attitude of the child and parent or custodian to the proposed procedure and to any alternative medical procedures or options
- Weighing up the advantages and disadvantages of the procedure and any available alternatives
- Assessing the nature and degree of risk to the child from the procedure and the alternatives
- Assessing whether the procedure needs to happen now or whether other options can be tested and, if unsuccessful, the procedure can be preformed in the future.

Surgery for intersex newborns and infants falls into the category of special medical procedures requiring court authorization because it is irreversible, involves risk and sometimes, namely when the aim is for the genitals match the assigned gender, is performed for cosmetic reasons rather than treating an illness -.

The first high court in the world to consider the question of whether parents' should or should not have the authority to choose surgery for their intersex children was the Constitutional Court of Columbia.⁴⁶

While it is generally assumed that parents will act in the best interests of their children, courts will scrutinize parents' decisions about their children's medical treatments when it seems they are not acting in their child's best interests or if they have a conflict of interest. Some people think that parents choosing surgery for their intersex infants involves a conflict of interest in the sense that it is difficult for parents to be sure that they are acting in their child's best interests when they are being pressured to make a quick decision.

The Constitutional Court of Columbia decided, in 1999, that 'under the then existing medical practices in Columbia' parents might not be 'in the best position' to make medical decisions for their intersex children for the following reasons:

1. parents typically lack information about intersexuality;
2. intersexuality is viewed as a disease that must be "cured"; and
3. the treating physicians convey a sense of urgency to provide a quick cure.⁴⁷

⁴⁴ Family Court of Australia. A Question of Right Treatment, 1998, 2

⁴⁵ Family Court of Australia. A Question of Right Treatment: pp. 24-25.

⁴⁶ Julie A Greenberg and Cheryl Chase. Columbia High court Limits Surgery on Intersexed Infants. Available at <http://www.isna.org/drupal/book/view/21> (Accessed September 7, 2004)

⁴⁷ Julie Greenberg. Legal Aspect of Gender Assignment. The Endocrinologist. 2003; 13(3):277-286. p.283

This suggests that the court was taking the view that intersexuality is not a disease and that there is no urgency to fix the problem surgically. The Court also thought that parents ‘may be motivated by their own concerns and fears rather than the “best interests” of their children.’⁴⁸

The court carried out ‘exhaustive consultations’ for more than a year, hearing evidence in support of both the traditional treatment model and alternative treatment recommendations. After hearing all the evidence, the court concluded that:

to prohibit surgeries until the children reach the age of consent would be engaging in social experimentation, but to allow the surgeries to continue under the standard protocol would not ensure that the best interests of the children are protected.⁴⁹

While the court did not rule against surgery it established rules *restricting* parents’ authority to authorize surgery.⁵⁰ It recommended a new category of consent in order to make parents ‘put their children’s best interests ahead of their own fears and concerns about sexual ambiguity’.⁵¹ The court required consent to be ‘qualified and persistent’ and required the development of procedures by legal and medical institutions to meet the following conditions:

1. The consent must be in writing.
2. The information provided must be complete. The parents must be informed about the dangers of current treatments, the existence of other paradigms, and the possibility of delaying surgeries and giving adequate psychological support to the child.
3. The authorization must be given on several occasions over a reasonable time period to make sure the parents have enough time to truly understand the situation.⁵²

Some medical procedures are indeed special, require much thought and sometimes legal scrutiny. Based on these decisions, we should conclude that parents should ordinarily decide but the courts should be involved when a particular decision to perform surgery on an intersex child appears to be against that child’s interests. This would involve someone seeking court intervention because they believed the child’s best interests were not being served. Alternatively, surgery for intersex conditions could be classed as a ‘special medical procedure’ requiring court authorization. Having to go to court to get authorization for surgical treatment could be traumatic for parents, but some parents may find welcome relief in sharing the weight of the decision. Next we summarise clinical guidance in these complex decisions.

The Clinical Perspective: Should early surgery be carried out?

