Sterilization and Minors with Intersex Conditions in California Law

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[T]he right to procreate is more than a byproduct of a right of choice. Its roots go deeper; they are constitutional in the physical sense, implicating the individual’s rights to physical integrity and to retention of the biological capabilities with which he or she was born into this world.¹

INTRODUCTION

California once proudly led the country in sterilizations of mentally disabled people. In the first half of the twentieth century, this practice, inspired by the then socially acceptable “science” of eugenics, was considered progressive. Such sterilizations became common around the country and were authorized by state law in California and many other states.²

Now, of course, involuntary sterilization is recognized as a human rights violation. Most states that have considered the question have concluded that sterilization of an incompetent person requires court oversight and an individualized best-interest inquiry in order to protect the person’s fundamental right to reproductive freedom.³ California again leads the way, with some of the

³. Anne Tamar-Mattis, Exceptions to the Rule Curing the Law’s Failure to Protect Intersex

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most developed law in the nation protecting mentally disabled people’s reproductive rights.

However, an overlooked group still faces involuntary sterilization. Infants and young children born with intersex conditions—congenital variations of the genitals, chromosomes, or internal sex organs⁴—frequently undergo medically unnecessary sterilization as part of treatment intended to make their appearance match their assigned sex, privileging a normative model of anatomy over the ability of these children to later reproduce. These children are not receiving the protection that is standard for other incompetent patients who face sterilization. Doctors, hospitals, and parents are therefore vulnerable to later lawsuits by a child with an intersex condition on whom they performed or authorized procedures that left the child sterile. This is a nationwide problem. However, California is well positioned to address the situation, as existing legal structures provide a strong and constitutionally sound framework for making such decisions in the best interest of the child. Once again, California can show leadership in protecting the rights of a vulnerable population.

I. STERILIZATION AS A BYPRODUCT OF “NORMALIZATION” OF CHILDREN WITH INTERSEX CONDITIONS

The term “intersex” encompasses many different medical conditions. What they have in common is some congenital atypicality in the child’s reproductive anatomy, sometimes visible at birth and sometimes discovered later. For example, a child may be born with “ambiguous” genitals that are not easily identifiable as male or female, with female-appearing genitals and an “enlarged” clitoris, or male-appearing genitals with a “micropenis.” A child may appear typically female at birth, but have XY chromosomes (a pattern more common in males) and internal testes instead of ovaries. Sex chromosome patterns other than the common XX and XY are possible, including XO, XXY, XYY, and others. Some children are born with both ovarian and testicular tissue in the gonads.⁵

When a child is born with an intersex condition, medical providers generally act quickly to assign a sex of rearing.⁶ This urgency is based on the

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4. An estimated one in 2,000 babies is born with a reproductive or sexual anatomy and/or chromosome pattern that doesn’t seem to fit typical definitions of male or female. The conditions that cause these variations are sometimes grouped under the terms ‘intersex’ or ‘DSD’ (Differences of Sex Development). These conditions include androgen insensitivity syndrome, some forms of congenital adrenal hyperplasia, Klinefelter’s syndrome, Turner’s syndrome, hypospadias, and many others.


5. Peter Lee et al., Consensus Statement on Management of Intersex Disorders, 91 ARCHIVES OF DISEASE IN CHILDHOOD 554–63 (2006) [hereinafter Consensus Statement].

6. This decision used to be based primarily on surgical convenience, i.e., whether it would be
sense that “initial gender uncertainty is unsettling and stressful for families” and, perhaps, for physicians. While genital surgery is not necessary for social or legal gender assignment, it is common to perform surgery in infancy or early childhood in an attempt to make the genitals appear “normal” for the assigned sex. Surgeons also remove structures that are not consistent with the sex assignment, such as testes in a child assigned female or a uterus in a child assigned male.

With a few exceptions, some noted below, these procedures are not medically necessary. They are also highly controversial, as they can result in a range of problems with sexual and psychological function. Treatments following surgery often continue over years and can be highly traumatic, and the necessity of most such genital surgery is not well supported by medical evidence. Adult patient advocacy groups have widely called for such procedures to be postponed until the patient is old enough to participate in the decision. Nonetheless, many caring doctors continue to recommend these procedures in the sincere belief that the child will be better off with a more typical genital appearance.

A significant portion of the time, these surgeries can result in sterilization. One common example is where a child is assigned a female gender but has viable testes. Doctors often recommend removal of gonads in infancy or before puberty in this situation to prevent a child who is being raised as a girl from developing masculine secondary sex characteristics. More rarely, a child with easier to surgically alter the genitals to a typical male or typical female appearance. Increasingly, modern standards of care base the decision on predictions about whether the child is more likely to develop a male or female gender identity, depending on the specific medical condition. However, these predictions can be wrong, with rates of failure running from 5–25 percent in some intersex conditions.

