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Laura Hermer

Mitchell Hamline School of Law, laura.hermer@mitchellhamline.edu

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A Moratorium on Intersex Surgeries?: Law, Science, Identity, and Bioethics at the Crossroads

Abstract

Should the law prevent all parents and guardians from requesting and consenting to cosmetic genital surgeries on children with certain intersex conditions before the children are mature enough to decide the matter for themselves? While such surgeries ought not to be encouraged, banning the surgeries altogether, as some advocate, would hobble, if not eliminate, the burgeoning scientific investigation of the best treatment practices for different intersex conditions. It would also remove a surgical option that, according to data in a number of studies, has resulted in subjectively satisfactory outcomes for many patients.

Keywords

Intersex children--Legal status laws etc., Sex reassignment surgery, Informed consent (Medical law)

Disciplines

Law and Gender | Medical Jurisprudence

A MORATORIUM ON INTERSEX SURGERIES?: LAW, SCIENCE, IDENTITY, AND BIOETHICS AT THE CROSSROADS

LAURA D. HERMER, J.D., L.L.M.*

INTRODUCTION

Should the law prevent all parents and guardians from requesting and consenting to cosmetic genital surgeries on children with certain intersex conditions before the children are mature enough to decide the matter for themselves?¹ In this Journal's 2005 symposium on intersex issues, Jo Bird proposed the use of human rights law to prohibit such early surgeries.² Toward a similar end, Hazel Glenn Beh and Milton Diamond, in the same symposium, proposed adopting restrictions on the ability of parents and guardians to consent to early cosmetic genital surgeries—restrictions that would, in practice, prohibit a far greater range of procedures than just those primarily affecting children with intersex conditions.³ In this response, I will explore why the approaches suggested by Bird, Beh and Diamond fall short of what is necessary to best manage the medical, social, and interpersonal issues raised in the early treatment of certain intersex conditions. Both approaches would harness the legal system to halt cosmetic genital surgeries on children with certain intersex conditions. In so doing, both approaches would also hobble, if not eliminate, the burgeoning scientific investigation of the best treatment practices for different intersex conditions which seeks to gather information from broad and objectively chosen groups of

* Research Professor, Health Law and Policy Institute, University of Houston Law Center. I would like to thank Susan Cancelosi and Patricia Gray for helpful comments on earlier drafts, and Drs. Lars J. Cisek and W. Hardy Hendren for graciously providing medical expertise. Any errors are mine alone.

¹ By “cosmetic genital surgeries,” I mean those surgeries on the genitalia of individuals with an intersex condition that are not required, at or near the time they are performed, for healthy physiological function. This definition clearly encompasses, for example, clitoral reduction surgeries when performed in infancy, but leaves the status of other surgeries—e.g., certain hypospadias and chordee repair and certain vaginoplasties—in question. It is likely that few procedures can be said in all cases to constitute a “cosmetic genital surgery” because what may be unnecessary for one person may be warranted or even required for another, given the medical circumstances of each individual. Most of the conditions considered in the legal literature to be intersex conditions are not in fact conditions that frequently, if ever, give rise to cosmetic genital surgeries. *See infra* Part II.

² Jo Bird, *Outside the Law: Intersex, Medicine and the Discourse of Rights*, 12 *CARDOZO J.L. & GENDER* 65, 74 (2005).

³ Hazel Glenn Beh & Milton Diamond, *David Reimer's Legacy: Limiting Parental Discretion*, 12 *CARDOZO J.L. & GENDER* 5, 21 (2005).

individuals.⁴ Furthermore, both approaches would remove a surgical option that, according to data in a number of studies, has benefited and satisfied numerous patients.⁵ Additionally, Bird's, Beh's and Diamond's solutions to the problem of early surgeries do nothing to constructively address the deep-seated and often murky social, interpersonal and psychological reasons such surgeries take place.⁶

This is not to say that I necessarily disagree with certain of Beh's, Diamond's and Bird's contentions. I continue to have grave reservations about the almost reflexive practice of cosmetic genital surgeries on infants and children with certain intersex conditions. These reservations remain despite—and at times because of—findings from the relative surge since I first wrote on this issue in studies published on the long-term subjective outcomes for individuals who had such surgeries in childhood. My original position on the matter of surgeries remains unchanged.⁷ Parents need to receive complete information about their child's condition. They need to be informed—ideally by a health care provider who does not favor early cosmetic genital surgeries—of the known risks and benefits of different treatment options, including waiting to perform cosmetic surgeries until the child reasonably can decide for him or herself what to do. Parents need to be given information about support groups for families of individuals with intersex conditions and be encouraged to make contact with such groups. But the surgeries themselves, if parents ultimately opt for early cosmetic surgery, should not be prohibited.

The last stipulation is currently unpopular in the legal literature.⁸ Nevertheless, I believe the proposition remains correct, at least for the time being, because there still exist little conclusive data with respect to any given intersex condition finding that the current and typical spectrum of practices are ineffective, yield bad results in most cases, or are flatly unethical.⁹ Even researchers who are on record as generally opposing early surgeries, such as Sarah Creighton and

⁴ See *infra* notes 57-78 and associated text.

⁵ See *infra* note 69, 72-73 and associated text.

⁶ See *infra* notes 47-56 and associated text.

⁷ See Laura Hermer, *Paradigms Revised: Intersex Children, Bioethics, and the Law*, 11 ANNALS HEALTH L. 195, 231-235 (2002).

⁸ Many of the commentators in the legal literature who have addressed the issue believe that the practice of cosmetic genital surgeries on infants and children with intersex conditions should be banned or curtailed through legal means. For a small sample, see, e.g., Marie Fox & Michael Thompson, *Cutting It: Surgical Interventions and the Sexing of Children*, 12 CARDOZO J.L. & GENDER 81, 97 (2005); Erin Lloyd, *From the Hospital to the Courtroom: A Statutory Proposal for Recognizing and Protecting the Legal Rights of Intersex Children*, 12 CARDOZO J.L. & GENDER 155, 187 - 88 (2005); Kate Haas, *Who Will Make Room for the Intersexed?*, 30 AM. J.L. & MED. 41, 62-66 (2004); P.L. Chau & Jonathan Herring, *Defining, Assigning and Designing Sex*, 16 INT. J.L. POL'Y & FAM. 327, 327 (2002).

⁹ Clitoridectomies (removal of the clitoris or phallus) have been considered outside the standard of care in the United States for at least a decade and a half, and feminizing genitoplasties (surgeries to make the genitals look "female") for individuals with a 46,XY karyotype and either micropenis or penile agenesis have been falling out of favor over about the last decade. Early vaginoplasties, however, are another matter. See *infra*, notes 10, 68-72 and associated text.

