Unnecessary surgery on intersex infants: Problems of theory become problems in practice

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Abstract
This paper discusses the medical treatment of intersex infants: children born with ambiguous genitalia, chromosomes, or hormones. The central thesis is that unnecessary surgery, defined as surgery that is not necessary to preserve the life or physical health of the infant, is unethical when performed on infants and should be postponed until the patient is able to participate in, and contribute to, the decision. Three lines of argument are presented: One based on the lack of clinical evidence supporting unnecessary surgery; one based on how unnecessary surgery limits the child’s future choices; and one based on how problematic notions of gender have resulted in problems in practice. Together and separately, the three arguments lead to the conclusion that performing unnecessary surgery on intersex infants is unethical, and wherever possible surgery should be delayed until the patient can participate in the decision.
I. INTRODUCTION

There is one question that almost invariably follows any birth announcement. “Is it a girl or a boy?” In most cases this is a simple question with a simple answer. Balloons are bought, rooms are painted, gifts are given. In a small but sizable number of cases, however, physicians and parents have reason at birth to question whether the child is a boy or a girl. Intersex infants – children born with ambiguous genitalia, chromosomes, or hormones – present a question that physicians and parents do not always have the answer to. The outward appearance of the genitalia, examination of internal genital structures, and other diagnostic means are used to determine the particular intersex condition and make a decision on whether to raise the child as a boy or a girl.

In common medical practice, along with a gender assignment comes immediate surgery to modify the external genital structures to conform with the assigned gender. In recent years, this practice has come under strong criticism from former patients, ethicists, and other physicians.

Unnecessary surgery

The thesis of this paper is that unnecessary surgery should not be performed on intersex infants. Wherever possible, surgery on intersex infants should be postponed until the patient is able to participate in, and contribute to, the decision.

“Unnecessary” is defined as changing the genitals or internal bodily structures in ways that are not necessary to preserve the life or physical health of the infant. For illustration, converting a “micropenis” into a clitoris and feminising the infant is unnecessary, whereas creating a urinary opening where none exists is critical to prevent the death of the infant.¹

Three lines of argument will be made to support the thesis statement.

¹ Unnecessary is used without the qualifier “medically” in order to capture the full scope of unnecessary surgeries. It will be shown that surgeries that are medically unnecessary are being portrayed as necessary for non-medical reasons. This is explored in the clinical evidence argument and the gender argument.
It will first be argued that unnecessary surgeries on intersex infants are unethical because they are unproven, have significant negative effects and often lead to poor outcomes. In addition, the apparent urgency they are assigned is unjustified. This is the clinical evidence argument.

Next, I will argue that performing unnecessary surgeries on intersex infants is unethical because it limits their future choices to make decisions about their own bodies and precludes their involvement in decisions with long-term implications for them. This is the future choices argument.

Finally, I will argue that unnecessary surgeries on intersex infants are unethical because they represent the application of an uncritical theory of gender that leads to problems in practice. This is the gender argument.

While each of the arguments stands independently in support of the thesis, they also build on each other to provide strong support for immediate changes in practice, some of which are already beginning to occur. Unnecessary surgeries performed on intersex are a violation of ethical practices and must be recognised as such.
II. INTERSEX

Intersex is a difficult category to define – even to label. This section will include an overview of the naming controversy, a working definition of intersex, and a general overview of intersex conditions and their frequency, including a limited description of the more common intersex conditions. In discussions of intersex, it is important to recognise that the history, names, and definitions can be as controversial as the medical management of the condition. It is therefore particularly important to be clear about the concept of intersex before discussing the treatment of persons with intersex conditions.

Naming

The terminology in this area is highly controversial and frequently loaded with particular histories, assumptions, and political goals. I do not wish to delve too deeply into these issues but I will address them briefly.

Hermaphrodite was the term used for individuals whose bodily structures – especially the genitals – did not fit with standard male or female anatomy, or combined aspects of both anatomies. The word hermaphrodite derives from Hermaphroditus, who was the son of Hermes and Aphrodite in Greek mythology. After being fused with a nymph, Hermaphroditus possesses both male and female genitals. Applied as clinical terminology, hermaphrodites were then divided into true hermaphrodites, male pseudohermaphrodites, or female pseudohermaphrodites. In true hermaphroditism, which is particularly uncommon, the infant is born with both ovarian and testicular tissue. Male pseudohermaphrodites have only testes, and female pseudohermaphrodites have only ovaries. Within both male and female pseudohermaphroditism there exist several different conditions.

In the early twentieth-century, intersex (alternatively intersexed or intersexual) emerged as the dominant clinical term to encompass the three types of

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2 Dreger, 1998b, 4.
3 Fausto-Sterling, 2000, 32-33.
Intersex is an umbrella term for conditions where “genital, gonadal, or chromosomal characteristics that are neither all ‘female’ nor all ‘male.’”\(^5\) Different explanations for this change can be made. One explanation is that the terminology ceased to be useful to clinicians or failed to communicate the conditions as physicians saw them.\(^7\) Other reasons include the hypocrisy and incoherence of the terms themselves: Can a person be “truly” male and female? Is a “pseudo” hermaphrodite a hermaphrodite, or true male? Further, patients and patient groups have complained that the terminology of hermaphroditism is “stigmatizing and misleading.”\(^8\)

A new label, Disorders of Sexual Differentiation (DSD), has emerged as a new umbrella term to describe intersex conditions. A recent consensus statement proposed the term for “congenital conditions in which the development of chromosomal, gonadal, or anatomical sex is atypical.”\(^9\) The term was introduced to reduce the confusion around terminology, among other reasons.\(^10\)

**Working definition**

It seems clear that the matter of terminology will not be definitively settled and will continue to change with medical discourse, clinical discoveries, and patient perspectives and activism. Throughout this paper, I will use intersex as an umbrella term for congenital conditions where the development of chromosomal, gonadal, or anatomical gender is atypical. This definition relies heavily on Kessler’s definition of intersex\(^11\) and Hughes et al.’s definition of DSD.\(^12\)

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\(^5\) Dreger, 1998b, 4.
\(^6\) Kessler, 1998, 166.
\(^7\) Dreger 1998b, 154-7.
\(^9\) Hughes, et al., 2006, 554.
\(^12\) Hughes, et al., 2006, 554.
The terminology of sex and gender

Although sex conventionally refers to biological characteristics and gender to behavioural ones, following Kessler and McKenna, I will use gender to refer to all signifiers of male and female, and sex to refer to acts of physical intimacy, such as intercourse. (Note that direct quotes from other authors will be left unmodified, but clarified when necessary.) This is intended to make a point. As I demonstrate later in the gender argument, gender’s meaning is socially constructed, and even the choice to label a particular body part as ‘male’ or ‘female’ – or neither – is a cultural choice. Referring to both body parts and behaviours under the term gender emphasises that the main points of discussion are the social meanings we attach to bodies and behaviours, which will become more clear in the exposition of the gender argument.

Although I prefer to avoid using the term sex to refer to gendered anatomy, I will continue to use the term intersex to describe this set of medical conditions for two reasons. First, it is the term most commonly used in the literature by physicians, ethicists, and patients. Intersex has effectively replaced the earlier terminology of hermaphroditism, and for this reason using the term places this paper clearly within the current treatment debate in the literature. Second, as I noted above, I will continue to use sex to refer to acts physical intimacy. While it is not often discussed openly, assumptions and cultural norms of sexuality have long played a guiding role in determining how intersex persons will be treated. For instance, treatment of intersex individuals in the 19th century centred on identifying and imposing a “true” gender, which included enforcing heterosexual norms. Even more recent treatment protocols focus on reconstructing the genitals to be suitable for heterosexual penetrative intercourse. Using the umbrella term of intersex appropriately situates this paper within a particular body of literature and recognises that the debate is not merely about gender but also sexuality.

13 Kessler and McKenna, 1978, 7.
14 This will be discussed further in the Gender argument.
15 Dreger, 1998b, 113.
16 Dreger, 1998a, 29.
Conditions
Even with the working definition, there is still some difficulty in defining precisely what counts as an intersex condition. To help give the reader a clearer picture of intersex conditions, I will briefly describe some of them,\(^\text{17}\) and give information about the frequency of intersex births.

Atypical chromosome compositions include XXY, XO, XYY, XXYY, XX males, 47,XXX females, and 47,XYY. XXY is also referred to as Klinefelter syndrome, and patients normally have a penis, small testes, impaired fertility and gynecomastia (breast development). Infants born XO have female external genitalia and undeveloped gonads that do not produce hormones in the fetal stage or at puberty. Persons with 47,XXY and 47,XYY present no symptoms and often go undiagnosed.\(^\text{18}\)

Androgen-insensitivity syndrome (AIS) is a genetic condition where the body is unable to react to androgens. Thus, although an XY infant will produce androgens such as testosterone prenatally, the child will be born with female or feminised/under-virilised genitals. AIS may be partial (PAIS) or complete (CAIS). AIS would previously have fallen into the category of male pseudohermaphroditism.\(^\text{19}\) 5-alpha-reductase deficiency (5ARDS) is a form of AIS where the XY foetus’ genitals are not masculinised before birth, but instead masculinise at puberty.\(^\text{20}\) Many infants born with 5ARDS are raised as girls initially, but there are different cultural and medical responses to the physical changes at puberty and the person’s gender identity.\(^\text{21}\)

Congenital adrenal hyperplasia (CAH) is an enzyme deficiency that leads to the overproduction of androgen in an XX foetus.\(^\text{22}\) Depending on the severity, the infant may be born with typical male genitals or more ambiguous genitals. One way of

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\(^{17}\) For more information, the Toronto Hospital for Sick Children runs a website with information on various conditions targeted at parents. Its descriptions, anatomical explanations, and diagrams are particularly helpful and easy to read. Available at http://www.sickkids.ca/childphysiology/cpwp/genital/genitalConditionsIntro.htm (Accessed 31 May 2007).


\(^{19}\) Kessler, 1998, 165.


\(^{21}\) Elliott, 1998.

\(^{22}\) Kessler, 1998, 165-166.
describing the genitals is the Prader Scale, from typical female (Stage 0) to typical male (Stage V).\textsuperscript{23} The salt-wasting form of CAH is fatal if not treated early on with medication.\textsuperscript{24} CAH would previously have fallen into the category of female pseudohermaphroditism.