⁴⁸ Julie Greenberg. Legal Aspect of Gender Assignment. *The Endocrinologist*. 2003; 13(3):277-286. p.283

⁴⁹ Greenberg. Legal Aspect of Gender Assignment. *The Endocrinologist*. 2003; 13(3):277-286. p.279

⁵⁰ Julie A Greenberg and Cheryl Chase. Columbia High court Limits Surgery on Intersexed Infants. Available at <http://www.isna.org/drupal/book/view/21> (Accessed September 7, 2004).

⁵¹ Greenberg 279

⁵² Greenberg 279; Sentencia SU-337/99, May 12, 1999, and T-551/00, Aug. 2, 1999.

Current practice guidelines for the surgical management of intersex newborns

- **American Academy of Pediatrics.**⁵³

These guidelines famously begin with the statement: ‘The birth of a child with ambiguous genitalia constitutes a social emergency.’⁵⁴ They emphasise the urgency of a prompt definitive diagnosis and treatment: ‘It is important that a definitive diagnosis be determined as quickly as possible so that an appropriate treatment plan can be established to minimize medical, psychological, and social complications.’⁵⁵ The point is also made that most genital abnormalities are not ambiguous in appearance and ‘only a minority of intersex patients have genitalia that are so ambiguous that the sex is uncertain’.⁵⁶

According to the Academy, decisions about the sex of rearing should be based on fertility potential, capacity for normal sexual function, endocrine function and testosterone imprinting.⁵⁷ ‘Ongoing counseling’ of parents and affected children is recommended because of ‘remaining uncertainties with regard to the long-term psychological and physical aspects of treatment.’⁵⁸ This document states that infants raised as girls will usually require clitoral reduction’.⁵⁹

The type of evidence supporting the recommendations in this document is not stated.⁶⁰ This guideline is due to be reviewed.

- **British Association of Paediatric Surgeons**⁶¹

This document it is meant to be an ‘evidence based summation of current thinking and suggested practice’.⁶² It notes the controversy relating to standard protocols but claims that a policy of prohibiting surgery until the fully informed consent of the patient can be obtained i.e. when the child becomes ‘Gillick Competent’ (that is, of sufficient maturity to be capable of giving independent consent during adolescence) seems ‘too prescriptive’ given that there are ‘so many specific issues related to the different diagnostic groups.’⁶³

⁵³ American Academy of Pediatrics. Committee on Genetics. Evaluation of the newborn with developmental anomalies of the external genitalia. *Pediatrics* July 2000; 106(1):138-142

⁵⁴ American Academy of Pediatrics. p. 138

⁵⁵ American Academy of Pediatrics. p.138

⁵⁶ American Academy of Pediatrics. p.139

⁵⁷ American Academy of Pediatrics. pp.140-141

⁵⁸ American Academy of Pediatrics. p.141

⁵⁹ American Academy of Pediatrics, p.141

⁶⁰ National Guideline Clearinghouse. Available at www.guideline.gov (Accessed 1 Dec. 2004)

⁶¹ L. Rangecroft, on behalf of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia. Surgical management of ambiguous genitalia. *Arch Dis Child* 2003;88:799-801; Draft Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia, July 2001

⁶² Draft Statement of this document i.e. Draft Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia, July 2001. Available at <http://www.baps.org.uk/documents/Intersex%20statement.htm> (Accessed Dec. 1, 2004)

⁶³ Draft Statement and Rangecroft p.799

This guideline recommends referral to a multidisciplinary team⁶⁴ and recommends making ‘no assignment of gender’ prior to referral.⁶⁵ It suggests that where continuing pressure from parents for early corrective surgery exists, ‘fully informed consent’ for procedures would require parents being made aware of ‘the possibility of non-surgical management with psychological support for the child and family’.⁶⁶

An appendix in the draft statement on clitoral surgery notes that although no data is available, clitorrectomy or clitoral amputation is thought to be rarely done in the UK now and it is presumed that clitoral recession is no longer performed although clitoral reduction is still carried out. It notes that there are few studies looking systematically at outcome. There are also no comparative data comparing women who have undergone surgery to women who have not had surgery even though there is an existing cohort of older patients from the UK who have not had genital surgery to compare with babies with ambiguous genitalia from the United States - almost all who have undergone genital surgery since the 1950s.⁶⁷

Other guidelines and recommendations exist.^{68 69 70 71} The most striking conclusion from the guidelines is that recommendations are being made in the absence of long term data about outcomes. Some evidence exists⁷² but there are serious problems with that evidence.