Catherine Minto, do not publicly support a ban; but rather counsel substantial caution and greater disclosure regarding risks and uncertainties, specifically with respect to feminizing surgeries.¹⁰

I. HUMANS, CITIZENS, AND PEOPLE WITH INTERSEX CONDITIONS

Those who believe that early cosmetic surgeries should be banned have raised several arguments. One argument, raised by Jo Bird, is that performing cosmetic surgeries on the genitals of infants and children with certain intersex conditions, before the children themselves are old enough to decide for themselves what they want, violates children's human rights. Bird posits that children with intersex conditions are, according to the law, "not considered to be fully human, and thus [not] the subject of human rights."¹¹ Surgery is used, she claims, to make intersex children human, where "human," or "citizen" elsewhere is "capable of being defined as 'male' or 'female' on a birth certificate."¹² Barring such surgery, an intersexed body is inconceivable and invisible, thus placing individuals with intersex conditions outside the scope of human rights law.¹³

This is an extreme contention. It would be a fascinating one, worthy of

¹⁰ With respect to feminizing surgeries, some authorities clearly state that they believe vaginoplasties—surgery to create or enlarge a vagina—should be deferred because the data shows that most women who have such operations in infancy or childhood will need another one at adolescence to permit tampon use and heterosexual intercourse. However, they urge only extreme caution and counseling about risks with respect to surgeries to reduce the size of the clitoris rather than a ban of the procedure, given the dearth of information about the long-term effects of such surgeries and the physiology of female orgasm. See, e.g., Catherine L. Minto et al., *The Effect of Clitoral Surgery on Sexual Outcome in Individuals Who Have Intersex Conditions with Ambiguous Genitalia: A Cross-Sectional Study*, 361 LANCET 1252 (2003); Sarah Creighton & Catherine Minto, *Managing Intersex*, 323 BMJ 1264, 1265 (2001); Sarah M. Creighton et al., *Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood*, 358 THE LANCET 124, 125 (2001). This view appears to have remained essentially unchanged in succeeding years. See, e.g., Cara Megan Ogilvie et al., *Congenital Adrenal Hyperplasia in Adults: A Review of Medical, Surgical and Psychological Issues*, 64 CLINICAL ENDOCRINOLOGY 2, 6-7 (2006). Additionally, Creighton and Minto are not the only researchers studying the issue, and other studies have reached different conclusions. See, e.g., N. M. Stikkelbroeck et al., *The Long Term Outcome of Feminizing Genital Surgery for Congenital Adrenal Hyperplasia: Anatomical, Functional and Cosmetic Outcomes, Psychosexual Development, and Satisfaction in Adult Female Patients*, 16 J. PEDIATRIC & ADOLESCENT GYNECOLOGY 289 (2003) (finding that while most vaginoplasties performed in infancy in their study population needed to be redone later, outcomes were generally positive with respect to sexual development and activity); Amy Wisniewski et al., *Psychosexual Outcome in Women Affected by Congenital Adrenal Hyperplasia Due to 21-Hydroxylase Deficiency*, 171 J. UROLOGY 2497, 2499 (2004) (finding that women with the simple virilizing form of classic congenital adrenal hyperplasia (CAH) generally reported satisfaction with genital appearance and function, although women with the more severe salt losing variety did not fare as well); Lieselotte Frost-Amer et al., *Clitoral Sensitivity After Surgical Correction in Women with Adrenogenital Syndrome: A Long Term Follow-Up*, 37 SCANDINAVIAN J. PLASTIC RECONSTR. SURGERY & HAND SURGERY 356, 358 (2003) (finding that clitoral sensitivity in women who were treated with early clitoroplasty and late vaginoplasty was not reduced in comparison with a control population of women who never had genital surgery).

¹¹ Bird, *supra* note 2, at 79.

¹² *Id.* at 68.

¹³ *Id.* at 79.

study, if it were supported by law and/or evidence.¹⁴ However, the contention appears rhetorical rather than factual. Even if Bird alleged merely that intersex children were in danger of statelessness—rather than lacking altogether in legal and ethical personhood—without the benefit of surgery, the claim would be dubious at best.¹⁵ Certainly no jurisdiction in the United States, at least, appears to require surgery on children with ambiguous genitalia prior to accepting a designation of sex on children's birth certificates.

If we take Bird's claim figuratively rather than literally, Bird does have a point. Sex and gender are essential components of both personal and social identity in many, if not most, societies.¹⁶ Both have innumerable potential ramifications on an individual's life, depending on where that individual resides, among a variety of other factors. Bird also correctly observes that international human rights conventions say nothing that specifically addresses the legal status of and protections for people with intersex conditions.¹⁷ Yet to jump to the conclusion that people with intersex conditions are in fact not protected, *qua* humans and citizens, under the law is unwarranted, particularly where Bird cites no legal support for the claim, and where at least one court has favorably cited international human rights law in prohibiting early genital surgery on a child with an intersex condition.¹⁸ Bird took a defensible contention – namely, given the integral roles that sex and gender play in cultures, legal systems, and identification, people with intersex conditions may be subject to particular forms of both hidden and overt discrimination, potentially unnecessary or unwanted procedures, and disparate treatment – and unfortunately pushed it too far.

II. THE TRICKY MATTER OF EVIDENCE

Evidence – whether the lack thereof or incorrect usage of it – bedevils many issues, and not just those pertaining to human rights. Misconstruals of the

¹⁴ A broad search of international treaties concerning human beings and human rights in a variety of contexts yielded no definition of “human,” “human being,” or “person” that in any way appears to lend support to Bird's contention. In fact, no definition of any such term was provided in any of the documents found in that search. *See, e.g.*, Council of Europe, Convention on Action Against Trafficking in Human Beings art. 4, May 16, 2006, 45 I.L.M. 12; Council of Europe, Convention on Nationality art. 2, Nov. 6, 1997, 37 I.L.M. 44; G.A. Res. 44/25, UN Doc A/Res/44/25 art. 1 (Nov. 20, 1989). To the contrary, some of these documents expressly included, for example, children, the elderly, disabled individuals and other potentially vulnerable persons within their scope, and identified members of such vulnerable populations as “persons.” *See, e.g.*, Europa, A Constitution for Europe, http://europa.eu/constitution/en/ptoc146_en.htm#a619; Council of Europe, Convention on Human Rights and Biomedicine and Explanatory Report arts. 6 & 7, Apr. 4, 1997, 36 I.L.M. 817.

¹⁵ Bird does also make this claim; *see* Bird, *supra* note 2, at 68.

¹⁶ *See, e.g.*, Phil Hubbard, *Sexing the Self: Geographies of Engagement and Encounter*, 3 SOC. & CULTURAL GEOGRAPHY 365, 365 – 66, 368 (2002).

¹⁷ Bird, *supra* note 2, at 80.

¹⁸ *See* Principio de Publicidad del Processor-Armonizacion con la intimidación del menor y su familia / Sentencia de Revisión de Tutela-Publicidad parcial para el caso, Sentencia Su-337/99, Cons. Ct. (Colombia) T-131547 (1999) (citing article 12 of the Convention on the Rights of the Child), available at <http://www.isna.org/node/149>. (last viewed Feb. 2, 2007).

scientific literature are distressingly common in legal articles on intersex issues. Bird, for example, claims contra all evidence that physicians in 2006 seek to remove the gonads of intersex individuals in a deliberate attempt to sterilize them, so they cannot pass on their intersex traits to others.¹⁹ This neglects that there may be significant issues with fertility that cannot be overcome in many people with an intersex condition other than congenital adrenal hyperplasia (CAH), due solely to physiological, genetic, or other features of their condition, rather than gonad removal.²⁰ It further neglects the significant increase in cancer risk from streak or dysgenetic gonads, as well as from testes that may be retained in the abdomen.²¹ It also ignores the fact that the American Academy of Pediatrics (AAP) expressly recommends retaining gonads, whether they are ova or testes, where the gonads are likely to be fertile and/or retain some endocrine function.²²

But the mistakes do not end here. To take a more common mistake, the data simply do not support many commentator's claims that 1.7 to 4% of all infants born each year possess genitalia that are so ambiguous that many surgeons would recommend cosmetic genital surgery in infancy or childhood.²³ The problem is

¹⁹ Bird, *supra* note 2, at 76. Bird is not alone in this error. See, e.g., Sara R. Benson, *Hacking the Gender Binary Myth: Recognizing Fundamental Rights for the Intersexed*, 12 CARDOZO J.L. & GENDER 31, 48 (2005).