Additionally, cases of atypical anatomy which may or may not have an additional underlying cause include clitoromegaly, micropenis, and hypospadias. The former two conditions describe a clitoris or penis that is outside the medically accepted norms for the genitals at birth. One commonly cited range was given by Blackless et al. (under 1cm for a female, over 2.5cm for a male), while other physicians have used their own personal experience and instincts as a guide.\textsuperscript{25} Hypospadias is the term used when the urethra does not exit at the centre of the glans of the penis. Instead, it may be off-centre, on the underside of the shaft, or larger than normal. The causes of hypospadias are unknown, but may be the result of endocrine disorders, genetic (hereditary) disorders, or environmental reasons. In addition, children with low birth-weights or born to younger or older mothers are more likely to have hypospadias.\textsuperscript{26} Like clitoromegaly and micropenis, most hypospadias do not signal an underlying condition.\textsuperscript{27}

**Frequency**

Since the intersex umbrella includes many different particular conditions it is difficult to identify with any certainty the frequency of intersex births. Even if a list of conditions were agreed upon – no simple task – there are a number of factors that continue to complicate the question. The first problem is reporting bias: Intersex conditions are not tracked and recorded centrally and thus collecting the data is difficult. Self-reporting through population surveys can also be unreliable since some

\textsuperscript{24} Donahoe, et al., 1991, 540.
\textsuperscript{25} Kessler, 1998, 43.
\textsuperscript{26} Mouriquand and Mure, 2004, 26.
\textsuperscript{27} Kessler, 1998, 42.
persons are not informed of their conditions. \textsuperscript{28} Intersex cases may go undiagnosed until later in life or never be diagnosed at all. The overall frequency of intersex and/or particular intersex conditions may vary over time, and historical examinations are even more difficult since births were conducted at home or by midwives prior to the \textsuperscript{19th} century, and these events have left us almost no documentary evidence. \textsuperscript{29} Additionally, some intersex conditions appear to have a genetic or hereditary component, and thus are more frequent in particular populations – 5-alpha-reductase deficiency syndrome (5ARDS) is one such example. \textsuperscript{30} Environmental events can also lead to an increase in certain intersex conditions within a particular population during a particular time period. \textsuperscript{31} It is not surprising, then, that there are many different reports of the frequencies of intersex conditions.

Blackless et al. reviewed medical literature on the frequency of intersex conditions from 1955-2000 and concluded “that approximately 1.7\% of all live births do not conform to a Platonic ideal of absolute sex chromosome, gonadal, genital, and hormonal dimorphism.” \textsuperscript{32} The group defines a typical male as having XY chromosomes, testes within the scrotum, the potential for fertility, and a penis between 2.5 and 4.5cm. A typical female is defined as having XX chromosomes, functional ovaries, a uterus, cervix, vaginal canal, inner and outer vaginal lips, and a clitoris between 0.2 and 0.85cm. (Note that the group uses a similar definition of intersex as this paper’s working definition, above.) If correct, this means that 1-2 out of every 100 births exhibits an intersex condition. Blackless et al. estimate that ten percent of intersex infants receive “corrective surgery.” \textsuperscript{33} Other research suggests that the frequency of intersex births is closer to 1 in 1000 \textsuperscript{34} or 1 in 4500. \textsuperscript{35} The latter

\begin{thebibliography}{99}
\bibitem{28} Protocols based on the optimal sex of rearing approach frequently included concealment of the condition from the child. This is discussed further in later sections.
\bibitem{29} Dreger, 1998b, 25.
\bibitem{30} Dreger, 1998b, 40-41.
\bibitem{31} Dreger, 1998b, 41.
\bibitem{32} Blackless, et al., 2000, 161.
\bibitem{33} Blackless, et al., 2000, 151.
\bibitem{34} Fausto-Sterling, 2000, 53.
\bibitem{35} Hughes, et al., 2006, 554.
\end{thebibliography}
estimates put intersex conditions at a similar overall frequency to cystic fibrosis or Down syndrome.\textsuperscript{36}

\textsuperscript{36} Dreger, 1998b, 43.
III. PRACTICES AND GUIDELINES

This section discusses the changing medical approaches to intersex births and outlines the most significant protocols in the management of intersex conditions. The earliest responses show how biomedicine first responded to intersexuality as a result of increased medical surveillance within a particular social and political context. As medicine evolved and social norms changed, practice did as well. John Money’s “optimal sex of rearing” approach, developed in the 1950s, became the dominant treatment model and remained, with some changes, for decades. In recent years it has come under heavy criticism and new protocols are being proposed. To give the reader a better understanding of current medical thinking on intersex, early responses to intersex persons will be discussed, followed by a discussion of Money’s theories and his John/Joan case. Two prominent and contemporary medical guidelines (from 2000 and 2006) will then be summarised and contrasted to show how critiques of past practice are impacting the debate on future treatment models.

Early responses to intersex persons

While there are scattered historical references of legal rulings that attempted to decide the status of particular intersex persons as either male or female in the 17th century, the involvement of biomedicine began in earnest in the 19th century.37 The increasing recognition of the existence of intersex persons (hermaphrodites, in the terminology of the time) is linked with increased medical surveillance, particularly through medical participation in the birthing process, as well the emergence of homosexual rights and women’s suffrage movements that were destabilising gender boundaries.38

The confusion about where intersex persons fit, and how to determine their “true” gender, led to great debate within the medical field. In the late 19th and early 20th century, physicians worked to establish criteria that would define clear and mutually exclusive boundaries between male, female and hermaphrodite. The leading model was the gonadal definition, whereby the gonads were the arbiters of true gender, regardless of the other parts, although some physicians were still swayed by

37 Dreger, 1999.
38 Dreger, 1999, 6.
secondary gender characteristics. The only category of true hermaphrodite was a person with ovo-testes, but since this diagnosis was only possible through autopsy the category was essentially limited to the dead. The problems created by pseudo-hermaphrodites (persons with ambiguous gender but clear gonads, thus having a true gender of either male or female) were “solved” by gonadectomy or the insistence that homosexual relations be avoided. Under the gonadal model, a Parisian model with a feminine appearance and a sexual attraction to men was labelled homosexual due to the presence of testes. (In the terminology of the time, she was a pseudo-hermaphrodite; her modern diagnosis would likely be AIS.)

New diagnostic techniques and complex or counter-intuitive cases such as the Parisian model above created controversies that challenged the gonadal definition. The increasing use of exploratory surgeries also produced evidence that made physicians question whether gonads were the best indicators of true gender. The desire to determine a single true gender, however, did not subside, and other means of diagnosing true gender were proposed and debated. Even without coming to a consensus, individual physicians took it upon themselves to determine a patient’s true gender and “help it along” by eliminating incongruous characteristics through surgery. Dreger places this as the beginning of what she terms “the age of surgery,” where doctors seek to change the body to fit the requirements of our radically dichotomous two-gender model. John Money would become the central figure in establishing the practice of surgically “fixing” ambiguous through his optimal sex of rearing approach.

**Money’s “optimal sex of rearing” approach**

A great deal of the treatment of intersex infants in the past decades has been influenced by the theories and case reports of John Money, a sexologist at Johns

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41 Dreger, 1999, 6-9.
42 Dreger, 1999, 10.
43 Dreger, 1998b, 54-55.
44 Dreger, 1999, 10-11.
45 Dreger, 1999, 11.
Intersex

Hopkins, and his colleagues. Money’s theory of gender plasticity argued that gender was a matter of socialisation, and an infant could be assigned any gender as long as the assignment was done as early as possible (before 18 months) and the body was surgically altered to conform to the gender assignment.\footnote{Money and Ehrhardt, 1972.} Parents and family also had to create the proper environment and never show doubt to the child about its gender. According to this radical view, “Gender was not only a social construction in theory, it could literally be constructed through human intervention.”\footnote{Kessler, 1998, 7.} Under Money’s optimal sex of rearing approach, intersex newborns were treated as an emergency and a determination of the “optimal” or most likely gender was made as quickly as possible.\footnote{Wilson and Reiner, 1999, 123.} Surgeons then operated to make the infant’s physical characteristics match the chosen gender and endocrinologists made a plan for the child’s hormone treatments.\footnote{Wilson and Reiner, 1999, 124.} (In addition to hormone problems that may be the result of the child’s intersex condition, surgery may damage, remove, or contradict the gonads, necessitating lifelong hormone treatment.) Parents were also counselled never to discuss the child’s condition or treatment to family, friends, or the child. It was believed that knowledge of the original anatomy would damage the process of healthy gender formation (i.e., rejection of the assigned gender or formation of the chosen gender with a heterosexual orientation).\footnote{Wilson and Reiner, 1999, 124.}

Money’s theories received their greatest boost through publication of the John/Joan case in 1972.\footnote{Money and Ehrhardt, 1972, 118-123. John/Joan are the anonymised names used in the original publication.} John was born one of two identical XY (male) twins, but at eight months his penis was destroyed in an accident during a circumcision procedure. The family was very distressed and unsure what to do.\footnote{Money and Ehrhardt, 1972, 118; Dreger, 1998a, 25.} Money and his team believed that without a penis John would not be able to develop a male gender identity and instead should be surgically reconstructed and raised as a female. According to their theory of gender plasticity, John would accept the new gender identity as long as his body was
altered to match it and he was taught to be, and treated as, a girl. The surgical team removed John’s testes and began constructing female genitals, and John became Joan. The team followed up with further surgeries, hormone treatment, and psychological counselling for Joan and the family.

The case was particularly important in supporting the theory of gender plasticity because as an identical twin, John’s brother provided the ideal control for the experiment. The reported success of the John/Joan case was used “as proof that physicians could essentially create any gender out of any child, so long as the cosmetic alteration was done early.” When applied to intersex cases, this view gave physicians great latitude to determine the gender of infants and then surgically alter the body to conform. It also required that the patient’s medical condition be hidden from them indefinitely.

While widely adopted and practiced, protocols based on Money’s work have come under wide-ranging criticism and new protocols have been, and continue to be, developed.

Although Money reported that John/Joan developed successfully as a girl, it was later discovered that Joan did not accept her female identity, refused to take oestrogen, and when informed of what happened requested and received surgery to live as a male. John later married and adopted children, but sadly, he committed suicide in 2004.