⁶⁴ Draft Statement and Rangecroft p.799

⁶⁵ Rangecroft p.799

⁶⁶ Draft Statement and Rangecroft p.799

⁶⁷ Appendix of Draft Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia, July 2001. pp. 7&8

⁶⁸ Joint Lawson Wilkins Pediatric Endocrine Society and The European society for Paediatric Endocrinology. Consensus Statement on 21-Hydroxylase Deficiency from the Lawson Wilkins Pediatric Endocrine Society and The European society for Paediatric Endocrinology. *J. Clin Endocrinol Metab* 2002;87(9):4048-4053

⁶⁹ Joel Frader; Priscilla Alderson; Adrienne Asch; Cassandra Aspinall; Dena Davis; Alice Dreger; James Edwards; Ellen K. Feder; Arthur Frank; Lisa Abelow Hedley; Eva Kittay; Jeffrey Marsh; Paul Steven Miller; Wendy Mouradian; Hilde Nelson; Erik Parens, Health Care Professionals and Intersex Conditions, *Archives of Pediatric and Adolescent Medicine* May, 2004;158:426-428

⁷⁰ Erica A. Eugster, Reality vs Recommendations in the Care of Infants With Intersex Conditions—Invited Critique, *Archives of Pediatric and Adolescent Medicine* May, 2004;158:428-429

⁷¹ Daaboul J. Frader J. Ethics and the Management of the patient with intersex: a middle way. *J Pediatr Endocrinol Metab*. 2001; 14:1575-1583

⁷² **Studies supporting early corrective genital surgery:** Warne GL, Grover S, Hutson J, Sinclair AH, Metcalfe S, Northam E, Freeman J, Loughlin E, Rillstone M, Anderson P, Hughes E, Hooper J, Todd S, Zajac JD and Savulescu J. A Long-term outcome study of intersex conditions. *Journal of Pediatric Endocrinology and Metabolism* In Press. (2005); Meyer-Bahlburg H, Migeon C, Berkovitz G, Gearhart J, Dolezal C, and Wisniewski A. Attitudes of adult 46,XY intersex persons to clinical management policies, *The Journal of Urology*, 2004; 171: 1615-1619; Migeon CJ, Wisniewski AB, Gearhart JP, Meyer-Bahlburg HFL, Rock JA, Brown TR, Casella SJ, Maret A, Ngai KM, Money J, Berkovitz GD. Ambiguous genitalia with perineoscrotal hypospadias in 46XY individuals: Long-term medical, surgical, and psychosexual outcome. *Pediatrics*, 2002;110:616-21; Claude J. Migeon, Amy B. Wisniewski, Terry R. Brown, John A. Rock, Heino F. L. Meyer-Bahlburg, John Money, and Gary D. Berkovitz. 46,XY intersex individuals: phenotype and etiologic classification, knowledge of condition, and satisfaction with knowledge in adulthood. *Pediatrics*, 2002; 110 (3): e32. **Studies which do not support early surgery:** Catherine L Minto, Lih-Mei Liao, Christopher R J Woodhouse, Phillip G Ransley, Sarah M Creighton. The effect of clitoral surgery on sexual outcome in individuals who have intersex conditions with ambiguous genitalia: a cross-sectional study. *Lancet*, 2003;361: 1252-1257; Creighton SM, Minto CL, Steele SJ. Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood. *Lancet*. 2001 Jul 14;358(9276):124-5;