²⁰ See, e.g., Am. Acad. of Pediatrics, *Evaluation of the Newborn with Developmental Anomalies of the External Genitalia*, 106 PEDIATRICS 138, 141 (2000). See also Maquelone G. Forest, *Ambiguous Genitalia/Intersex: Endocrine Aspects*, in PEDIATRIC UROLOGY 626, 627, 644 (John P. Gearhart et al., eds., 2001).

²¹ Am. Acad. of Pediatrics, *supra* note 20, at 141; Forest, *supra* note 20.

²² Am. Acad. of Pediatrics, *supra* note 20, at 141 (stating that “[a]ll female infants virilized because of CAH or maternal androgens are potentially fertile and should therefore be raised as girls,” that it is “advantageous to retain a gonad appropriate to the assigned sex if it is likely to function adequately,” and that, while

[t]he incidence of tumors is increased in histologically normal undescended testes, particularly those residing in the abdomen . . . a case can be made for retaining such a testis in patients with mild androgen insensitivity, true hermaphroditism, or mixed gonadal dysgenesis provided biopsy results show normal testicular tissue, the testis can easily be brought down into the scrotum, and the patient can be kept under long-term observation.

See also, e.g., David A. Diamond et al., *Sex Assignment for Newborns with Ambiguous Genitalia and Exposure to Fetal Testosterone: Attitudes and Practices of Pediatric Urologists*, 148 J. PEDIATRICS 445, 447 (2006) (noting that 95% of the 99 % of pediatric urologists surveyed would assign an infant with a 46 XX karyotype with classic CAH as a girl would do so because of the infant's potential for fertility as a female rather than as a male).

²³ A number of authors, for example, made this error in this journal's recent symposium issue. See, e.g., Beh & Diamond, *supra* note 3, at 11 (claiming that as many as 1.62% of all infants may be subject to such surgeries; this figure includes not only Blackless et al.'s *infra* note 23—estimate of how many may be subject to surgery, but also their estimate of the number of people with non-classic CAH, whose condition does not show up in infancy, whom they allege on scant data may be subject to cosmetic surgery at puberty or thereafter but refrain from including in their final estimate of the percentage of children likely subject to early surgery); Sara R. Benson, *Hacking the Gender Binary Myth: Recognizing Fundamental Rights for the Intersexed*, 12 CARDOZO J.L. & GENDER 31, 33 (2005); Elizabeth Reilly, *Radical Tweak: Reallocating the Power to Assign Sex*, 12 CARDOZO J.L. & GENDER 297, 299 (2005). The figure of 1.7% comes from Melanie Blackless et al., *How Sexually Dimorphic Are We?*, 12 AM. J. HUM. BIOLOGY 151, 159 (2000). It was used in Anne Fausto-Sterling's *Sexing the Body*, from which it was then widely quoted. See ANNE FAUSTO-STERLING, *SEXING THE BODY* 53

not with the original statistic. The 1.7% estimate pertains not to the number of people born each year who may be subjected to cosmetic genital surgery, but rather to those born with various conditions that could be designated “intersex” and may or may not ever result in genitalia that appear ambiguous.²⁴ According to Melanie Blackless and her co-authors, 1.5% of all children born alive have late-onset, or non-classic, congenital adrenal hyperplasia.²⁵ Presuming this statistic is correct, non-classic CAH accounts for 87% of all the births cited as exhibiting “non-dimorphic sexual development”—i.e., an intersex condition.²⁶ Yet girls with non-classic CAH have genitals that look typically “female” at birth.²⁷ They are *not* candidates for surgery, as their genitals appear “normal” for a girl by anyone’s standard.²⁸ The effects of non-classic CAH appear, if at all, only at or after puberty and usually do not involve the significantly virilized genitalia found in the much more rare condition of classic CAH,²⁹ affecting 0.00779% of all live births.³⁰

If one removes non-classic CAH from the statistic, then only 0.228% of all live births remain. According to Blackless and her co-authors, even this statistic catches up too many infants; according to them, only approximately 0.08% of all live births might be subject to cosmetic genital surgery.³¹ This results in a rather different picture of just how sexually polymorphic humans are, physiologically, than one might gather from some of the legal literature, at least from the standpoint of how many infants might be subject to genital “normalizing” surgery as a result of an intersex condition.

This is hardly to say that cosmetic genital surgeries for children with intersex conditions do not raise significant social and ethical issues. They do, and the relevant bioethical issues remain significant matters for debate. However, those who see glimpses of a future gender utopia for all of us by “creat[ing]... legal space for intersex” may, if they examined the matter a little more carefully, find some problems with this chosen strategy, as the degree of prevalence of intersex conditions resulting in ambiguous genitalia apparent at birth are much less common than some authors claim.³² It is simply not true, using the data from

(2000). The figure of 4% interestingly, comes from John Money, the now oft-reviled Johns Hopkins psychologist, as reported by Fausto-Sterling. See Anne Fausto-Sterling, *The Five Sexes*, 33 SCIENCES 20, 21 (1993).

²⁴ See Blackless, *supra* note 23, at 159.

²⁵ FAUSTO-STERLING, *supra* note 23, at 53 (citing Blackless, *supra* note 23, at 161).

²⁶ *Id.*

²⁷ See, e.g., Forest, *supra* note 20, at 647.

²⁸ *Id.*

²⁹ A common complaint is an early onset of puberty, as well as hirsutism and problems with menstruation. See, e.g., Deborah P. Merke & Stefan R. Borenstein, *Congenital Adrenal Hyperplasia*, 365 LANCET 2125, 2127 (2005).

³⁰ FAUSTO-STERLING, *supra* note 23, at 53.

³¹ See Blackless et al, *supra* note 23, at 161. The statistic of 0.228% includes complete androgen insensitivity syndrome, which is generally never detected at birth but rather only at puberty, as well as Turner’s Syndrome and Klinefelters’ Syndrome, with respect to neither of which cosmetic genital surgery is performed. See, e.g., Forest, *supra* note 20, at 628 – 29, 631 – 33, 643.

³² See, e.g., Bird, *supra* note 2, at 66 (“one of the likely effects of the creation of a legal space

Blackless's study, that as many as one in six hundred or even one in three hundred babies are subject to immediate and allegedly "emergent" cosmetic genital surgery in infancy.³³ Using this misconstrued statistic to allege that not only do we need to stop cosmetic genital surgeries on children, but also that the condition is so common that we need to discard our rigid notions of gender and sexual distinctions and instead accept a more fluid notion, is disingenuous at best.³⁴ It hurts one's argument to base it on a fallacy.³⁵

III. PRACTICAL IMPLICATIONS OF PROPOSED APPROACHES TO INFORMED CONSENT FOR EARLY COSMETIC GENITAL SURGERIES

So what, then, is ethically required of us as a society in our approach to cosmetic genital surgeries in infancy? Should we ban them on the ground that to allow parents to consent would so gravely violate a child's right to bodily integrity and autonomy that any such consent should be considered invalid? Should we say that they should be considered unlawful under the common law, on the ground that there are incurable problems with the informed consent process? Should we continue to permit them, but seek to have a non-surgical member of the child's team of physicians provide parents with as complete information as possible about their child's condition and prognosis, as well as about the (usually)³⁶ purely elective option of genital surgery, benefits and drawbacks, and information about long-term outcomes (including whether long-term data are missing, minimal, or inconclusive)? Should we refrain from any attempt to alter present medical norms on the assumption that the medical community will do what's best, as based on present medical practice and knowledge?