Revelations from the John/Joan case, as well as the reports of intersex patients who had been treated according to similar protocols, led to a reconsideration of the theories and methods. Two postulates of Money’s arguments can be summarised as: persons are born with a neutral gender identity at birth; and healthy gender development

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53 When genitoplasty is performed on infants and young children, it generally cannot be completed in one step and involves a series of surgeries and hormonal interventions. This is discussed in the clinical evidence argument.
54 Dreger, 1998a, 25.
56 Dreger, 1998a, 25.
57 Dreger, 1998a, 31.
58 Dreger, 1998a, 25. See also Diamond and Sigmundson, 1997. Prior to his suicide, John’s brother died of a drug overdose, his marriage had ended, he was unemployed and had been conned into bad investments. Colapinto, 2004.
requires the appearance of gender-appropriate genitalia. Within Money’s argument lie further assumptions about gender, biology and physician authority that continue to be questioned. Money’s argument assumes that radically dimorphic categories of genitals are natural (i.e. not socially constructed); that genitals that do not fit into the two categories should be corrected; that gender should be as dimorphic as genitals; that genitals are essential markers of gender; and that medicine “has the legitimate authority to define the relationship between gender and genitals.” Criticisms of the optimal sex of rearing approach will be dealt with more completely in the three argument sections.

Clinical guidelines
Two recent guidelines are summarised and compared here to provide a better picture of current medical thinking on how to respond to intersex infants, and show how clinical guidelines are beginning to respond to heavy criticism of earlier treatment paradigms. The guideline published by the American Academy of Pediatrics (AAP) in 2000, Evaluation of the newborn with developmental anomalies of the external genitalia, was published as criticisms of current practices became louder and more prominent. The Consensus statement on management of intersex disorders, published in 2006 by the Lawson Wilkins Pediatric Endocrine Society and European Society for Paediatric Endocrinology Consensus Group, offers a markedly different approach that belies the relatively short time between the two documents. Reading the two guidelines together provides the contemporary backdrop for the ethical arguments that will be made on intersex interventions.

American Academy of Pediatrics 2000 Guideline
The American Academy of Pediatrics’ guideline begins with the statement that an intersex birth “constitutes a social emergency” and warns that “words spoken in the delivery room may have a lasting impact on parents and their relationship with their

60 AAP, 2000.
61 Hughes, et al., 2006.
Parents should be involved in discussions to determine the child’s gender of rearing, and each infant requires individual consideration based on “physical examination, laboratory studies, and parental feelings.” Physicians are encouraged to discuss the child’s genitals with the parents, explain that all genitals have their origin in the same foetal tissue, and that

…both incomplete development or overdevelopment of the external genitalia can occur, and that the abnormal appearance can be corrected and the child raised as a boy or a girl as appropriate.

The implication in this statement is that “correction,” that is, surgical modification of the abnormal genitals, is part of the process of determining and establishing a gender for the child. The guideline notes that clear criteria are necessary for what counts as an intersex birth, and that “only a minority of intersex patients have genitalia that are so ambiguous that sex is uncertain.”

A number of factors are listed as important in the determination of gender of rearing. Virilised female infants are potentially fertile and should therefore be raised as girls. The “capacity for normal sexual function” is the next criteria. According to the guideline, “the size of the phallus and its potential to develop at puberty into a sexually functional penis are of paramount importance when is considering male sex of rearing.” To be considered adequate, the stretched penis of a full-term infant should be at least 2cm. For female assignment, a low-lying vagina is “advantageous…but this alone is not of critical importance.” A high-lying or undersized vagina “present more of a surgical challenge” but can be justified when fertility is probable. A gender assignment that agrees with the gonads is also beneficial if they are functional, thus avoiding or minimising the need for lifelong

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63 AAP, 2000, 138.
64 AAP, 2000, 138.
65 AAP, 2000, 139.
66 AAP, 2000, 141.
67 AAP, 2000, 141.
68 AAP, 2000, 141.
69 AAP, 2000, 139.
70 AAP, 2000, 141.
hormone therapy. The effects of testosterone imprinting on the foetus are unclear, but “caution should be exercised” since it appears to have an impact in the gendered behaviour of children.

With regard to surgery, “infants raised as girls will usually require clitoral reduction” in an early surgery, and vaginoplasty may begin at the earliest surgery or be delayed to one year or later. Surgery to correct the phallus or testes is performed within 18 months.

The guideline acknowledges the growing debate on the treatment of intersex infants, including advocates of delaying surgery to allow the patient to participate directly in the decision. However, “the principles outlined in this review should minimize [the problems raised by critics and the possibility of incorrect gender assignment] when conducted by an appropriately constituted intersex team.” The question of participation is thus side-stepped by arguing that if the correct gender assignment is made, the patient can be assumed to approve the decision retroactively – a form of future-oriented consent. The guideline concludes that psychiatric follow up, as well as access to supports groups, is valuable for patients and families. There is no direct discussion of how the intersex condition should be communicated to the patient in the future.

Consensus Statement on Intersex, 2006

The recent Consensus statement on management of intersex disorders marks a significant shift from earlier protocols. The consensus group – made up of 48 persons, including prominent intersex activists and patients in addition to physicians – incorporated into their guideline the criticism of previous treatment models from a variety of sources.

71 AAP, 2000, 141.
72 AAP, 2000, 141.
73 AAP, 2000, 141.
74 AAP, 2000, 141.
75 AAP, 2000, 141.
76 AAP, 2000, 142.
First, the *Consensus* does not begin with the statement that an intersex birth is an “emergency,” although this is prominent in an overwhelming number of earlier articles on the topic.\(^{77}\) Instead, it says that an intersex infant “prompts a long term management strategy that involves a myriad of professionals working with the family.”\(^{78}\) A new umbrella term is proposed, Disorders of Sexual Differentiation, which is defined as “congenital conditions in which development of chromosomal, gonadal, or anatomical sex is atypical.”\(^{79}\) The authors write that psychosexual development has three components – gender identity, gender role, and sexual orientation – that are influenced by factors including androgens, chromosomes, brain structure, social circumstances and family dynamics. Gender dissatisfaction, which is defined as “unhappiness with assigned sex,” is recognised as more common among persons with DSD but nonetheless difficult to predict even with the above factors.\(^{80}\) It is worth noting that gender dissatisfaction here is defined from the patient’s subjective perspective, rather than from the perspective of others, such as parents and physicians who might make judgements based of criteria such as preferences in dress, play, and sexual orientation. The statement goes as far as to state explicitly that homosexuality does not mean that the gender assignment was incorrect,\(^{81}\) recognising the earlier tendency to count it as a failure of gender socialisation. (The heteronormativity of earlier intersex protocols will be discussed further in the gender argument.) Additionally, a wide understanding of quality of life is presented, encompassing love, dating, attraction, intimacy, sexual functioning, marital and child rearing opportunities “regardless of biological indicators of sex… The focus should be on interpersonal relationships and not solely on sexual function and activity.”\(^{82}\)

The *Consensus statement* proposes that under optimal management, no gender assignment will be made prior to expert evaluation, but all patients should receive a gender assignment. The multidisciplinary team should include specialists in

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77 Fausto-Sterling, 2000, 45.
78 Hughes, et al., 2006, 554.
79 Hughes, et al., 2006, 554.
80 Hughes, et al., 2006, 554.
81 Hughes, et al., 2006, 554.
82 Hughes, et al., 2006, 558.
paediatrics, endocrinology, surgery, urology, psychology, genetics, gynaecology, neonatology, as well as social workers, nurses and ethicist(s). Open communication between the physicians and family is essential, and their concerns should be respected and addressed. DSD should not be considered “shameful” and “ample time and opportunity should be made for continued discussion.” The consensus group also notes that support groups are important to families and patients.  

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In choosing a gender assignment, the Consensus lists influential factors as

…the diagnosis, genital appearance, surgical options, need for life long replacement therapy, the potential for fertility, views of the family, and sometimes the circumstances relating to cultural practices.  

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A special note is also added that infants presenting with micropenis should be raised as male, and that the decision on infants with ovo-testicular DSD (formerly “true hermaphrodite”) should consider fertility, assuming that the “genitalia are, or can be made, consistent with the chosen sex.”  

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With regard to surgery on intersex patients, the surgeon must outline “sequence and subsequent consequences from infancy to adulthood.”  

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In general, when making surgical decisions treatment teams should consider options that “facilitate the chances of fertility.”  

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Surgery for clitoromegaly should only be considered for cases of severe virilisation, which is defined as a score of III, IV, or V on the Prader scale.  

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(On the Prader scale, 0 is typical female anatomy, and V is typical male anatomy.) In such cases, surgeons should work to preserve sexual sensation in the clitoris with an emphasis on “functional outcome rather than a strictly cosmetic appearance.”  

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The Consensus notes that when the vagina and urethra are not separate congenitally (which would be represented in the middle of the Prader scale) there is limited evidence on the ideal timing but defers to a 1996 American Academy of Pediatrics

83 Hughes, et al., 2006, 554-555.
84 Hughes, et al., 2006, 556.
85 Hughes, et al., 2006, 556.
86 Hughes, et al., 2006, 556.
87 Hughes, et al., 2006, 557.
88 Hughes, et al., 2006, 557.
89 Hughes, et al., 2006, 557.
guideline. In the case of an “absent or inadequate vagina,” surgery should be performed in adolescence when the patient is “motivated and a full partner in the procedure.”

The Consensus statement also acknowledges the complications and potential negative outcomes associated with certain procedures, such as clitoroplasty and vaginoplasty, and that long-term data is frequently unavailable, inadequate, or shows great “variability.” There is also no controlled data on early versus late surgical interventions and the impact on quality of life or gender assignment. The guideline concludes by calling for further research in DSD conditions, in the development of gender identity, in “information management with regard to timing and content” (i.e., when and how to discuss DSD with patients and families), on the appropriate timing of surgery, and in particular to rectify “a major shortfall in long term outcome” data.