- The John-Joan case is not useful in terms of evidence. That case did not involve a child with an intersex condition and genital ambiguity. The child was harmed but the real harm was caused by the botched circumcision.⁷³
- '[S]ystematic prospective or even systematic retrospective overall outcome studies' are not available.⁷⁴
- There are criticisms that the traditional treatment model fails to recognize the experience of intersexed people. This raises the question: 'How do we know what the experience of intersexed people is?'
- It is not easy to obtain the experience of intersexed people. 'Self-descriptions' of the long-term effects of reconstructive surgery and of the anomalies themselves are 'rare.'⁷⁵ According to W.G. Reimer, while clinically useful studies that claim to provide overall outcomes such as health related quality of life do exist they are problematic – they are too narrow in scope, 'too simplistic in their understanding of quality of life' and data is difficult to interpret and not useful if there is a lack of systematization within research and clinical care.⁷⁶
- There are doubts about the representativeness of individuals studied. Recruiting individuals from intersex support groups is thought to give a negative bias⁷⁷ in terms of surgical management while recruiting individuals from clinics gives a positive bias.⁷⁸ We do not know the experience of those who do not take part in follow-up studies eg. in a study of the attitude of intersex patients it was found that most were satisfied with the management of their condition and with the gender they were assigned.⁷⁹ We have to question the value of this finding given that more than a quarter of the patients could not be contacted and nearly a quarter refused to participate.⁸⁰
- Small sample size is a recurrent problem.

May B.,Boyle M.,Grant D., A comparative study of sexual experiences. *Journal of Health Psychology*, 1996; 1(4): 479-492; Dittman RW, Kappes ME, Kappes MH, Sexual behaviour in adolescent and adult females with congenital adrenal hyperplasia. *Psychoneuroendocrinology*, 1992; 117 (2/3): 153-70; Reilly, JM, Woodhouse, CRJ. Small penis and male sexual role. *J. Urol.* 1989;142: 569-71.

⁷³ Tom Mazur. A lovemap of a different sort from John Money – A first person history of pediatric psychoendocrinology – Book Review. *Journal of Sex Research*, 2004, 41(1): 115-116; Vern L. Bullough. The contributions of John Money: A personal view. *The Journal of Sex Research* 2003; 40 (3): 230-236

⁷⁴ W. G. Reiner. Mixed-method research for child outcomes in intersex conditions. *BJU International*. 2004; 93 Supplement (3):51-53. p.51.

⁷⁵ W. G. Reiner. Mixed-method research for child outcomes in intersex conditions. *BJU International*. 2004; 93 Supplement (3):51-53. W.G. Reiner is a urologist who has become a psychiatrist

⁷⁶ Reiner 2004 p.51.

⁷⁷ Schober, Justine M. Schober. Feminizing Genitoplasty: A Synopsis of Issues Relating to Genital Surgery in Intersex Individuals. *Journal of Pediatric Endocrinology & Metabolism*, 2004; 17:697-703. pp. 701-2

⁷⁸ Meyer-Bahlburg H, Migeon C, Berkovitz G, Gearhart J, Dolezal C, and Wisniewski A. Attitudes of adult 46,XY intersex persons to clinical management policies, *The Journal of Urology* 2004; 171: 1615-1619.

⁷⁹ Meyer-Bahlburg H, Migeon C, Berkovitz G, Gearhart J, Dolezal C, and Wisniewski A. Attitudes of adult 46,XY intersex persons to clinical management policies, *The Journal of Urology* 2004; 171: 1615-1619.

⁸⁰ Meyer-Bahlburg H, Migeon C, Berkovitz G, Gearhart J, Dolezal C, and Wisniewski A. Attitudes of adult 46,XY intersex persons to clinical management policies, *The Journal of Urology* 2004; 171: 1615-1619.

- Some argue that ‘researcher bias’ results when studies are not independent from treating physicians.⁸¹
- The fact that surgery is better now means that retrospective studies may not be very useful.
- Studies ask superficial questions⁸²
- In a review of current research relating to feminizing genitoplasty, Schober claims ‘no definitive information is currently available regarding the “best time” for surgical intervention’ and the risk/benefit analysis has not yet been established.⁸³
- There are some studies about clitoroplasty and vaginoplasty but little data on functional outcome available.⁸⁴

The threat to future autonomy

The threat to future autonomy is one of the reasons some people object to early surgery for intersex newborns. They are concerned about what happens when parents make irrevocable decisions for their children and they worry that the intersex child’s autonomy or developing autonomy will be affected by the way his or her condition is managed.