A. Bird's Approach

According to Bird, altering the natural appearance of the intersex child's genitals constitutes a human rights violation and is a form of discrimination.³⁷ She states that such surgeries violate Article 19 of the Convention on the Rights of the Child, which provides in relevant part that "States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or

for intersex would be the increasing social space for those who choose to occupy it").

³³ It would be one thing if there were data to support it, but I found no articles in law journals that based such a claim on data that did not ultimately derive from Blackless et al.'s study.

³⁴ See *supra*, note 31 and associated text.

³⁵ There are many good reasons – ones supported by strong evidence and that we see all around us, daily – to take a more fluid approach to gender and sexual distinctions than our society usually does. Taking a more fluid approach might also help end the practice of early genital surgeries. But seeking to end those surgeries without correspondingly seeking to transform our attitudes towards sex and gender puts the proverbial cart before the horse. See *infra*, notes 50, 53 and associated text.

³⁶ Cloacal extrophy is an exception. See, e.g., W. Hardy Hendren, *Cloaca, the Most Severe Degree of Imperforate Anus. Experience With 195 Cases*, 228 ANN. SURGERY 331, 343 (1998).

³⁷ *Id.* at 79.

negligent treatment, maltreatment or exploitation.”³⁸ Anything short of allowing the child to decide for him- or herself whether to have surgery done constitutes violence in violation of human rights law, according to Bird.³⁹ To allow the parents to decide for the infant or child, or, even worse, to allow any of the parents’ considerations to enter into the calculus, makes the child’s body into “other than the child’s own” or into “a social or familial body.”⁴⁰

Yet the fact is that our bodies and psyches do not exist *sui generis*, but rather are all shaped in part by familial and societal forces.⁴¹ Should parents, then, not be permitted to consent to cochlear implants for their deaf children, for example? Should they wait until the child can choose for him or herself, after having lived his or her childhood as deaf and developed neurologically, psychologically, and socially in that manner? Some argue that parents should not be able to make that choice,⁴² however, in most cases parents are permitted in this society to make decisions on behalf of their minor children, including medical decisions, to the extent that their children lack the maturity to act on their own.⁴³ One hopes that a parent would act solely in what s/he considers to be the best interest of the child when making a decision about whether to seek cosmetic surgery for the child’s intersex condition. Evidence regarding other types of elective surgeries suggests that most probably do, even if the parent’s assumptions turn out to be mistaken, or where the child, once grown up, would him- or herself have chosen a different course.⁴⁴ If that action conflicts with what the parent would him or herself choose if only his or her own wishes were at stake, then one hopes the parent would find the maturity and understanding necessary to come to terms with the action.⁴⁵

Evidence suggests that parents consider social norms in determining the best decision to make for their child when considering elective surgery to alter the child’s appearance. Most people in the United States can be readily identified as

³⁸ Convention on the Rights of the Child, art. 19, para. 1, Nov. 20, 1989, G.A. Res. 44/25, 61st plen. mtg., U.N. Doc. A/RES/44/25. Bird cites the Declaration of the Rights of the Child, but the quote she provides is nowhere therein to be found, and rather is found in the Convention on the Rights of the Child.

³⁹ Bird, *supra* note 2, at 74 – 75.

⁴⁰ *Id.* at 74.

⁴¹ See generally, MELISSA HINES, *BRAIN GENDER* (2004); W. Andrew Collins et al., *Contemporary Research on Parenting: The Case for Nature and Nurture*, 55 AM. PSYCHOLOGIST 218 (2000).

⁴² There is, in fact, a strong ongoing debate regarding the use of cochlear implants and their impact on deaf culture and families. See generally, Maya Sabatello, *Disability, Cultural Minorities, and International Law: Reconsidering the Case of the Deaf Community*, 26 WHITTIER L. REV. 1025 (2005); Amy Elizabeth Brusky, *Making Decisions for Deaf Children Regarding Cochlear Implants: The Legal Ramifications of Recognizing Deafness as a Culture Rather than a Disability*, 1995 WIS. L. REV. 235 (1995).

⁴³ For an excellent and thorough legal/historical discussion, see Barbara Bennett Woodhouse, “Who Owns the Child?”: *Meyer and Pierce and the Child as Property*, 33 WM. & MARY L. REV. 995 (1992).

⁴⁴ See *infra*, notes 46, 47.

⁴⁵ This does not always happen. For a discussion of this issue, as well as of the consequences of changes to the present decisional paradigm in this country, see *infra*, notes 57-66 and associated text.

either male or female in gender and sex, despite a broad—and relatively widely accepted—spectrum of behaviors and appearances.⁴⁶ Research regarding parental decision-making with respect to elective medical procedures for children has shown that a primary impetus for the decision is psychosocial or cultural considerations, sometimes even to the exclusion of medical considerations.⁴⁷ For example, two of the studies examining circumcision found that a majority of parents insisted on circumcising their male child for non-medical reasons.⁴⁸ In one study, the fact that the physicians in the study counseled against routine circumcision was largely irrelevant to the parents' decision. In the other, 80% of the parents had already made up their minds to circumcise their boy before talking with a physician, and only a statistically insignificant number changed their minds after hearing the physician's thoughts on the matter.⁴⁹ In both studies the decision to circumcise appeared to be most closely correlated with social or cultural factors, such as whether the father was also circumcised and concerns about cleanliness.⁵⁰

The studies regarding circumcision may help explain the findings of a recent study examining reasons for parental decision-making with respect to cosmetic surgery on the genitals of their girls with CAH. The authors of that study found that the vast majority of parents were happy with the amount of medical information given to them by their children's physicians, were satisfied with their child's surgery, and would agree to surgery even if they knew it would compromise the sensitivity of their children's genitals.⁵¹ No parent in the study would have deferred surgery until the child could decide for herself.⁵² A substantial percentage of parents considered social or cultural factors such as "genital appearance" and "sexual orientation" to be important in making their decision.⁵³

⁴⁶ Cf., e.g., Sabine C. Koch, *Constructing Gender: A Lens-Model Inspired Gender Communication Approach*, 51 *SEX ROLES* 171, 171–72 (2004) (discussing research regarding the perception of gender cues).

⁴⁷ See, e.g., Emma Daniel et al., *Trying to Do My Best as a Mother: Decision-Making in Families of Children Undergoing Elective Surgical Treatment for Short Stature*, 10 *BRIT. J. HEALTH PSYCH.* 101, 102 (2005); Hannake Viser-van Balen et al., *Motives for Choosing Growth-Enhancing Hormone Treatment in Adolescents with Idiopathic Short Stature: A Questionnaire and Structured Interview Study*, 5 *BMC PEDIATRICS* (2005), <http://www.biomedcentral.com/1471-2431/5/15>; MS Brown & CA Brown, *Circumcision Decision: Prominence of Social Concerns*, 80 *PEDIATRICS* 215 (1987).

⁴⁸ Jeffrey Tiemstra, *Factors Affecting the Circumcision Decision*, 12 *AM. J. BOARD FAM. PRACTICE* 16 (1999); Brown, *supra* note 47.

⁴⁹ Tiemstra, *supra* note 48; Brown & Brown, *supra* note 47.

⁵⁰ Tiemstra, *supra* note 48; Brown & Brown, *supra* note 47.