Changing practices

Although published at the time of growing criticisms of intersex treatment protocols, the AAP guideline retains much of the optimal sex of rearing approach. There is a predisposition towards early cosmetic surgery to align the infant’s genitals and gender assignment, but the criteria it gives provide less encouragement to raise and surgically alter a male with micropenis or an absent phallus as a female. (The protocol says that it is preferable for working gonads to be left alone, but also that a sexually functional penis is necessary to male gender identity.) In response to criticisms of early practice, the guideline states that practices (both diagnostic and surgical) have improved and that the criticisms are thus not strong enough to change recommendations for early surgery.

In contrast, the Consensus statement acknowledges much greater uncertainty surrounding the data on the effectiveness of intersex interventions and their long-term outcomes, and highlights areas that require additional research – which are numerous. Quality of life for intersex patients is defined in a wider sense that is centred on the

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90 Hughes, et al., 2006, 557.
91 Hughes, et al., 2006, 558.
92 Hughes, et al., 2006, 557, 558.
93 Hughes, et al., 2006, 560.
patient’s life experience rather than the physician’s evaluation of the appearance of the genitals. Significantly, cosmetic surgery is no longer taken for granted as necessary for gender assignment, and the guideline states that most interventions can be delayed. There are also specific recommendations that are most likely direct responses to earlier guidelines and protocols. These include that males with micropenis should be raised as male, and that physicians and parents should plan to inform the child of his or her condition in a staged, age-appropriate manner.

The recognition of uncertainty and the willingness to consider alternative approaches in the medical management of intersex is perhaps the most important contribution of the Consensus to the discussion. This contribution makes the three central arguments of this thesis particularly significant. With the door open to change, we can look back at mistakes that have been made, begin to understand why they were made, and support better model for future treatment.
IV. CLINICAL EVIDENCE ARGUMENT

The central claim in this section is that there is insufficient evidence to support performing unnecessary surgery on intersex infants. Further, much of the evidence available actually indicates that unnecessary surgery is not merely unsupported but actually harmful to intersex infants. With this knowledge, it is unethical to continue the practice of performing unnecessary surgeries on intersex infants.

Clinical (in)effectiveness and (un)certainty

Surprisingly, surgery performed on the genitals of intersex infants is treated as standard practice even though it is based on questionable goals, carries frequent and significant complications, has limited or completely unavailable follow-up data, and is arguably unsuccessful and ineffective.94

A number of different reasons are given for performing early genital surgery on infants but justifications are weak or limited.

It is generally felt that surgery that is carried out for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and the parents. The systematic evidence for this belief is lacking.95

In addition to casting doubt on this justification for early genital surgery, it should also be noted that according to the rejected belief above the surgery was partly justified for its benefits to the parents rather than directly to the child. A recurring theme in the critical literature on intersex is that surgeries are not performed in the child’s best interest but rather in service of other goals. This is further explored in the gender argument.

At the level of specific surgical interventions, almost all have been criticised as ineffective, risky, or counterproductive. Surgery to reduce or reshape the clitoris may lead to decreased sexual sensitivity, loss of clitoral tissues, and cosmetic problems.96 These results were confirmed by a rare follow-up study that showed that “sexual

94 Kessler, 1998; Dreger, 1998a, 32.
95 Hughes, et al., 2006, 557.
96 Hughes, et al., 2006, 558.
function could be compromised by clitoral surgery.”  Particular of note is that “of the three sexually active participants who had undergone the newer technique of nerve-sparing clitoral reduction, however, two had the worst possible score for orgasm difficulties.” Unfortunately, in this area even “state-of-the-art” techniques are hardly comforting. It has also been reported that the choice of which surgical technique to use is not a fully informed decision by the medical team. Rather than making the decision based on the effectiveness of a particular technique in addressing a particular situation (i.e., varying degrees of clitoromegaly), surgeons may be ignorant of prominent techniques or choose techniques developed at their own institution. (In the latter case, surgeons using the Lattimer technique in 1993 regretted that they had no follow-up data because the procedure was “too new.” The Lattimer technique was first published in 1961.)

Vaginoplasty, the creation or extension of the vaginal cavity, carries “the potential for scarring the introitus [vaginal cavity], necessitating repeated modification before sexual function can be reliable.” Additional side effects include stenosis, infection, and psychological trauma. With the limited availability of follow-up data, risks may vary based on the particular procedure. Additionally, post-operative care requires vaginal dilation, where an object must be placed into the vagina on a regular basis to prevent it from closing up. For infants and young children, dilations must be performed on their behalf by the parents. Dilations can be difficult for the parent and the child, and present another reason why the surgery should be postponed until the patient is able to make the decision and take on the post-operative responsibilities.

Hypospadia repair can also be worse than the problem itself. Creation of a new urethra for the outlet of urine at the tip of the penis is difficult and often requires multiple surgeries. Skin grafts used to recreate the urethra break down because they

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97 Minto, et al., 2003, 1252.
98 Minto, et al., 2003, 1257.
101 Hughes, et al., 2006, 558.
102 Dreger, 1998a, 32.
are not designed to handle urine like the natural urethra and must be frequently repaired. Repeated surgeries also negatively affect the cosmetic outcome.\textsuperscript{104} A recent article reviewing eight common methods of hypospadias repair found that all eight caused complications, including stenosis, fistula, poor cosmetic result, and the need for repeated surgeries.\textsuperscript{105} The article concludes that “hypospadias surgery remains a difficult challenge, as several factors contributing to success remain unknown.”\textsuperscript{106} An article evaluating the long-term success of one particular procedure (oral mucosa graft urethroplasty) notes that along with successes there are common, and sometimes severe, negative complications.\textsuperscript{107} The article also points out that some hypospadias are primarily “a cosmetic problem” and not a functional one.\textsuperscript{108} As a result, the question of whether the risks outweigh the benefits of surgery is left open by the authors.\textsuperscript{109}

Performing surgery on infants with micropenis to turn them into girls is often carried out because it “requires less surgery to achieve an acceptable outcome;” however, long-term data shows “great variability” on quality of life.\textsuperscript{110} This means that a major surgery is being performed to remove an undersized phallus along with the testes, reshape the genital area and create a vaginal cavity, while there is no data showing that the process succeeds in its goal of improving quality of life. Additionally, surgical feminisation irreversibly eliminates the patient’s fertility. On the other hand, adults with “untreated” micropenis (i.e., the penis is not removed) do well overall, and are also able to form lasting bonds with sexual partners.\textsuperscript{111}

Beyond the risks of surgery, physicians and parents do not know if their surgical decisions will be the ones that their child would choose if they postponed the decision. The failure of the John/Joan case is a notable example, although counter-

\begin{footnotesize}
\begin{enumerate}
\item Hawbecker, 1999, 112.
\item Mouriquand and Mure, 2004, 31-33.
\item Mouriquand and Mure, 2004, 33.
\item Nelson, et al., 2005.
\item Nelson, et al., 2005, 1077.
\item Nelson, et al., 2005, 1078.
\item Nelson, et al., 2005, 1078.
\item Hughes, et al., 2006, 558.
\item Reilly and Woodhouse, 1989, 569, cited in Dreger, 1998a, 29.
\end{enumerate}
\end{footnotesize}
examples have been reported. Nonetheless, “gender dissatisfaction” is more likely in intersex persons but still difficult to predict. As an example, recent data show that more than 65% of patients with cloacal extrophy reared as female live as female, but even at this rate – or even at 95% – it is impossible to know in advance whether a decision to assign gender to an infant surgically is the correct decision. Performing invasive and irreversible surgery as part of a gender assignment, when we know that the child may not accept the gender assignment, is very likely to lead to a negative outcome. Further, should the child choose a different gender identity, cosmetic genital surgeries will be less effective because his or her body has already been damaged by the first set of surgeries.

What is extremely disturbing is that “risky surgeries are being performed as standard care and are not being adequately followed-up.” Summarising the current state of follow-up literature, Kessler reports that there are no meta-analyses, and what exists are mostly the reports of surgeons discussing their own procedures. In these analyses, far too many patients are “lost to follow-up,” there are limited comparisons to alternate techniques, and no use of control groups (i.e. intersex infants who are not operated on). Continuing to practice as normal in such a situation is clearly a violation of medical ethics.

**False emergencies**

Intersex interventions have a tendency to be treated as urgent crises that require immediate surgical resolution. Protocols based on the work of John Money insist that genital surgery begin before 24 months, and earlier if possible, to ensure proper psychosocial development in line with the child’s gender assignment. A guideline issued in 1996 by the American Academy of Pediatrics (AAP) recommended that surgery on males with ambiguous or “defective” genitals be performed before 15 months, or at the latest, 36 months, “a time when the trauma of surgery is relatively

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113 Hughes, et al., 2006, 554.
114 Hughes, et al., 2006, 556.
115 Dreger, 1998a, 32.
less difficult. However that period has the disadvantage of potentially prolonging the child’s ‘defective’ status.”\textsuperscript{117} In 2000, the AAP similarly wrote that the birth of an intersex infant is a “social emergency.”

However, there is no clinical data demonstrating the benefits of either early or late surgical assignment in psychosocial development.\textsuperscript{118} As noted above there is significant evidence that unnecessary surgeries are frequently harmful, and this risk is reason enough to delay procedures until the intersex person can participate in the decision. The more recent \textit{Consensus statement} acknowledged that gender uncertainty can be stressful for families, encouraging expedited assessment and decision making, but also states that “ample time and opportunity should be made for continued discussion” with the family.\textsuperscript{119} The Consensus Statement also recognises updated data and thinking on managing intersex. For instance, it recommends that vaginoplasty should be “performed in adolescence when the patient is psychologically motivated and a full partner in the procedure.”\textsuperscript{120} Additionally, it believes that surgeons should “facilitate the chances of fertility” for the intersex child.\textsuperscript{121} Early surgery on an infant will either be neutral to this goal or have a detrimental effect on fertility by damaging or removing gonadal or other tissue. Delaying surgery allows the patient to participate later on and weigh the implications of surgical intervention on fertility, as well as other quality of life factors.