According to one commentator:

Intersexed people have their autonomy violated because their doctors and parents are allowed to make decisions about how their genitals should look.⁸⁵

And, an adult who was born intersexed claims:

Intersexuals aren’t encouraged to be autonomous ... who we are is dictated to us.⁸⁶

Intersex people who underwent surgery when they were young may have been harmed but the harm is not to their autonomy. To begin with, very young children do not have autonomy - immaturity precludes autonomy. Nevertheless, that is not the focus of the concerns expressed above and will not eliminate worries about threats to children’s autonomy. There is a need to make a distinction between two ideas:

- (i) the future autonomy of the child, and
- (ii) the child’s developing autonomy.

Damage to cognitive abilities would harm the young person’s developing autonomy but the harm alluded to in the above quotes refers to a child’s future autonomy and the idea that choices made by parents will close off certain options, thereby limiting the

⁸¹ Frader et al. 2004, p.428; Erica A. Eugster, p.428

⁸² Meyer-Bahlburg H, Migeon C, et al. 2004: 1618

⁸³ Schober, 2004: 698.

⁸⁴ Schober, 2004: 701-2

⁸⁵ Dreger A (1999). A history of intersex: From the age of gonads to the age of consent. In Dreger A. (ed.). *Intersex in the age of ethics*. Maryland: University Publishing Group: 17

⁸⁶ Sharon E. Preves. For the sake of the children: Destigmatizing intersexuality. In Dreger A. (ed.). *Intersex in the age of ethics*. Maryland: University Publishing Group. 1999: 50-65 (p.56)

child's autonomy. This is what some commentators refer to as 'a child's right to an open future'.⁸⁷

Appealing to a child's future autonomy in this way is not useful. Autonomy is not just about the number of options a person has open to them. Although autonomy is sometimes used as a synonym for freedom or liberty, autonomy is about more than that. A person's liberty or freedom can be affected by a reduction in options but the availability and range of life options is not what makes a person autonomous. Autonomy is a richer concept. It is about self-rule and making decisions about how one's life should go. It is about acting or choosing in a way that reflects preferences and values and depends on a particular kind of thinking.

As long as there are basic opportunities to grow and learn, autonomy does not depend on the circumstances in which a person finds themselves. It is possible to be autonomous and make autonomous decisions within narrowed horizons and also when options are not to our liking. Autonomous decisions can be made in reduced circumstances such as that brought about by illness.⁸⁸ Most importantly, whether or not surgery is performed, some options will be open and others irrevocably closed:

1. if surgery is not performed, the child will later have a choice of whether or not to have surgery but no choice over whether he/she is stigmatized as an intersex child during early development
2. if surgery is performed, the child will have choices opened as a result of having a more "accepted" appearance but no choice later on whether to have surgery.

Someone with an intersex condition who has undergone surgery as an infant may be harmed by the surgery because sensation is affected, by the feeling of shame generated by having the surgery or by being stigmatized because of their condition. That person may have different options available than if they had not had the surgery. Fertility may be affected, for example. –However, their autonomy is not determined by these factors. Certainly the sex assigned will influence a person's plans and choices but autonomy is characterized by a person's capacity to think critically about their preferences, desires and wishes, and their 'capacity to accept or attempt to change these in light of higher-order preferences and values.'⁸⁹ In exercising that capacity, a person 'defines their nature, gives meaning and coherence to their life and takes responsibility for their choices'.⁹⁰ Ultimately, it is the result of these choices and the way they are made that determines the kind of person they become – and that may be an autonomous, mostly autonomous, sometimes autonomous or never autonomous person.⁹¹

⁸⁷ Feinberg J. 'The child's right to an open future' In Aiken W, and LaFollette H. (eds). *Children's rights, parental authority, and state power*. Totowa, NJ: Rowman & Littlefield, Adams & Co. 1980:124-53; reprinted in Feinberg, *Freedom & fulfillment*. Princeton, NJ: Princeton University Press, 1992:76-97

⁸⁸ Spriggs, M. (1998). Autonomy in the face of a devastating diagnosis. *J Med Ethics*, 24(2), 123-126.