⁵¹ Jennifer E. Dayner et al., *Medical Treatment of Intersex: Parental Perspectives*, 172 *J. UROLOGY* 1762, 1763 (2004).

⁵² *Id.* at 1764.

⁵³ *Id.* Interestingly, "capacity for sexual responsiveness" was the most important factor cited by the parents (80%). *Id.* The term, however, was not defined. It may have been interpreted by parents to mean "capacity for penetrative sexual activity" rather than "sensitivity," given that 95% of parents who agreed to surgery would still have agreed even if they knew that their child's genital sensitivity would be compromised as a result. *Id.* If so, these results show a high degree of parental concern not merely for children to appear "normal," but also for creating and maintaining heteronormativity. This would correlate with the finding that 70% of parents considered their daughter's sexual orientation to be important in deciding to have the surgery. *Id.*

I suspect, though cannot prove, that most of the parents in the CAH study did not base their decision to subject their children to feminizing genitoplasties on malicious or selfish considerations. Rather, it is more likely that they based their decision on what they thought would be best for their children, given that we live in a strongly gendered society in which a reasonable amount of conformity to the norm is often considered necessary to “fit in.” Parents make decisions affected by social norms every day, regarding matters ranging from the relatively trivial and easily reversible—e.g., whether a parent should let her eight-year-old son grow his hair long despite school complaints⁵⁴—to the serious and permanent—e.g., whether the aging parents of a woman with moderately severe Down Syndrome should be permitted to have their daughter sterilized.⁵⁵

So does parental reliance on social considerations mean that parents ought not to be able to choose certain forms of socially-motivated surgeries, such as cosmetic genital surgeries for intersex conditions, for their child? To answer this, one could examine to what extent the social norms potentially at issue are harmful to people with intersex conditions, certainly at least to the extent that they may influence parents to consent to early surgeries. Such an examination would presuppose, however, that the surgeries are in fact more harmful—physically, psychologically, and otherwise—than the alternative to most children with intersex issues. To determine whether this assumption is correct—to the extent that is it possible to do so⁵⁶—one must look at the research concerning long-term outcomes in patients who had cosmetic genital surgeries in infancy or childhood.

It would be one thing if there were conclusive or even substantial evidence showing that the surgical course sought by the parents will more likely than not lead to harm. In such a case, Bird’s contention that it is a human rights violation to perform such surgery in the absence of consent by the child her- or himself would have more merit. Such evidence is growing with respect to certain diagnoses. For some time, it has been largely agreed that clitoridectomy for CAH girls should not be performed as it severely compromises genital sensitivity.⁵⁷ Also, the standard

⁵⁴ See, e.g., *Bd. of Trs. of Bastrop Indep. Sch. Dist. v. Toungate*, 958 S.W.2d 365 (Tex. 1997) (reh’g. overruled Feb 13, 1998).

⁵⁵ See, e.g., *Conservatorship of Valerie N.*, 707 P.2d 760 (1985); *In re Matter of Grady*, 426 A.2d 467, 470 (1981).

⁵⁶ There appear to be few long-term studies should compare the outcomes of individuals with a given intersex condition who had early genital surgeries with those who had no surgery at all. Without being able to compare the experiences of those who had surgery for a specific intersex condition with those who did not, it is impossible to say whether early surgery is generally preferable to none, or vice versa. Rather, most of the evidence that exists regarding the experiences of people with intersex conditions who never had cosmetic genital surgery is anecdotal. See, e.g., *Intersex Society of North America, What Evidence Is There that You Can Grow Up Psychologically Healthy with Intersex Genitals (without “Normalizing” Surgeries)?*, available at <http://www.isna.org/faq/healthy> (last viewed Nov. 7, 2006).

⁵⁷ See, e.g., Minto et al., *supra* note 10, at 1256-57. It would seem that this result would go without saying, but even recently one study found that a minority—13%—of European medical centers in the study sample still performed clitoridectomies in feminizing genitoplasties. See Felix G. Riepe et al., *Management of Congenital Adrenal Hyperplasia: Results of the EASPE Questionnaire*, 58

of care is changing for micropenis and penile agenesis, although neither arguably are intersex conditions.⁵⁸ This is arguably in part a result of David Reimer's case as some of the data on long-term results of surgical reassignment of boys into girls are conflicting.⁵⁹ Some studies have found that a majority of boys with micropenis who were assigned to a female gender, castrated, and given feminizing genitoplasties in infancy later suffered severe gender identity disorder and ultimately decided to live as males.⁶⁰ Others, however, have not.⁶¹ Additionally and significantly, other studies have found that males with micropenis can have satisfying sexual function as adults.⁶² Whether coincidentally or causally, a recent study found that about two-thirds of pediatric urologists would treat a 46, XY child with cloacal exstrophy⁶³ as a boy, rather than attempt to reassign such a child surgically as a girl.⁶⁴ As some have pointed out,⁶⁵ this is a significant change from what the standard protocol would have been as recently as ten years ago.⁶⁶

HORMONE RESEARCH 196, 199 (2002).

⁵⁸ Micropenis is where the length of the penis is less than 2.5 standard deviations below the mean; penile agenesis is where the child is born with no penis at all. See Marc Cendron, *Disorders of the Penis and Scrotum*, in PEDIATRIC UROLOGY 729-32 (John P. Gearhart et al., eds., 2001).

⁵⁹ For more on David Reimer's case, see generally JOHN COLAPINTO, *AS NATURE MADE HIM: THE BOY WHO WAS RAISED AS A GIRL* (2000).

⁶⁰ See generally, e.g., William G. Reiner & Bradley P. Kropp, *A 7-Year Experience of Genetic Males with Severe Phallic Inadequacy Assigned Female*, 172 J. UROLOGY 2395 (2004); Amy B. Wisniewski et al., *Congenital Micropenis: Long-Term Medical, Surgical and Psychosexual Follow-Up of Individuals Raised Male or Female*, 56 HORMONE RESEARCH 3, 9-10 (2001); Milton Diamond & Keith Sigmundson, *Sex Reassignment at Birth: Long Term Review and Clinical Implications*, 151 ARCHIVES PEDIATRIC & ADOLESCENT MED. 298 (1997).

⁶¹ See, e.g., Heino F.L. Mayer-Bahlburg, *Gender Identity Outcome in Female-Raised 46,XY Persons with Penile Agenesis, Cloacal Exstrophy of the Bladder, or Penile Ablation*, 34 ARCHIVES OF SEXUAL BEHAVIOR 423 (2005) (concluding in a review of the literature that there is an increased chance that the patient groups in question will revert to a male gender if originally assigned to a female one, but observing that predictors of gender change remain unclear, and that sexual functioning and overall quality of life issues need to be better studied); Susan J. Bradley, *Experiment of Nurture: Ablatio Penis at 2 Months, Sex Reassignment at 7 Months, and a Psychosexual Follow-up in Young Adulthood*, 102 PEDIATRICS e.9 (1998), available at <http://www.pediatrics.aappublications.org/cgi/content/full/102/1/e9>.