It must also be recognised that while variant genitals may be indicative of an underlying condition that poses a health risk to the infant, the genitals themselves are not dangerous as long as urine can exit the body. Of all causes of ambiguous genitals, only CAH is dangerous to the patient as a newborn, with crisis occurring 11 to 14 days after birth.\textsuperscript{122} In some conditions, such as AIS, the gonads have a high risk of becoming cancerous, but removal can be delayed to adolescence because cancer does

\begin{footnotes}
\item[118] Hughes, et al., 2006, 558.
\item[119] Hughes, et al., 2006, 555-556.
\item[120] Hughes, et al., 2006, 557.
\item[121] Hughes, et al., 2006, 557.
\end{footnotes}
not occur earlier.\textsuperscript{123} (Certain other conditions can cause cancer earlier and should be dealt with in a timely fashion.) In either case, the genitals themselves are not dangerous but instead helpful to the medical team in determining whether there is an actual and immediate danger to the child.

**Evidence is not enough**

It is distressing to know that a history of repeated “medical interventions and negative sexual experiences [for intersex infants] may have fostered symptoms of post-traumatic stress disorder.”\textsuperscript{124} The emergence of evidence that contradicts long-held treatment models is currently leading to new analyses of the treatment models themselves. The answer in this case is not simply to refine surgical techniques and improve long-term monitoring of patients to better evaluate their outcomes (although the latter is very important). The evidence given above, documenting surgical failures and false emergencies, provides at least enough doubt for a moratorium on unnecessary surgery on infants. The following chapters will expand this argument to show such actions fail to respect the future choices of intersex infants and reflect the imposition of a highly problematic model of gender with real-world implications.

\textsuperscript{123} Hughes, et al., 2006, 557-558.

\textsuperscript{124} Hughes, et al., 2006, 558.
V. FUTURE CHOICES ARGUMENT

A second argument against unnecessary surgery can be built by considering how surgery performed on infants affects their abilities to make decisions about their bodies in the future. In this section, I will introduce the area of paediatric decision-making and differentiate it from ordinary (i.e. capable adult) medical decision-making, and then further highlight the special challenges that intersex cases add to paediatric decision making. Using potentiality arguments, I will argue for reasonable limits on the rights of parents and physicians to choose unnecessary surgery for intersex infants, and that the most ethically course of action is to delay unnecessary surgery.

Paediatric decision making

The main difference between ordinary and paediatric decision-making is the three-way relationship between the child/patient, parents, and health care team. While families are often involved in ordinary decision-making, the formal decision maker and the patient are the same person. In paediatric decision-making, the parents and the health care team make the decision for the child. Paediatric decision-making also differs from substitute decisions made on behalf of incapable adults. Incapacitated adults who were previously capable may have left an advanced directive to direct or guide their preferred medical treatment. Alternatively, substitute decision makers may invoke precedent-autonomy or a substituted-decision standard to make a decision based on the patient’s previous choices, beliefs and values. In these cases, decision-making can arguably be said to be directed by the patient. If the patient was never capable, there remains a difference from paediatric decision making because the paediatric patient can be expected to develop autonomy in the future. The developing autonomy of the child is central to the conclusions of this section.

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125 This section draws and expands on work done for a previous class, Human Dignity and Applied Ethics, taught by Marcus Düwell and Niels Nijsingh at Universiteit Utrecht.

126 I use parents interchangeably with legal guardians.
The rights of parents to make decisions for their children are “fairly wide” but not absolute.\footnote{Pinnock and Crostwaite, 2005, 370.} Parents have significant latitude to make decisions that are not in the “strictly best interests” of the child.\footnote{Pinnock and Crostwaite, 2005, 370.} Paediatric medical societies recognise this in their guidelines. One example is the Christian Medical and Dental Association, which writes that

\begin{quote}
We recognise that between ideal child rearing and abusive or negligent child rearing, there is a wide range of [...] discretion. In regard to these discretionary matters, we must respect parental authority by working through the parents to improve the child's welfare.\footnote{Christian Medical and Dental Association, 2001.}
\end{quote}

The ages at which parental authority lapses varies between jurisdictions. In the United Kingdom, parents have decision-making authority until the age of 18.\footnote{Taylor, 1999, 570.} In Canada, the age of consent varies by province. In Ontario, for example, there is no formal age cut-offs for accepting or refusing treatment. Judgements on the capacity of children are thus made on a case-by-case basis, but with a presumption of capacity.\footnote{Health Care Consent Act, 1996, §4.2.} An exception to this is that advance directives are only valid if made after the age of 16.\footnote{Health Care Consent Act, 1996, §4.1.}

Where the child is able to participate but is not the decision maker, assent may be required in addition to parental consent. Assent is the primary means of ensuring that the child’s wishes with respect to treatment are taken into account.\footnote{Pinnock and Crostwaite, 2005, 370.} Unlike consent, assent is not a means of protecting children from the risks of treatment or research. Protecting the child is the responsibility of parents, and in the case of research, it is also the responsibility of research ethics boards. Assent is about treating children with respect.\footnote{Diekema, 2006, s10.} According to the Belmont report, meeting our obligation of respect for persons creates two moral requirements: “the requirement to acknowledge autonomy
and the requirement to protect those with diminished autonomy.” Decisions that are made fully autonomously involve free (or at least freer) choice among a wide range of options. Assent decisions, on the other hand, are heavily constrained by paternalism because they are limited to the decisions made available by consenting parents. Since children, and particularly young children, are not fully autonomous agents, they are protected by the requirement for prior parental consent. However, protecting a person’s autonomy should not limit the development of autonomous skills. Involving children in decision-making through the process of assent is one way of fostering the development of autonomy, as well as recognising the autonomous skills children already have.

There is great disagreement on whether assent is necessary, and in which situations. Factors include the child’s legal status, developmental capacity, and the particular situation. With adults, obtaining informed consent is obligatory in all but the most emergent situations, but the assent of the child can only be sought after parental consent has been given. The age at which assent should be required varies widely in the literature and in practice. The American Academy of Pediatrics endorses seven years as the age at which assent should be sought from children in research, but practices vary widely. For one particular American multi-site paediatric study, institutional research ethics boards insisted that researchers set the age of required assent as young as six and as old as 15 years. Kon argues that while clear age cut-offs for assent are simpler, “such policies fail to address the varied needs of children at different stages of development.” The urgency, severity and necessity of a particular intervention are also important factors in determining the decision-making authority of the child. For instance, in a situation where refusing treatment is low-risk, physicians should accept the dissent of a sufficiently capable child. However, in a time-sensitive emergency, “it is morally permissible to pursue a cautious approach

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135 National Institutes of Health, 1979, Part B.
137 Kon, 2006, 1806. Note that in the United States and Canada, multi-site research projects involving human subjects must always be reviewed by institutional research ethics boards at each participating site.
139 Zutlevics and Henning, 2005, 680.
and treat the patient even if it is against their will.” It is also argued that this cautious approach can be extended to override even parental decisions. Zutlevics and Henning point out that in order to develop competence (and thus autonomy), the child needs to be alive, thus defending a general, but not exclusive, paternalistic preference towards life-sustaining interventions over autonomous treatment refusals. In cases where refusing treatment is high-risk, but not time-sensitive, the authors emphasise conducting thorough competence assessments and determining whether the decision can be postponed instead of refused to better understand the child’s objections.

A number of situations have been identified in the literature where assent should not be sought from children. Several commentators stress assent should not be sought unless it will be honoured, but others recognise that certain limitations may still be placed on assent. For instance, Zutlevics and Henning argue that capable older children should be able to make their own decisions, but that the child’s parents can still override that assent. Taken further, the argument can be made that requesting assent from children fails to respect the autonomy of their parents, by potentially blocking the parents’ decisions (but of course, at the expense of respecting the child). Other commentators believe that it may be better to use best interests criteria rather than autonomy in some cases, primarily when the child is young but even for older children when the benefit is significant. In life-and-death cases, there are frequent arguments for choosing life regardless of the child’s choice, since, as noted above, a child needs to live in order to fully develop their autonomy.

In summary, paediatric decision-making is a three-way process between the child, parents and physician where the parents normally have decision-making authority and the child participates depending on his or her abilities and the particular situation. The rules and practices of paediatric decision-making have evolved to meet different

141 Pinnock and Crostwaite, 2005, 371.  
142 Zutlevics and Henning, 2005, 680.  
143 Kon, 2006, 1809.  
144 Zutlevics and Henning, 2005, 679.  
challenges in the course of treatment and research. These range from preventing children from making decisions above their level to protecting children from potential harm and abuse. In the process, though, it can be difficult to find common principles or frameworks to assess the proper course of action in order to respect children as developing autonomous agents. This is particularly the case for the youngest children and those that are just beginning, or about to begin, to develop autonomous skills.

**Arguing from potential**

One way of bringing clarity to the issues of paediatric decision-making, and specifically decision making for intersex infants, is to look at arguments from potential. We can see in children the developing potential that leads towards fuller autonomy and formal independence. In infants, the development of autonomy is at such early stages that it can be said that their autonomy is solely a potential autonomy. Arguments from potential are most frequently used in debates around the status of human foetuses and embryos. In these cases, questions are taken up to determine whether – and which – positive or negative duties we hold to the embryo based on our understandings of its potential. Examining these arguments will then give us a way of evaluating paediatric decisions.

One example of the use of potentiality arguments was the U.S. Senate Select Committee that examined experimentation on human embryos. The committee took up the question, “What features of the embryo (if any) command respect?” The importance of answering this question, both in the case of the committee and the current question in intersex infants, is that it makes clear what rights or protections belong to the subject in question. The committee issued both a majority and a minority report that used different forms of the argument from potential. The majority argued that the embryo commands respect because of “its orientation to the future” and that this respect is sufficient to “prohibit destructive non-therapeutic experimentation.” The majority report also defended the idea that the embryo deserved respect by arguing that there was no morally evident distinguishing point.

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146 Buckle, 1998, 228.
147 Buckle, 1998, 228.
between human developmental stages. As a result, the embryo “should be regarded as if it were a human subject for the purposes of biomedical ethics.” This version of the potentiality argument can be summarised as such:

Treat some entity as if it were already something which it is not yet, and it reaches this conclusion by considering some feature(s) which the entity already possesses, and which will help it to become that sort of entity which it is not yet.

In other words, while the embryo is not currently a person who “commands respect,” it will develop into a person and thus should be treated as a person.