⁸⁹ Dworkin G. *The Theory and Practice of Autonomy*. Cambridge: Cambridge University Press. 1988, p.20

⁹⁰ Spriggs M. *Autonomy and patients' decisions*. Lexington Books, Maryland, 2005: 241

⁹¹ Ibid.

Early surgery does not clearly compromise later autonomy. However it may remove options that we believe should be available to people – that is how their body is to appear. It may reduce important freedoms, but it does not clearly affect autonomy. Sharon Preves reports that although the in-depth life history interviews she carried out with intersex adults tell of ‘pain, sorrow, bewilderment, and anger’, they also include accounts of ‘empowerment, identification, and reappropriation of intersexuality as a positive aspect of the self.’⁹² This capacity to cope with the stigma of being intersexed is suggestive of autonomy: “I don’t think I would turn it in. I mean I’ve thought about this a lot. I really don’t think that I would choose to be other than I am”⁹³ This comment reveals critical thinking and the ability to choose or change one’s own attitude.

Children’s developing autonomy

Although it does not make sense to talk about harm to the intersex child’s future autonomy, it may make sense to talk about harm to a child’s developing autonomy. Autonomy is not something that appears fully developed. Training children to become autonomous requires practice. Therefore, it might be claimed that aspects of the traditional medical model undermine or harm developing autonomy by not allowing the child to exercise choice or practice decision making. John Stuart Mill’s argument about individuality as one of the elements of well-being could be interpreted as an argument about why we should value autonomy and why preventing children from making decisions can thwart the development of their autonomy.⁹⁴ Mill argues that we express our individuality and our humanity when we make choices. Qualities such as ‘perception, judgement, discriminative feeling, mental activity, and even moral preference’ are, according to Mill, the ‘distinctive endowment of a human being’ and are exercised and developed only in the making of choices.⁹⁵ The value is not in the choice but in Mill’s idea of character or self-development (which we can interpret as autonomy) and in fully developing the necessary capacities:

He who lets the world, or his own portion of it, choose his plan of life for him, has no need of any other faculty than the ape-like one of imitation. He who chooses his plan for himself, employs all his faculties.⁹⁶

Some adult intersexuals tell of childhoods in which they lacked information about their conditions (a basic requirement for meaningful decision making) and lacked choice in the sense that they were not able to refuse repeated genital examinations performed without their consent:

Because [the hospital I went to] is a teaching hospital, they would line up shoulder to shoulder all the way around from one side of the bed at the head, all the way across to the front and back up the other side. And everybody got a peek and a poke between my legs. And along about nine [years of age] that

⁹² Sharon Preves. ‘For the sake of the children: Destigmatizing intersexuality’. In Alice Domurat Dreger. *Intersex in the Age of Ethics*, Hagerstown: University Publishing Group, 1999:51-65 [p.59]

⁹³ Preves, 1999, 60

⁹⁴ LaFollette, Circumscribed autonomy: Children, care, and custody. In: Bartowiack and U. Narayan (eds). *Having and Raising Children*, State College, PA: Penn State Press, 1998:137-52

⁹⁵ Mill, *On Liberty*, Pp.1-104 in *On Liberty and Considerations on Representative Government*, edited by R.B. McCallum. Oxford: Basil Blackwell, 1948. p.51

⁹⁶ Mill, *On Liberty*, 51-52.

started getting real uncomfortable for me. But I was not allowed the power to say, “No, I don’t want to play this game anymore.”⁹⁷

...you know while you’re laying there that you don’t have the right to say, “No. Stop. I don’t want you to do this.”⁹⁸

How would such an experience undermine developing autonomy? The capacities needed for autonomy and making autonomous decisions need to be developed, and as mentioned previously, that requires practice. To some extent it means we need to treat children as though they are already autonomous.⁹⁹ Preventing the exercise of choice may threaten developing autonomy, though it is not likely to undermine it entirely.