⁶² See, e.g., Cendron, *supra* note 58, at 732 (citing A.P. van Seters & A.K. Slob, *Mutually Gratifying Heterosexual Relationship with Miropenis of Husband*, 14 J. SEXUAL MARITAL THERAPY 98 (1989), and J.M. Reilly & C.R. Woodhouse, *Small Penis and the Male Sexual Role*, 142 J. UROLOGY 569 (1998)); Bassam Bin-Abbas et al., *Congenital Hypogonadotropic Hypogonadism and Micropenis: Next Term Effect of Testosterone Treatment on Adult Penile Size—Why Sex Reversal Is Not Indicated*, 134 PEDIATRICS 579 (1999); C.R.J. Woodhouse, *Sexual Function in Boys Born with Exstrophy, Myelomeningocele, and Micropenis*, 52 J. UROLOGY 3 (1998). But see Mayer-Bahlburg, *supra* note 61 (finding sexual difficulties reported in the literature for children with micropenis who were raised as male).

⁶³ Cloacal exstrophy is a condition in which the child's perineum and sometimes lower abdomen is split down the midline, bifurcating and exposing both the bladder and genitals. The phallus is not only bifurcated, but also often quite small. See, e.g., John P. Gearhart, *The Bladder Exstrophy-Epispadias-Cloacal Exstrophy Complex*, in PEDIATRIC UROLOGY 539-40 (John P. Gearhart et al., eds. 2001).

⁶⁴ Diamond, *supra* note 22, at 447.

⁶⁵ Beh & Diamond, *supra* note 3, at 26 n.124 (quoting *Surgery May be Hasty for Unclear Gender Intersex*, SCI. LETTER, Mar. 15, 2005, at 989).

⁶⁶ Diamond, *supra* note 22, at 448.

However, there have been few other recent changes in the standard of care, other than perhaps generally to err on the side of assigning gender based on the child's genotype and gonadal sex.⁶⁷ The problem is that there is little consensus among researchers with respect to other long-term surgical outcomes. Some researchers, most notably Sarah Creighton, Naomi Crouch, Catherine Minto and other colleagues at the University College London Hospitals in England, have found that a select sub-sample of individuals with CAH who had early cosmetic genital surgery experienced decreased sensation and had sexual problems.⁶⁸ Others, such as Lieselotte Frost-Arner and her colleagues at the University of Malmo in Sweden, found no significant discrepancy between the clitoral sensitivity of women with CAH who had undergone one clitoral reduction surgery in their childhoods and women without CAH who had no genital surgeries.⁶⁹ With respect to women with complete androgen insensitivity syndrome (CAIS)⁷⁰ Catherine Minto and her colleagues found the vast majority—90%—of their study population experienced sexual problems such as reduced sexual frequency and difficulty regarding vaginal penetration.⁷¹ Amy Wisniewski and her colleagues, on the other hand, found most—78%—of the CAIS women in their study population to be satisfied with their sexual function.⁷² Over 70% reported a libido of average strength or stronger, and an even greater number reported an ability to experience orgasms.⁷³ Similar discrepancies and inconclusive results hold with respect to studies of long-term surgical results in other intersex conditions.⁷⁴ There simply are few definitive results coming from a variety of research groups that would suggest that a given surgical practice should end.

The variability in results does not counsel a ban on early surgeries. It does not suggest, either, that allowing parents to consent to such surgeries violates children's human rights. Rather, it counsels caution. It further underscores the necessity of providing parents with full information about potential surgical

⁶⁷ *Id.* For example, 99% of the pediatric urologists in the same study cited above would assign the 46XX CAH infant with severe virilization as a girl (93% of the study group would also seek to perform cosmetic surgery on the child's genitals before the age of 18 months). *Id.* at 447.

⁶⁸ See, e.g., Naomi Crouch et al., *Genital Sensation After Feminizing Genitoplasty for Congenital Adrenal Hyperplasia: A Pilot Study*, 93 BRIT. J. UROLOGY INT'L 135 (2003). The study looked at data from only six of the twenty women who agreed to participate. Unfortunately, outcomes for the full group appear not to have been published.

⁶⁹ Frost-Arner et al., *supra* note 10, at 356.

⁷⁰ In CAIS, a child with a 46,XY genotype has no sensitivity to androgens, and hence develops phenotypically as a female, at least with respect to external genitalia and secondary sex characteristics. However, the child's gonads are testes, rather than ovaries, and the child lacks a uterus, fallopian tubes and cervix. See Forest, *supra* note 20, at 643.

⁷¹ Catherine Minto et al., *Sexual Function in Women with Complete Androgen Insensitivity Syndrome*, 80 FERTILITY STERILITY 157 (2003).

⁷² Amy Wisniewski et al., *Complete Androgen Insensitivity Syndrome: Long-Term Medical, Surgical, and Psychosexual Outcome*, 85 J. CLINICAL ENDOCRINAL. METAB. 2664 (2000).

⁷³ *Id.*

⁷⁴ See generally, e.g., *id.*; Stikkelbroeck et al., *supra* note 10; William G. Reiner & John P. Gearhart, *Discordant Sexual Identity in Some Genetic Males with Cloacal Exstrophy Assigned to Female Sex at Birth*, 350 NEW ENG. J. MED. 333 (2004); Bradley, *supra* note 61.

outcomes, particularly where the data is varying or unsettled, if the subject of early cosmetic genital surgeries is broached. The fact is a number of long-term studies find that a majority of their study populations are largely satisfied in adulthood with the appearance and function of their genitals.⁷⁵ This is at odds with the assertion, implicit in a number of articles in legal literature, that most people with intersex conditions who had early genital surgeries are unhappy with the results.⁷⁶ If the results were uniformly poor with respect to all genital surgeries for all intersex conditions, there might be a strong ground for a legal ban if the standard of care didn't quickly change.⁷⁷ As it is, however, the data in most instances do not uniformly support such a ban.⁷⁸

B. Beh and Diamond's Approach

The variable long-term results for surgical outcomes in many intersex conditions also militate against Hazel Glenn Beh and Milton Diamond's approach to the issue. They suggest adopting Jennifer Rosato's 2000 proposal for identifying and dealing with parental conflicts of interest in general medical decision-making for children.⁷⁹ Rosato proposes basing authority for such decision-making in bioethical principles rather than principles traditionally underlying the parent-child relationship.⁸⁰ This would give parents less deference in certain circumstances than the law typically has provided to them, but more deference in others.⁸¹

Rosato suggests that parental decision-making power should be limited where certain types of conflict exist between the parents' interests and the child's interests. According to Rosato, such conflicts exist, for example, where "the decision-maker makes treatment decisions that fall outside the range of reasonableness; where extraordinary medical treatment is involved; or where the treatment decision involves a countervailing constitutional right of the patient that, when exercised, is likely to interfere with the family member's decision."⁸² Beh

⁷⁵ See, e.g., Frost-Arner et al., *supra* note 10, at 358; Wisniewski et al., *supra* note 10, at 2497; N.M. Stikkelbroeck et al., *supra* note 10; Thomas S. Vates et al., *Functional, Social and Psychosexual Adjustment After Vaginal Reconstruction*, 162 J. UROLOGY 182 (1999); Kurt Newman et al., *Functional Results in Young Women Having Clitoral Reconstruction as Infants*, 27 J. Pediatric Surgery 180 (1992).

⁷⁶ See, e.g., Erin Lloyd, *From the Hospital to the Courtroom: A Statutory Proposal for Recognizing and Protecting the Legal Rights of Intersex Children*, 12 CARDOZO J.L. & GENDER 155, 181 (2005); Bird, *supra* note 2, at 75-76; Morgan Holmes, *Distracted Attention: Intersexuality and Human Rights Protections*, 12 CARDOZO J.L. & GENDER 127, 133 (2005); Haas, *supra* note 8, at 48

⁷⁷ For example, one could plausibly argue for a ban on clitoridectomies in those countries in which they still are used in cosmetic genital surgeries. See *supra* note 57.