In contrast, the minority report argued that the embryo’s implantation in the uterus was a morally significant event in the developmental process, and thus concluded that the embryo could not command respect prior to implantation. The minority uses a different version of the argument from potential to back up their claim: They argue that all objects have an infinite number of potential outcomes, but the potential outcomes for subjects are determined primarily by outside forces; that is, the subject’s potential is not sufficient on its own, but is dependent on outside influences. Thus, potential is “only in virtue of decisions by others” about the subject. Since the embryo is at the whim of outside forces prior to implantation, to say that its potential has already been set to full human development is premature.

Both instances of the argument from potential described above are criticised by Buckle for their inadequacies, but this critique helps us to better understand the structure of potentiality arguments and how they may be applicable to paediatric decision making. In general, potentiality arguments hold that the potential to be morally significant is morally significant in itself. The problem is that this implies that the subject itself is not morally significant. Arguing either that the capacity to develop moral significance is itself morally significant, or that moral behaviour is

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sensitive to future consequences, can strengthen the argument. Another way to look at this is to accept that the subject cannot “command” respect but nonetheless choose to extend respect to it. In practice, this instability pushes us to treat subjects with respect but recognise that this protection is not absolute.

The respect for capacities argument is concerned with the subject’s potential to become. This developmental potential is therefore individual, in the sense that it hinges on there being a constant identity between the potential and final subject of respect. The first challenge to this line of argument is that it is necessary to determine what capacities are morally significant and thus deserving of respect. For the committee to account for an embryo, the capacities would have to be drawn quite broadly. A further difficulty comes from the need for a constant identity between the potential and final subject. Buckle wonders at which point the egg becomes the embryo, and whether the egg, embryo, foetus, and person share the same identity. On its own, I do not believe that this is a sufficient criticism because it is possible to start the chain of identity at the point where the subject obtains the morally significant capacities. The criticism remains, however, because as Buckle points out, subjects can emerge from other subjects and stop sharing their identity.

The consequentialist argument is concerned with the subject’s potential to produce, rather than to become, a subject commanding respect. While the respect for capacities argument was concerned with the identity of the individual subject, the consequentialist argument considers the “value of possible future states of affairs” that can be compared to other possible futures. This recognises that subjects do not only have one potential, an evident but overlooked point in the embryo debate. The argument then allows for the consideration and balancing of different actions toward

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156 Buckle, 1998, 238.
the subject based on how it will affect possible futures. In the context of embryos, it could justify their experimental use if it led to cures for major human diseases.\footnote{Buckle, 1998, 243.}

### Potentiality and intersex

Paediatric decision-making exists in a different context than the embryo debate but potentiality arguments can be adapted and fruitfully applied. In fact, the application of potentiality arguments to children is even clearer than to foetuses because their developmental potential is more evident. Depending on age, the child’s potential for autonomy will have already begun transforming into actual autonomy. In the case of intersex infants, decisions about surgical reassignment are often made soon after birth. While the infants are clearly not autonomous, or even partially autonomous, their strong and clear potential to become autonomous individuals creates an obligation towards actions that protect and enhance their future autonomy. We can now consider more directly the implications of particular potentiality arguments on the treatment of intersex infants.

Potentiality arguments that focused on capacities were problematic with embryos, particularly because a constant identity was very difficult to show: The connection between the identity of the present embryo and the future person can be questioned. With infants and children, however, it is much simpler to see the link between the current child and the future autonomous adult: The child’s developing autonomy and increased decision making abilities are easily observable and can clearly be seen as differing in degree, rather than kind, from the autonomous skills of adults. This meshes well with current practices in paediatric decision making that allow increased decision making authority as the child grows older. For intersex infants, we are led to the conclusion that actions that limit future choices should be avoided where possible.

Consequentialist potentiality arguments can also be useful in paediatric decision-making. Within the scope of medical decisions, this set of arguments insists that we consider the consequences of respecting (or not respecting) a child’s wishes. For instance, overriding a child’s refusal of a blood transfusion could be justified because it gives the child a chance to live and further develop his or her autonomy (and
possibly refuse blood as an adult making an autonomous decision). On the other hand, it also pushes parents and physicians to consider the implications of overriding a child’s preference: It may lead to a breakdown of trust and the therapeutic relationship that makes future participation in treatment more difficult.\textsuperscript{161} The consequentialist argument can also be influential in decisions where the child (particularly an infant) has no possibility of involvement but whose future choices will be affected by the decision. A prime example of this is unnecessary genital surgery on intersex infants, which is often done without full understanding and creates a litany of potential complications, as discussed in the previous section.

The issues of potentiality and autonomy were also taken up in two significant rulings of the Colombian Constitutional Court. In responding to constitutional and human rights questions on the treatment of intersex infants, the court issued a special ruling, \textit{Sentencia SU-337/99}, which the Court used to organise previous rulings and create a strong precedent.\textsuperscript{162} The \textit{Sentencia de unificación} begins by stressing the importance of a patient’s autonomy, and that decisions on a free person’s health and body should be made directly by the patient, and not a substitute decision maker.\textsuperscript{163} Informed consent is also necessary because omitting it means that the physician’s will, and not the patient’s, is being acted on.\textsuperscript{164} The Court recognises that autonomy is a \textit{prima facie} obligation, however, and in certain cases, such as emergencies, it can be overruled by beneficence. In these cases the burden of proof falls on the party – whether physicians or parents – that seeks to override the patient’s autonomy.\textsuperscript{165} According to the ruling, parents and guardians are allowed to make decisions on ordinary matters, even against the child’s wishes.\textsuperscript{166} The principle here is future-oriented consent, the presumption that the child will retroactively approve. However, the Court limits the applicability of future-oriented consent as a means to override (or

\textsuperscript{161} Zutlevics and Henning, 2005, 680.
\textsuperscript{162} Colombian Constitutional Court (CCC), 1999. Special thanks to Camilo Martínez for his assistance translating key sections of the Court rulings.
\textsuperscript{163} CCC, 1999, \textit{Sentencia SU-337/99}.
\textsuperscript{164} CCC, 1999, \textit{Sentencia SU-337/99}.
\textsuperscript{165} CCC, 1999, \textit{Sentencia SU-337/99}.
pre-empt) children’s decisions on their bodies. The child is “a freedom and an autonomy in development, that thus has constitutional protection.” Explicitly recognising the invasiveness and irreversibility of intersex surgeries, the court says that although it may seem beneficent to make an early decision on surgery, autonomy suggests that irreversible interventions should be postponed until the patient can consent. The court reiterates this in a related ruling, saying that the surgery’s invasiveness is enough to justify postponing until the patient can consent.

Applying potentiality arguments to the case of intersex infants shows there are reasonable limits to the rights of parents and doctors to perform unnecessary surgeries on infants, and versions of these arguments have in fact been used in prominent courts to promote the rights of intersex persons. Potentiality arguments rooted in capacities incline us to involve children as much as possible, and consequentialist arguments show when decisions negatively affect the future choices of children they should not be taken lightly. Together and separately, these arguments show that non-urgent surgery that significantly affects future quality of life and limits the opportunities of persons to express their autonomy later on should be avoided. Where unnecessary surgery can be postponed, we are ethically bound to wait.

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170 It is outside of the scope of this paper to define at what age an intersex infant can participate in the surgical decision, and whether it is a matter of assent or consent. Cases of surgery for minors will be handled differently in different individual situations and different jurisdictions. In addition to the literature on paediatric decision-making discussed above, there is also a literature on transgender youth that may provide insight to particular cases.
VI. GENDER ARGUMENT

Up to this point, this paper has focused on the ordinary responses of bioethics to ethical questions in medicine, which could be related to the principles of beneficence and non-maleficence (the clinical evidence argument) and autonomy (the Future choices argument). The case has been made that performing unnecessary surgeries on intersex infants is not in their best interests because it is ineffective and damaging, and because it limits their future autonomy by making irreversible decisions before they are able to participate.

In this section I present a further argument that unnecessary intersex surgeries are unethical because they represent the medical imposition of an uncritical model of gender that is problematic, sexist and heteronormative. While arguments based on principles such as beneficence, non-maleficence and autonomy are subject to balancing, the gender argument adds the weight of social context to the mix, further strengthening the thesis against unnecessary surgery.

After discussing the implicit gender assumptions in Money’s optimal sex of rearing approach and other prominent responses, I will examine whether contemporary guidelines still reflect the same assumptions. I will then use the cases of intersex and transgender persons, as well as a historical perspective on gender, to establish how the gendered assumptions that support much of previous intersex practice are not nearly as certain or stable as they appear. The argument will be completed by showing how the uncritical use of problematic gender assumptions leads to the maltreatment of intersex infants through unnecessary surgery.

Gender in intersex practice

As discussed already, Money’s optimal sex of rearing approach and arguments for gender plasticity were received as quite radical. The “proof” that gender was a social construction, provided by the later-debunked John/Joan case, was taken up not only by surgeons treating infants with ambiguous genitalia but also by feminist theorists.

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Money concluded, “From the sum total of hermaphroditic evidence, the conclusion emerges that sexual behaviour and orientation as male and female does not have an innate, instinctive basis.”¹⁷³ In the nature versus nurture argument, Joan was the living embodiment of the victory of nurture over nature. As Money and Ehrhardt wrote,

> The evidence […] shows rather conclusively that there are in human beings some gender-dimorphic behaviour differences based on antenatal hormonal history, but that these differences do not automatically dictate or totally preordain the course of postnatal dimorphism of behavioural differentiation.¹⁷⁴

Arguing that gender was not a solely or primarily biological issue became part of the ongoing debate in gender theory on the differences, and the meaning of differences, between men and women and how this affected their places in society. This validated and encouraged a great deal of work on how to move forward on the topic of gender inequality.

However, Money’s radical (and on one viewing, progressive) theories were built on a number of conservative assumptions. Kessler, who admits having “been eager to embrace Money’s theory of gender plasticity,”¹⁷⁵ identifies five assumptions about gender, identity and the body in Money’s work.

1. Genitals are naturally dimorphic; there is nothing socially constructed about the two categories.

2. Those genitals that blur the dimorphism belonging to the occasional intersexed person can be and should be successfully altered by surgery.