Helping intersexed children to develop autonomy is an important ethical consideration. But it is not clear that early surgery necessarily precludes that as many opportunities for the exercise of choice in life still remain. Though autonomy has been the main focus of ethical discussion it is not the main ethical issue. The main ethical issue is the question: does early surgery makes the child’s life go better or worse.

Does early surgery make an intersex individual’s life go better or worse?

What is there about early surgery that can make the individual’s life go worse?

- Poor surgical outcomes
- Attitude that intersexuality is shameful.¹⁰⁰

Poor surgical outcomes is an obvious cause of harm but it is not the only or the primary reason that former patients ‘feel harmed’. Cheryl Chase argues that ‘the primary source of harm described by former patients is the underlying attitude that intersexuality is so shameful that it must be erased ... Early surgery is one means by which that message is conveyed to parents and to intersexed children.’

Another source of harm is the claim that ‘surgery is better now’. This silences intersexed adults and ‘relieves surgeons indefinitely of the responsibility of listening to any former patient.’¹⁰¹

The Intersex Society of North America refers to a ‘wealth of literature’ expressing grief about the physical and emotional suffering caused by the surgery and anger towards the doctors who performed the surgery and the parents who consented to the surgery. Significance is also placed on the fact that there are no adults coming forward to say that they are grateful for having had early surgery performed.¹⁰²

⁹⁷ Sharon E. Preves. *Intersex and Identity: The Contested Self*, New Brunswick: Rutgers University Press, 2003:66

⁹⁸ Preves, 2003, p.72.

⁹⁹ La Follette H. Circumscribed autonomy: Children, care, and custody. In: Bartowiack and U. Narayan (eds). *Having and Raising Children*, State College, PA: Penn State Press, 1998:137-52.

¹⁰⁰ Cheryl Chase. Surgical progress is not the answer to Intersexuality. *The Journal of Clinical Ethics*. 1998;9(4):385-392. p.385

¹⁰¹ Chase, 1998: 387.

¹⁰² Intersex Society of North America, [<http://www.isna.org/drupal/>] Amicus Brief on Intersex Genital Surgery, 1997, (Accessed 10 October, 2004)

The availability of literature about harm to intersex individuals who had early surgery is cause for concern but it is not necessarily an indication that surgery made most intersex individuals lives go worse. It is possible that there is no audience for tales of successful surgery. Individuals who had surgery and are happy with it may not want to reveal their experience. What is more, unhappy outcomes would seem to be easier to name and describe eg. in terms of grief and anger. How would we know if surgery made an individual's life go better? There is a need for information about the experience of those who feel that surgery was the right decision.

Parental attitudes

There is some suggestion that parental attitude rather than the decision to operate or not has more influence on intersex children's successful development. In a study of children born with a small penis, 'parental attitude' was reported to be the 'strongest influence' on childhood experiences.¹⁰³ Parents who were well informed and open with their children produced children who were 'confident and well adjusted.' Parents who were not open with their children, who focused on their abnormalities and told the child 'to hide himself' produced shy, anxious, poorly adjusted children.¹⁰⁴

The importance of parental attitude is demonstrated further in the case of Ilizane Broks, a self-assured, seemingly well-adjusted 17 year old with an intersex condition who has been brought up with full knowledge of her condition and 'imbued' with a 'healthy sense' of her 'own identity and worth'. She has been taught to 'ignore the prejudice of the ignorant' and to be proud of her difference.¹⁰⁵ Ilizane has Complete Androgen Insensitivity Syndrome (CAIS). She has both male and female genitalia. She looks like a girl, has a vagina but no uterus or ovaries and has testes and XY chromosomes, which denote a boy. Ilizane overturns the image of the ostracized, cruelly teased intersex child. She delights in her father's story about her first day at school when she was a five-year old. When each child was asked to stand on a chair and introduce themselves to the class Ilizane climbed onto a chair and said: "Hello, my name is Ilizane. I'm not a girl and I'm not a boy ... I'm an intersex!" Ilizane retains her early confidence, claiming she would like to be an actress: "I really like the idea of standing up in front of people and saying 'Hey, this is me. Or rather, this isn't me. All is not as it seems ...'"¹⁰⁶

In Ilizane's case, her parents resisted the suggestion to remove her testes and have left the decision to their daughter. Ilizane admits however, that if she had CAH the more common condition, she might have opted for surgery by now.¹⁰⁷ The point being made here is that the child's environment matters – not in the sense that environment determines gender – but in the sense that acceptance and openness regarding the child's condition influences how well or how badly the child's life will go.