⁷⁸ This excerpt, for example, data concerning clitoridectomies as discussed above. See *supra* note 9 and associated text.

⁷⁹ Beh & Diamond, *supra* note 3, at 26.

⁸⁰ Jennifer Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 TEMPLE L. REV. 1, 3-4 (2000).

⁸¹ *Id.* at 68.

⁸² *Id.* at 43.

and Diamond use Rosato's framework to argue that early cosmetic genital surgeries implicate each one of these conflicts: They are "unreasonable, extraordinary medical intervention[s] that impact significant constitutional interests of the child."⁸³

Unfortunately, they take this conclusion largely for granted. With regard to reasonability, Rosato argues that

[u]nreasonableness should not be found simply because a doctor disagrees with the family's view of the patient's best interests. To be unreasonable, the decision regarding treatment must be contrary to what most decision-makers would decide in the same situation. In other words, it must be against the prevailing social consensus.⁸⁴

Beh and Diamond observe that "the surgery might not meet Rosato's concept of unreasonableness because while the surgery is controversial, it remains for the time being an accepted medical practice among a minority of physicians."⁸⁵ For support, Beh and Diamond cite to a study, mentioned above, that found that approximately two-thirds of the pediatric urologists surveyed would assign a child with a 46,XY karyotype who has cloacal exstrophy as male rather than as female.⁸⁶

There are two problems with Beh and Diamond's reliance on this study. First, the quoted finding concerns gender assignment, not surgery. Beh and Diamond fail to note that the study assumed that 100% of the physicians surveyed would perform surgery on that child's genitals in infancy.⁸⁷ Second, they fail to mention that the same study also found that 93% of the same group would perform cosmetic genital surgery on a female with CAH before the child was eighteen months old.⁸⁸ Accordingly, in neither case was surgery the "minority" option. Rather, it was unquestionably what the vast majority of surveyed pediatric urologists – who nevertheless represent only one group among many potential "decisionmakers" in this context for the purpose of Rosato's test – believed to be appropriate care.

The issue of "extraordinary medical treatment," does not come out quite the way Beh and Diamond say. According to Rosato's paradigm, interventions such as sterilization and organ donation typify this sort of extraordinary medical treatment to which the ability of parents to consent, without third-party review, should be constrained.⁸⁹ Sterilization has been cited as one of the common crimes

⁸³ Beh & Diamond, *supra* note 3, at 26-27 (footnotes omitted).

⁸⁴ Rosato, *supra* note 80, at 44-45.

⁸⁵ Beh & Diamond, *supra* note 3, at 26. This takes for granted the notion that "most decision-makers" in Rosato's context are physicians. However, Rosato does not limit her universe of decision-makers in this way; rather, she speaks of the "prevailing *social* consensus," not "medical consensus." Rosato, *supra* note 80, at 45.

⁸⁶ Beh & Diamond, *supra* note 3, at 26 (quoting *Surgery May Be Hasty for Unclear Gender Intersex*, SCI. LETTER, Mar. 15, 2005, at 989, available at 2005 WLNR 3750081).

⁸⁷ Diamond, *supra* note 60, at 447. This is because the nature of the condition requires surgical attention, irrespective of any issues involving surgical sex assignment.

⁸⁸ *Id.*

⁸⁹ Rosato, *supra* note 80, at 45.

against people with intersex conditions.⁹⁰ Yet sterilization is *not* applicable to most instances of intersex surgeries. Since at least 2000, when new AAP guidelines came out regarding management of intersex issues, physicians have increasingly considered the future fertility of patients of all karyotypes in determining sex assignment and have increasingly sought to preserve fertility.⁹¹ Thus, in most cases the debate is not about removal of the possibility of procreation. Instead, the primary issue most often involves cosmetic appearance.

If cosmetic intersex surgeries that do not diminish fertility should be banned, what happens to parental ability to consent to other “extraordinary” cosmetic surgeries, such as those on congenital limb malformations or cleft lips? The latter conditions are rare.⁹² Surgeries for them change as new techniques are developed, and as new studies find problems with prior treatment approaches, and find better successes with new treatments.⁹³ Are such surgeries so “extraordinary” that parental decision-making concerning them should be constrained? They arguably would be under Beh and Diamond’s approach.

But such surgeries don’t implicate gender, one might respond. Certainly one can dispute this claim: although this is sometimes debated in the medical literature,⁹⁴ the shape, structure, or even type of genitals one has does not, in itself, determine one’s gender.⁹⁵ Yet even if one accepts the claim as true, gender is but one integral aspect of personal identity. One’s appearance – particularly that of one’s face – is another.⁹⁶ Who is to say which of them is more fundamental than

⁹⁰ See, e.g., *supra* note 19-22 and associated text.

⁹¹ See, e.g., Diamond, *supra* note 22; Am. Acad. of Pediatrics, *supra* note 20.

⁹² According to the Centers for Disease Control, cleft defects occur in as many as one in 700 births worldwide. See Centers for Disease Control and Prevention, *Birth Defects: Frequently Asked Questions*, available at <http://www.cdc.gov/ncbddd/bd/faq1.htm> (last viewed Aug. 9, 2006). Among the most common—though still rare—defects include heart defects—one out of every 100–200 births—and neural tube defects—one out of every 1,000 births. *Id.*

⁹³ See, e.g., John B. Mulliken & Dolores Martínez-Peréz, *The Principle of Rotation Advancement for Repair of Unilateral Complete Cleft Lip and Nasal Deformity: Technical Variations and Analysis of Results*, 104 *PLASTIC & RECONSTRUCTIVE SURGERY* 1247, 1248 (1999) (describing a fifteen year history of using trial and error to modify and improve techniques for reconstructing cleft lips).

⁹⁴ See, e.g., C. Nihoul-Fékété, *Does Surgical Genitoplasty Affect Gender Identity in the Intersex Infant?*, 64 *HORMONE RESEARCH* 23 (2005).

⁹⁵ As is clear from reports in the literature describing the rejection by some intersex people of their surgically assigned gender and assumption of a different gender, one’s gender does not necessarily correspond with the appearance of one’s genitals. See, e.g., Tom Mazur, *Gender Dysphoria and Gender Change in Androgen Insensitivity or Micropenis*, 34 *ARCHIVES OF SEXUAL BEHAVIOR* 411, 414 (2005) (finding that only nine out of ninety-nine individuals diagnosed with PAIS in the study group self-reassigned their gender later in life, and that none of the subjects with CAIS or micropenis self-reassigned later in life); Peggy T. Cohen-Kettenis, *Gender Change in 46,XY Person with 5 α -Reductase-2 Deficiency and 17 β -Hydroxysteroid Dehydrogenase-3 Deficiency*, 34 *ARCHIVES OF SEXUAL BEHAVIOR* 399, 407 (2005) (finding that “about half of the persons with female appearing external genitalia developed a male gender identity . . . and about half of the persons with genital ambiguity developed a female gender identity, suggesting that genital appearance at birth does not determine psychosexual outcome in a consistent way”) (citation omitted).

⁹⁶ Cf. Agneta Marcusson et al., *Quality of Life in Adults with Repaired Complete Cleft Lip and Palate*, 38 *CLEFT PALATE CRANIOFAC. J.* 379 (2001) (finding a self-rated, significantly lower quality of life in adults with repaired complete cleft lips and palates, as compared with a control group of

the other? Should parents and guardians therefore be prohibited from consenting to any and all surgeries that might alter their child's personal identity in some significant respect? One could propose reasonable arguments in the affirmative, but one should also be clear about the claim's broader implications before doing so.