7. Consensus Statement, supra note 5, at 556.
9. Interestingly, while there is widespread belief among physicians treating these conditions that normal genital appearance is critical, there is little agreement about what constitutes “normal” infant genitalia. KATRINA KARKAZIS, FIXING SEX: INTERSEX, MEDICAL AUTHORITY, AND LIVED EXPERIENCE 134–35 (2008). Depending on the source, for example, an adequate infant penis must be at least 1.5, 1.9, 2, or 2.5 cm. Id. at 101–02. Standards for acceptable female genitals are even more vague, and surgical decisions are often based on the surgeon’s subjective judgment about what looks “good.” Id. at 150–52.
10. Elective genital restructuring on children raises significant legal and human rights questions that the author has addressed elsewhere. See Tamar-Mattis, supra note 3. This paper focuses only on situations where sterilization is involved, although much of the analysis could apply to the impact of non-sterilizing genital restructuring on the child’s privacy interests.
11. One intersex adult recalls this experience as a teen: “When I went to the urologist’s office [for post-surgical vaginal dilation], I figured he’d realized that every time he was inserting his finger, the opening wasn’t getting any bigger. He gets to the fourth one and manages to insert it. What I wanted to do was scream out in pain, but I didn’t, because I had always been told you just don’t do that.” Karkazis, supra note 9, at 224.
12. See generally Karkazis, supra note 9.
13. This can happen in cases of partial androgen insensitivity, 5-alpha reductase deficiency, bladder exstrophy with aphallia, and some other conditions. See Consensus Statement, supra note 5, at
male-appearing genitals will be raised as a male, but will be discovered later to have a uterus and ovaries. In such cases, a hysterectomy may be recommended before puberty to prevent the child from becoming distressed by the onset of menses. Not all children with intersex conditions are sterilized. Some are born infertile, and some retain fertility after medical treatment. There are also some situations that fall in a “gray area.” In some such cases, removal of gonads is medically urgent due to high risks of cancer, but in others it could be safely postponed until after puberty or the actual risk of cancer is fairly low. Any time potential fertility is removed by an elective medical procedure, however, the fundamental right to control reproduction is compromised.

In spite of the widespread controversy and the absence of strong evidence of medical benefit, doctors in California seem to rely on the consent of the parents for legal authorization when they perform these procedures on children with intersex conditions. In many such cases, it is not clear that parental consent for sterilization is valid without court oversight.

II. CALIFORNIA’S HISTORICAL STRUGGLE WITH STERILIZATION OF DEVELOPMENTALLY DISABLED PEOPLE

In 1909, California passed its first law authorizing the sterilization of developmentally disabled people and then proceeded to lead the nation in the number of people sterilized. Progressive reformers led these efforts, and, like doctors treating children with intersex conditions today, many believed they were acting in their patients’ best interest. In 1978, however, as a result of growing public awareness of the rights of the disabled, California passed laws that effectively barred such sterilizations. Following a wave of cases nationwide recognizing the need for judicial oversight to protect the

556–57.

14. This can happen in cases of congenital adrenal hyperplasia, although most children with this condition born in the United States are identified shortly after birth and raised as female. See Christopher P. Houk & Peter A. Lee, Approach to Assigning Gender in 46,XX Congenital Adrenal Hyperplasia with Male External Genitalia Replacing Dogmatism with Pragmatism, 95 J. CLINICAL ENDOCRINOLOGY & METABOLISM 4501, 4507 (2010).

15. For example, a child might be born with the potential for fertility with appropriate medical intervention, but that potential may be taken away as a result of childhood procedures. In some cases there is a risk of gonadal cancer, and preventive removal is recommended.


17. Failure to conduct adequate follow-up studies has resulted in significant gaps in knowledge about the outcomes of treatment across a variety of measures. Consensus Statement, supra note 5, at 558–60. This makes it impossible to state how many children with intersex conditions are fertile, how many are sterilized, and how many of these sterilizations might be justified by significant cancer risk.


20. Lombardo, supra note 2, at 30–32. For example, institutions that housed mentally disabled people believed they could allow greater freedom to patients who were sterilized. Buck v. Bell, 274 U.S. 200, 205–06 (1927) (Holmes, J.).

fundamental rights of incompetent patients facing sterilization, the Supreme Court of California found that a complete bar to sterilization of the developmentally disabled violated their constitutional right to privacy, which encompasses procreative choice in both directions.\(^{22}\) The Court indicated that conservators must be able to consent to sterilization procedures for conservatees, albeit with judicial oversight and procedural requirements in place, to protect the disabled person’s best interests and fundamental rights.\(^{23}\)

Subsequently, the legislature passed a detailed statutory scheme permitting sterilization of developmentally disabled people with strong procedural protections.\(^{24}\) Conservators must prove beyond a reasonable doubt several factors before a court can authorize sterilization.\(^{25}\) For example, the conservatee’s inability to give consent must be permanent.\(^{26}\) Several portions of the statute also direct courts to look at whether less invasive or less permanent procedures would be warranted.\(^{27}\) The conservatee must be represented by counsel, who is required to oppose the petition.\(^{28}\) Furthermore, there is an automatic appeal.\(^{29}\) These provisions have been effective for many years and have been found to pass constitutional muster in protecting both the constitutional rights and the best interests of incompetent patients.\(^{30}\)

III.