3. Gender is necessarily dichotomous (even if socially constructed) because genitals are naturally dimorphic.

4. Dimorphic genitals are the essential markers of dichotomous gender.

5. Physicians and psychologists have legitimate authority to define the relationship between gender and genitals.¹⁷⁶

¹⁷³ Fausto-Sterling, 2000, 46.
¹⁷⁴ Money and Ehrhardt, 1972, 117.
Having laid bare the above assumptions, gender in the optimal sex of rearing approach is no longer as flexible, or as radical, as it first seemed. Although gender plasticity claims that we are not born with male or female gender identities, we are nonetheless limited to these two mutually exclusive and exhaustive categories. The theory does not go as far as to question the categories of male and female themselves (which I will do below); it merely argues for a different point of entry into them. Gender plasticity also places a great deal of importance on bodily structures in determining gender identity: even though gender is learned through nurture, it is nonetheless argued that any discordance between gender identity and genital appearance will lead to a failure in the development of a healthy gender identity. Additionally, the preference of form over function is evident in the protocol: The course of treatment for an otherwise ordinary male child with an undersized penis is feminisation through hormones and cosmetic genital surgery that leaves the child infertile and, as shown in the clinical evidence argument, with a potentially poor outcome.

With regard to the fifth assumption, that physicians have authority to define the relationship between gender and genitals, this is evident for a number of reasons. Treating an intersex birth as a medical emergency that must be dealt with immediately and making gender identity depend on genital appearances places decisions about gender within the medical purview, regardless of recommendations that parents should be involved in the decision. The early timing also means that the patient cannot participate. Parents may then assume that the physician has more expertise in making the decision than they do, since it is most likely a very new situation to them. This assumption also appears to be accepted by physicians; when disagreements between physicians and parents or patients on genital surgery are discussed in the literature, they are often referred to as “non-compliance” or “refusal.” This implies that the “choice” for surgery is a false one, even though legitimate (and convincing) reasons for refusal do exist.177

177 Kessler, 1998, 63-64. Refer also to the clinical evidence argument.
Fausto-Sterling describes three unexamined assumptions within the Money-based protocols: That there should be two genders; that only heterosexuality is normal; and that particular gender roles define a healthy man or woman.\textsuperscript{178} Kessler also deals with the first assumption and I will not address it again. The second, heteronormativity, plays out in numerous ways. It is evident very early on in early medical responses to intersex persons, such as the Parisian model, where doctors sought a clinical determination of her gender in order to determine whether her sexual relations were appropriate – i.e., heterosexual – or not.\textsuperscript{179} In the limited follow-up data that is available on intersex persons, success is often defined in heterosexual terms.

“Successful” genitals are defined in simplified heterosexual terms: Is the vagina capable of receiving the penis for intercourse?\textsuperscript{180} (As opposed to, for instance, is the clitoris sexually responsive?) In longer-term follow-ups, success in gender assignment, as well as cosmetic success, is often defined by marriage.\textsuperscript{181} By making heterosexuality a determinant of success, it becomes part of the gender role that defines a healthy man or woman (Fausto-Sterling’s third assumption). Other traditional gender roles (particularly in Money’s work, below) are evident in the advice given to the parents of an intersex child and the judgements made about their children’s success in taking on the assigned gender role.

To demonstrate more clearly how these assumptions work in practice, and how contemporary practices are beginning to question them, I will briefly discuss how they enter into the optimal sex of rearing approach, the AAP 2000 guideline, and the 2006 Consensus statement.

Optimal sex of rearing approach

The implicit gender assumptions in the optimal sex of rearing approach are easy to find once we start looking for them. In recounting how Joan’s mother instilled and enforced gender roles in her two children, Money and Ehrhardt recount that when Joan’s twin brother was found peeing in the garden at age 4, the mother said nothing.

\textsuperscript{178} Fausto-Sterling, 2000, 44.
\textsuperscript{179} This was discussed in the Practices and guidelines section. See also Dreger, 1999, 6-9.
\textsuperscript{180} Dreger, 1998a, 29.
\textsuperscript{181} Kessler, 1998, 106.
and laughed it off. When Joan was caught without underwear (at the same age) in the
garden, the mother reported that “I gave her a little swat on the rear, and I told her that
nice little girls didn’t do that.”\footnote{Money and Ehrhardt, 1972, 120.} When the children asked about breasts, the mother
explained that they were for breastfeeding, and when the boy said he wanted breasts,
the mother explained that he could only be a father, and “grow muscles so he could
take care of mommy and baby, and go to work in car [sic] like daddy does.”\footnote{Money and Ehrhardt, 1972, 120.} These
statements show how the mother enforces gender identity differently for her children,
and how different normal adult roles are presented for males and females. Money and
Ehrhardt endorse the mother’s choices, stating that she did a good job of teaching not
merely about the different reproductive abilities of boys and girls,\footnote{Although without noting that Joan would be infertile and unable to breastfeed.} but also about
how boys and girls (and men and women) hold different social roles.

The mother of these two children was particularly good in pointing out
the specifics of the female and male adult reproductive roles […] she
successfully offered explanations geared to the specific advantage of
being a female on the one hand, and a male on the other.\footnote{Money and Ehrhardt, 1972, 121.}

[Girls and boys are prepared] for their other different roles, such as
wife and husband or financial supporter of the family and caretaker of
children and house.\footnote{Money and Ehrhardt, 1972, 121.}

Thus the link between genitals and gender, and the mutual exclusivity of male and
female, are upheld in the optimal sex of rearing approach by emphasising separate
gender roles and identities for male and female children.

It is somewhat more difficult to speak of Money and Ehrhardt’s precise stand on
heteronormativity. Clearly, gender roles are described in traditional terms – daddy /
mommy, provider / carer – but the authors recognise that social roles are changing.\footnote{Money and Ehrhardt, 1972, 122.}

On homosexuality, the authors note that it is a social category ascribed to particular
practices, and through non-Western examples show that our ascriptions, while
strongly held, are culturally relative. While relative, Money and Ehrhardt see the
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ascriptions nonetheless fitting into a two-gender model, with permissible sexual acts divided by gender, age and social place. The issue feels somewhat unresolved in the book, but evidence abounds that many people working on similar approaches retained heteronormativity as an assumption until its being questioned relatively recently.  

Contemporary guidelines

The American Academy of Pediatrics 2000 guideline reflects an actualisation of all five of the unacknowledged assumption that Kessler identified, with some exceptions. As noted earlier, the guideline describes an intersex birth as “a social emergency” and advises parents that “abnormal [genital] appearance can be corrected.” This highlights that variant genitals do not constitute their own category but instead “can be and should be successfully altered by surgery.” There is no suggestion that the categories of male and female are arbitrary or socially constructed in any sense, and the importance of genitals as gender markers is highlighted by giving minimal length requirements for the male penis, without which a female gender should be assigned socially and surgically. Additionally, girls with oversized clitorises “require” surgery to reduce their size. These examples show that genitals, while not necessarily the source of a particular gender assignment, are the central ways of marking that assignment. Finally, the guideline does state that parents should be involved in the determination of the child’s gender, but physicians still retain a great deal of their power to define gender and the genitals because the decisions are made early on, before the parents may be fully knowledgeable and well before the child can participate. The physicians remain the primary interpreters of the child’s situation. (Perhaps we should not find this bias surprising, since the guideline, like the Consensus statement, is written for physicians rather than parents.)

The Consensus statement retains a number of the assumptions but also breaks from them in very significant ways. There does not appear to be a break from the

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189 AAP, 2000, 138. See also the Practices and guidelines section, above.
191 AAP, 2000, 139, 141.
192 AAP, 2000, 141.
assumptions that genitals and gender are naturally and necessarily dichotomous. However, genital surgery is no longer taken for granted. In the case of micropenis, surgery is ruled out,193 and in general, surgeries should “facilitate the chances of fertility” and be reserved for “severe” cases.194 Physicians still have some authority to define the relationship between gender and genitals, but this is lessened for two primary reasons. First, the Consensus no longer describes intersex as an emergency. Instead, it encourages providers to take time with the family and make sure they are fully informed. Also, it endorses delaying surgery where possible so the patient can participate.195 Second, success is defined in patient-centred terms, such as quality of life, instead of simply objective means that rely on the evaluation of medical professionals. The Consensus also tackles the assumption that homosexuality is equated with failure in the gender reassignment process, instead explicitly stating that homosexuality does not mean that the wrong gender was assigned, or that socialisation failed.196

Although the assumptions discussed above still exist in contemporary intersex treatment, we can say that they are now open to being questioned and revised. This is the case not only in the Consensus statement but also more explicitly in the critical literature on the treatment of intersex infants. Exposing these assumptions is essential to making real change in the medical management of intersex infants. Now that that step has been taken, we can critically examine the assumptions and then show how these problems of theory become problems in practice.

**The problem of gender**

The weaknesses of our simplistic, radically dichotomous two gender model will now be shown by highlighting how it is challenged by the cases of intersex and transgender persons. After disrupting the link between gender and genitals, a brief historical analysis will show that the ways we perceive gender differences and the link

193 Hughes, et al., 2006, 556.
194 Hughes, et al., 2006, 557. “Severe” was used in reference to a female infant with virilised genitalia that score high on the Prader Scale, described earlier.
195 Hughes, et al., 2006, 557.
196 Hughes, et al., 2006, 554.
between gender and the body are social constructions that have changed over time in response to different social contexts.

Intersex anatomies shine a bright light on the question of how sexually dimorphic humans are, and the connection between genitals and gender. Human bodies are modestly dimorphic with respect to body size and voice timbre, but we tend to assume that we are radically, or absolutely, dimorphic with regard to reproductive characteristics such as chromosomes, gonads, hormones, and internal and external genitalia. In practice, however, we see that there is not a single developmental pathway for males or females, and in fact there is some overlap between the two supposedly separate categories, even in matters of reproduction and sexuality. As noted previously, intersex births occur at a frequency between 1 in 4500 and 1.7%, which is evidence of significant number of instances where dimorphism is not simple, and the link between anatomy and gender identity is often unpredictable in these cases.