Constitutional issues are arguably an even harder case for Beh and Diamond. While the Supreme Court has found the Constitution to fundamentally protect certain procreational rights,⁹⁷ as well as certain associational rights regarding sex,⁹⁸ it would be difficult to argue that those rights extend to "self-identity" and "sexuality," in forms that would arguably make cosmetic genital surgeries unconstitutional. To extend these cases to issues involving intersex conditions, one would likely have to claim that a proposed cosmetic genital surgery would deny to a person his or her sexuality per se or certain per se associational rights regarding sexual conduct, rather than "merely" potentially impacting the quality of his or her sexuality.⁹⁹ Among other issues, one would need to get over the hurdle that physicians, who would likely qualify under present rules in most jurisdictions as medical experts on the subject, widely regard certain forms of intersex surgeries as making sexual relations possible, where they would supposedly not otherwise be.¹⁰⁰ While there arguably exists a constitutional right to avoid unwanted medical treatment—in addition to the strongly recognized common law one¹⁰¹—this right generally falls back on parents or guardians with respect to children, leading us back to an informed consent analysis.¹⁰²

The surgeries implicate social issues more than anything else. These issues do not merely involve matters of gender, but rather concern stigma. According to Brenda Major and Laurie T. O'Brien, "people who are stigmatized have—or are believed to have—an attribute that marks them as different and leads them to be devalued in the eyes of others."¹⁰³ The features that are regarded as a mark of stigma are generally defined by the more powerful groups within a given society or culture.¹⁰⁴ "[S]tigma exists when labeling, negative stereotyping, exclusion, discrimination, and low status co-occur in a power situation that allows these

individuals who never had cleft lip or palate).

⁹⁷ See, e.g., *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Roe v. Wade*, 410 U.S. 113 (1973); *Carey v. Population Services Intl*, 431 U.S. 678 (1977); *Planned Parenthood of Southeastern Penn. v. Casey*, 505 U.S. 833 (1992).

⁹⁸ See, e.g., *Lawrence v. Texas*, 539 U.S. 538 (2003); *Loving v. Virginia*, 388 U.S. 1 (1967); *McLaughlin v. Florida*, 379 U.S. 184 (1964).

⁹⁹ Cf., *Lawrence v. Texas*, 559 U.S. at 578.

¹⁰⁰ See, e.g., Peter A. Lee et al., *Consensus Statement on Management of Intersex Disorders*, 118 PEDIATRICS e488 (2006), available at: <http://www.pediatrics.org/cgi/content/full/118/2/e448> (discussing surgical outcomes and rationales, and social and cultural factors).

¹⁰¹ See, e.g., *Washington v. Glucksberg*, 521 U.S. 702, 720, (1997).

¹⁰² See *supra*, notes 42-56, 79-93 and associated text.

¹⁰³ Brenda Major & Laurie T. O'Brien, *The Social Psychology of Stigma*, 56 ANN. REV. PSYCHOLOGY 393, 395 (2005).

¹⁰⁴ *Id.*

processes to unfold.”¹⁰⁵ Stigma is a significant force in most, if not all, societies.¹⁰⁶

It may be that issues involving stigma, as much as anything else, can explain the reason that the parents in the CAH study, discussed above, would agree to cosmetic genital surgery on their daughters even if they knew surgery might result in diminished genital sensitivity.¹⁰⁷ Parents generally want their children to “fit in.” This is why, for example, it seems almost simply like common sense that parents would have a child’s cleft lip repaired. To allow the child to remain with his or her condition, particularly because it concerns the face, would subject the child to likely stigma. On the other hand, much like the genital surgeries in question, surgery for cleft lip changes a child’s appearance.¹⁰⁸ The results often can only approximate “normal,” not actually achieve it.¹⁰⁹ Repairs can require several revisions during childhood, as the first surgery is not always fully successful.¹¹⁰ Nevertheless, it would be unlikely that many would seriously advocate putting an end to cleft lip surgeries in childhood, on the ground that such surgeries violate informed consent ideals or human rights law. Why, then, should it automatically be any different for cosmetic genital surgeries for children with intersex conditions?

CONCLUSION

Once again, the foregoing is *not* to say that cosmetic genital surgeries should always or even ever be carried out on children with certain intersex conditions.¹¹¹ Rather, it is to suggest the following: First, with the possible exception of cases in which viable gonads would be removed, it is unlikely that most cosmetic genital surgeries would meet any of the tests Beh and Diamond propose, using Rosato’s paradigm, for removing certain medical decisions from parental discretion. The evidence and law simply do not support such a conclusion at present. Second, a U.S. court examining informed consent issues would likely take the social matters discussed above into account, whether knowingly or unconsciously.¹¹² The strength of convention should not be underestimated in this regard. Accordingly, it

¹⁰⁵ *Id.*

¹⁰⁶ *Id.*

¹⁰⁷ See *supra*, notes 51, 53 and associated text.

¹⁰⁸ See, e.g. John B. Mulliken et al., *The Principle of Rotation Advancement for Repair of Unilateral Complete Cleft Lip and Nasal Deformity: Technical Variations and Analysis of Results*, 104 PLASTIC & RECONSTRUCTIVE SURGERY 1247 (1999). See also M. Gussy & N. Kilpatrick, *The Self-Concept of Adolescents with Cleft Lip and Palate: A Pilot Study Using a Multidimensional/Hierarchical Measurement Instrument*, 16 INT. J. PEDIATRIC DENTISTRY 335 (2006).

¹⁰⁹ See, e.g., Gussy & Kilpatrick, *supra* note 108.

¹¹⁰ See, e.g., Mulliken, *supra* note 108.

¹¹¹ It is absurd to claim that those of us who do not presently support a ban on early cosmetic genital surgeries for people with certain intersex conditions are therefore in favor of such surgeries. See, e.g., Beh & Diamond, *supra* note 3, at 20.

¹¹² See, e.g., Flatt ex. rel. Flatt v. Kantak, 687 N.W.2d 208, 224–25 (N.D. 2004) (refusing to find an equal protection violation in the failure of North Dakota’s statute criminalizing only female circumcision).

is dubious whether throwing the issue to the courts would yield any “better” results with respect to early surgeries than would leaving the matter in the hands of parents,¹¹³ particularly if significant improvements were more universally implemented in the information and support that health care providers give to parents.¹¹⁴ Third, and more broadly, the social issues implicated in the discussion go far beyond the issue of early cosmetic genital surgeries. Those of us who are interested more generally in such issues would do well not to ban early surgeries as a means, for example, of expanding space for those whose gender or sexual identity does not fall within the current range of what is considered “typical.” Rather, by seeking expanded space for those who differ from the present norm, we may in turn expand space for the intersexed.

¹¹³ See, e.g., Laura D. Hermer, *Midwifery: Strategies on the Road to Universal Legalization*, 13 HEALTH MATRIX 325, 357–59 (2003) (discussing court deference to physician’s opinions in the context of litigation concerning midwifery).

¹¹⁴ See, e.g., Claudia Kolker, *The Cutting Edge: Why Some Doctors Are Moving Away from Performing Surgery on Babies of Indeterminate Gender*, SLATE (2004), <http://www.slate.com/id/2102006/> (discussing Texas Children’s Hospital’s move to an interdisciplinary team approach that includes a psychologist, endocrinologist, urologist, geneticist and ethicist in counseling parents of intersex children).