Key points in the management decisions about intersex

The preceding discussion suggests a number of points to bear in mind in minimizing harm:

- Surgery is most justified when there is a clear health risk

¹⁰³ Reilly, JM, Woodhouse, CRJ. Small penis and male sexual role. *J. Urol.*, vol 142, 1989, p 569-71.

¹⁰⁴ Reilly (1989), op. cit.

¹⁰⁵ Olga Craig. We are not what we seem. *The Sunday Age*, March 28, 2004, Agenda: 10-11

¹⁰⁶ op. cit.

¹⁰⁷ op. cit.

- An early decision to do surgery (when appropriate) does not have to be a quick or rushed decision
- One can assign a gender without doing surgery to match.
- Promote the idea that parental attitude is important - parents who are informed and open tend to produce confident well-adjusted children.¹⁰⁸
- Rather than promoting surgery or a moratorium on surgery we should promote the idea that education, information and positive attitudes in relation to intersex conditions matter most.
- It is important to look at the reason why a significant minority are not happy with the management of their condition.

It is still not clear what we should or should not do. Sometimes surgery has caused harm. Sometimes surgery may be the right decision. We need criteria to guide decisions.

A decision whether to perform surgery or not to perform surgery has to be made. In addition to the relevant medical facts, we need criteria to guide decisions on behalf of intersex newborns. Deference to parents as the most suitable people to be making medical decisions on behalf of their children (with help from doctors and with the relevant information) is based on the belief that parents are the best placed and most likely people to seek the best interests of their children. Nevertheless, given the controversy about early surgery for intersex newborns the idea that parents should (i) leave the decision until the child is old enough to decide or, (ii) try to decide as the child would decide when old enough may seem like attractive options. But there are difficulties. First, leaving the decision for the child to decide when old enough carries the possibility of harm. It amounts to a decision not to perform early surgery rather than a way to respect autonomy. Second, in trying to decide as the child would, parents may end up making a decision that they *think* is not in their child's best interests and turns out *is not* in the child's best interests - based on an assumption about what a child who has not attained competence would decide when older.¹⁰⁹ Getting it wrong would surely be worse when parents make a decision that they did not believe in.

Conclusion

Box 3. Why management of intersex is an important ethical issue

The controversy surrounding the surgical management of intersex conditions in newborns is an important ethical issue because it:

- raises questions about the authority of parents and others to make irrevocable decisions for young children.
- tests the idea that surgery is only justified when it is for disease or malfunction.
- raises questions about what constitutes disease or malfunction.

¹⁰⁸ Reilly (1989), op. cit.,

¹⁰⁹ Gerald Dworkin, *The Theory and Practice of Autonomy*, Cambridge: Cambridge University Press, 1988: 85-99

- questions the legitimacy of medical interventions that are carried out on one person in the interests of another.
- helps shed light on the soundness of claims about threats to a child's future autonomy.
- poses questions about what we should base treatment decisions on when there is little guidance in terms of evidence of outcomes.
- illustrates the shift from physician-centred medicine and paternalism to patient-centred medicine and the need to listen to patient experience (narrative).
- highlights the need for evidence in the form of systematic outcomes studies

The management of children born with intersex conditions raises many profound ethical issues. It is often argued that the main ethical issue is about future autonomy. We have argued that freedom, but not future autonomy, may be compromised by early surgery to assign sex. It is important to promote the development of autonomy in children with intersex conditions but this can be done in a number of ways, including particularly open disclosure of their condition and its management, without precluding early surgery. We have argued that the critical ethical issue is whether early surgery benefits or harms a particular individual in the sense of making that person's overall life go better or worse. Strikingly, there is very little empirical evidence to answer this question. The management of intersex speaks to the moral imperative to conduct ethically informed scientific research. Only then will we know what we should do.