The link is even less clear when we consider transgender persons. Transgender is an umbrella term for persons who identify with a different gender than they were assigned at birth. Transgender persons may or may not seek to change their bodies through hormones and surgeries. The category does not usually include intersex persons, and there are both unique and shared issues between the two groups. There is also a great deal of controversy over the role of medical authority and medical guidelines in the diagnosis and treatment of Gender Identity Disorder, the clinical term for “a strong and persistent cross-gender identification,” coinciding with “persistent discomfort” in the patient’s gender identity and “clinically significant distress or impairment.” A key difference between intersex and transgender persons is that the latter group ask for their bodies to be a certain way and make choices for themselves – which is not to say that they are not the victims of the same problematic

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197 Sexual dimorphism refers to the differences between males and females in a species.
200 Hughes, et al., 2006, 554.
201 American Psychological Association, 1994, §302.
system of gender. Without going into too much detail, the immediate lesson that I would like to bring up is that even when there is no genital ambiguity, gender identity is not a certain or simple fact. Transgender persons are born with matching or consistent hormones, chromosomes and genitals, but nonetheless identify with a different gender. A number of difficult questions are raised by transgender persons that further fray the link between gender and genitals that is implicit in the optimal sex of rearing protocol and related medical approaches. First, a person who wishes to be recognised medically and legally as a different gender (and in some cases have the surgery paid for by private or public health insurance) must be diagnosed with Gender Identity Disorder. The diagnosis is made most often according a clinical guideline in which one of the requirements is completion of the “Real-life experience.”

During the real-life experience, the transgender person must spend a set amount of time living in the desired gender role, obtain a gender-appropriate name, and receive the attestation of others that he or she is living in the desired gender role. Although seemingly straightforward at first glance, operationalising gender is a strange process unless we resort to traditional gender stereotypes. A second break between gender and medical facts come when we consider the situation of an adult with XY (male) chromosomes who is taking oestrogen. This could easily refer to a transgender person seeking a female identity, but it is also a treatment for prostate cancer – and in the latter case, does not lead to questioning a person’s gender. In this case, the social context matters more than the medical facts in determining the relationship between gender and the body.

Given that the link between gender and the body that is assumed in protocols such as the optimal sex of rearing approach, it is worth asking where this link originated, and why the conventional view of gender as radically dichotomous is so ingrained.

202 This and other ethical issues in the medical response to transgender persons are addressed in Lear, 2005.
205 To judge by reality television, key steps to becoming a woman are waxing your chest, planning a bridal shower and catching the bride’s bouquet. See Lear, 2005, 14.
Laqueur argues that our current system of gender, the two-gender model, became dominant during a political epistemological shift that he places in the 18th century.\textsuperscript{206} The two-gender model is marked initially by the emphasis of differences between men and women at every level, from outward appearance to cellular makeup. While current medical thinking has updated our thinking on aspects such as cellular biology, we nonetheless retain the assumption that male and female are mutually exclusive categories.\textsuperscript{207} This marks a significant change from the earlier model, which viewed men and women as differences in degree, rather than in kind. Instead of a radical dichotomy, the Greeks saw men and women as different points along a continuum.\textsuperscript{208} Male and female genitals were not opposites; they were actually the same parts but inverted. This was reflected in the naming of the genitals.\textsuperscript{209} Aristotle saw true gender not in the genitals but in the “heat of the heart.”\textsuperscript{210} (Women were said to lack the “vital heat” necessary to externalise the penis.\textsuperscript{211})

This is not to argue that the earlier single-gender model is preferable to the contemporary model. The key point is that both systems are socially determined ways of seeing the same bodies, and they see different meanings in precisely the same objects. Laqueur’s thesis is that gender reflects social and political realities and power relationships, and the change to the two-gender model coincided with advances in medical knowledge as well as new theories of human rights that came out of the Enlightenment.\textsuperscript{212} This had the potential to change the political place of women, but the two-gender model gives a new defence for the different status of women (i.e., that women are biologically different from men and thus not entitled to the same rights). As Fausto-Sterling pointed out, a person’s gender defined their rights of inheritance,

\begin{thebibliography}{9}
\bibitem{206} Laqueur, 1992, 5. Note that Laqueur uses the term “two-sex model.”
\bibitem{207} Laqueur, 1992, 5.
\bibitem{208} Fausto-Sterling, 2000, 34.
\bibitem{209} Laqueur, 1992, 4-5. It is interesting to note that modern biology has, in some sense, proved the Greeks right: Human genitals all develop from the same primordial gonad (AAP, 2000, 138), and in performing genital reassignment surgeries, surgeons often reuse or repurpose the genitals to form their “opposite.”
\bibitem{210} Fausto-Sterling, 2000, 33.
\bibitem{211} Laqueur, 1992, 4-5.
\bibitem{212} Laqueur, 1992.
\end{thebibliography}
due to the law, and political participation. It is also worth noting that the shift to the two-gender model coincides with the increasing medicalisation of intersex persons described by Dreger.

**How gender acts on bodies**

Although assumptions based on gender are founded on social constructions with weak epistemological foundations, these assumptions have real and profound effects on the treatment of intersex infants. The strict link between gender and genitals, and the radically dichotomous understandings of gender and genitals, make it easy to see surgery as imperative. The imperative tends to be described in articles with strong, emotive words that show a negative attitude towards variant genitals. Some examples include:

- “…disfiguring and embarrassing phallic structure…”
- “The anatomic *derangements* [were] surgically corrected”
- “patients born with *obtrusive* clitoromegaly have been encountered”
- “…babies born with an *ungainly* masculine enlargement of the clitoris evoke grave concern in their parents.”
- “…total elimination of the *offending* shaft of the clitoris.”
- “… the size of the glans is *challenging* to a feminine cosmetic result.”
- “who cannot be a boy with this *insignificant* organ… They must be raised as females… They are *doomed* to life as a male without a penis.”

The ability of the genitals to evoke such strong reactions is remarkable, and hints at the underlying social concerns of physicians that are masked as medical crises. The phallic structure is *embarrassing*; the clitoris is *obtrusive*; the clitoral shaft is *offensive*; the boy’s organ is *insignificant*… But who is embarrassed? Who does the clitoris encroach upon? Who was offended? Who looks down on the insignificant

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213 Fausto-Sterling, 2000, 35.
215 These quotes are collected in Kessler, 1998, 35-38.
organ? Clearly, a great social burden is placed on the genitals; a burden so strong that demanding it be “corrected” is part of describing it. Left unsaid are the real source of these demands; the link between gender and genitals.

Ideas about gender and genitals also inequitably affect the way infants are assigned a gender. More children with XY (male) chromosomes are reassigned as girls than vice versa. The justification for this is, colloquially, that it is easier to dig a hole than to build a pole. A penis has more stringent requirements than a vagina: It must be big enough (at least 2.5cm at birth), capable of becoming erect or flaccid, and have a urethra that exits at the tip, allowing the child to pee while standing. A vagina, on the other hand, is a hole big enough for a penis. Note also that the goal of the vagina is heterosexual penetration, a further reflection of the heteronormative assumptions in many protocols. Additionally, it must be pointed out that while surgeries to reduce the size of the clitoris in intersex infants are often deemed necessary, female genital cutting in other cultures is a cruel and inhumane practice, even though the results are roughly similar. Unfortunately, as demonstrated in the clinical evidence argument, surgically forming the female anatomy (“digging a hole”) is not a simple process, but a multi-part procedure that involves significant risks and a high chance of failure.

Fertility is also treated weighted differently for infants: While ovaries should be preserved where possible, the optimal sex of rearing approach favours castration and female assignment for a boy with an undersized penis.

Kessler argues that routine genital surgeries, performed in spite of their documented failures and complications, demonstrate “the culture’s interest in enforcing dichotomous gender with dichotomous genitals.” Clearly, the theoretical problems of unexamined gender assumptions can cause real harm to intersex infants. It is

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216 Note also that the subject of discussion is not referred to as a penis but as an “organ” – implying that its size eliminates the possibility of ever being considered a penis.
218 Dreger, 1998a, 29.
219 Dreger, 1998a, 33. Interestingly, the circumcision of males and females evokes different responses and different critiques and justifications, worth studying in their own right but outside of the scope of this paper.
plainly unethical to apply such a problematic standard to intersex infants, and an end must be put to unnecessary surgeries performed in this way.
VII. CONCLUSIONS

This paper has put forward three separate arguments in support of the thesis that unnecessary surgery should not be performed on intersex infants, and that wherever possible, surgery on intersex infants should be postponed until the patient is able to participate in, and contribute to, the decision.

First, the clinical evidence argument presented data showing that surgical interventions on intersex infants are frequently unsuccessful and ineffective, and that there is a dearth of clinical evidence in their favour (and clinical evidence in general). Surgical interventions are also performed on infants based on the claim that intersex anatomies represent a crisis that must be solved immediately through surgery. Instead, the evidence presented showed that in almost all cases, genital surgery can be safely and reasonably delayed until the patient is able to participate in the decision.

Second, the future choices argument defended the claim that it is unethical to perform unnecessary surgery on intersex infants that will limit their future ability to make choices about their own bodies and that can be postponed until the patient can participate in the decision. Potentiality arguments supported the claim that as decision makers in development, infants are entitled to be protected from actions that will unnecessarily limit their future choices.

Third, the gender argument showed that unnecessary surgeries on intersex infants are unethical because they represent the medical imposition of a problematic model of gender that results in poor outcomes. Implicit gender assumptions in intersex practice were exposed and problematised, showing how problems of theory became problems in practice, ending in suboptimal care for intersex infants.

The arguments are ethically pluralistic in that they draw on different methods of ethical justification, including consequentialist, principlist, rights-based and duty-based theories. Rather than leading to incoherence, the varied arguments allow individuals with various ethical starting points to see that the conclusion is defensible from multiple perspectives. Each of the three arguments is able to stand independently and provide sufficient justification to support the thesis. Taken together, however, the three arguments build on each other to prove that unnecessary intersex surgeries
represent a flawed system of gender that is applied with negative results, on a population that cannot participate and is effectively limited in their future choices by the intervention.

Future guidelines on the diagnosis and treatment of intersex individuals must reflect these conclusions. The medical response to intersex infants should be centred on the infant’s actual medical needs, rather than the burdens of gender, to ensure the best care for each individual. Delaying surgery also allows the intersex person to take personal responsibility for their own health and gender, rather than resting it in the medical community.

There are a seemingly endless number of ethical, clinical, practical and theoretical challenges to contemporary intersex practice. By focussing on what has become the defining act of intersex treatment – unnecessary surgeries – and eliminating it, patients, parents and physicians will have the space to openly address the other challenges without being rushed by false emergencies, limited by surgical damage, or burdened by false gender assumptions.221

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Intersex

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