A VIABLE FRAMEWORK FOR PROTECTION OF MINORS WITH INTERSEX CONDITIONS

There is no statute or case law in California that directly addresses the sterilization of children with intersex conditions or any other minor.\(^{31}\) However, the fundamental right to reproductive freedom is based in the state and federal constitutions, not in statutory text.\(^{32}\) It seems highly unlikely that a court would find this right should receive less protection simply because the minor asserting it is not developmentally disabled. Minors, like adults, have a constitutionally

\(^{22}\) Id. at 772–777.

\(^{23}\) Id. at 776–77.

\(^{24}\) Conservatorship of Angela D., 83 Cal. Rptr. 2d 411, 417 (1999).


\(^{26}\) PROB. § 1958(a).

\(^{27}\) See, e.g., PROB. §§ 1955(b) (requiring that the person be examined by two professionals who in their report must indicate if they think another alternative would be warranted), 1958(e) (requiring the court to find beyond a reasonable doubt that all less invasive procedures are unworkable), 1958(g) (stating that the current state of medical knowledge does not seem to indicate that sterilization may not soon be unnecessary).

\(^{28}\) Angela D., 83 Cal. Rptr. 2d at 420-21.

\(^{29}\) PROB. § 1962(b).

\(^{30}\) Angela D., 83 Cal. Rptr. 2d at 422-23.

\(^{31}\) Sections 1950–1969 only apply to developmentally disabled adults. PROB. § 1952 (defining procedure to authorize conservator “to consent to the sterilization of an adult”). Title 22, sections 70707.1–70707.9 of the California Code of Regulations, which address procedural requirements for sterilization of competent adult women, does not apply to unemancipated minors and does not address the question of parental consent. CAL. CODE REGS. tit. 22, §§ 70707.1–70707.9 (2006).

protected right to reproductive freedom in California, and other state courts have concluded that parental authority generally does not include the ability to consent to elective sterilization. When there is a difficult decision to make about non-necessary sterilization, a court is likely to find that a child has a right to judicial review of the parents’ decision.

Of course, parents do generally have a constitutionally protected right to make medical decisions for their child, especially those that are medically necessary. However, courts have limited parents’ rights to make some decisions for their children, notably in situations involving reproductive rights. In American Academy of Pediatrics v. Lungren, one of California’s leading cases addressing the reproductive rights of minors, the court upheld a minor’s right to make decisions about abortion despite the fact that parents can control her decisions and limit her exercise of freedom in many other areas. In Lungren, the court was particularly concerned that a decision about abortion is irreversible and will impair the minor’s exercise of privacy rights throughout her life. Similarly, elective sterilization of a child with an intersex condition will permanently impair the minor’s exercise of privacy rights and therefore falls outside of normal parental authority.

Given the significant attention paid in California to involuntary sterilization, it is reasonable to wonder why doctors who perform these procedures on children with intersex conditions are not already routinely seeking court oversight, if only for their own protection should these patients later seek a legal remedy to the involuntary sterilization. One reason may be that these procedures, though not necessary to preserve life or health, have long been considered standard treatment of intersex conditions. However, the California Supreme Court has held that a minor’s “reasonable expectation of privacy” cannot be overcome solely by the existence of past practices, because that would “defeat the voters’ fundamental purpose in establishing a constitutional right of privacy.” This suggests that even a well-entrenched medical practice involving involuntary sterilization could still violate the California Constitution, which prioritizes the preservation of fundamental rights such as reproductive choice.

Another reason doctors fail to secure court oversight might be a belief that

33. Id. at 816. See also Planned Parenthood v. Danforth, 428 U.S. 52, 74 (1976) (“Constitutional rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults, are protected by the Constitution and possess constitutional rights.”).
35. “Parents during a child’s minority have the legal right (and obligation) to act on behalf of their child’s rights and interests,” Lungren, 940 P.2d at 815.
36. Id. at 815–16.
37. Id. (citing Bellotti v. Baird, 443 U.S. 622, 642 (1979) (Powell, J., plurality opinion)).
38. Lungren, 940 P.2d at 817.
parental consent is adequate any time sterilization is not the main goal but a secondary effect of treatment. This is commonly the case with procedures addressing intersex conditions. Providers do not set out to render their patients infertile. Rather, they are trying to improve genital appearance, prevent the emergence of secondary sex characteristics that they believe will be undesirable—such as growth of facial hair in a child assigned female or menstruation in a child assigned male—and, in certain instances, reduce risk of cancer. Because there is a treatment goal, providers may not think of the procedure as sterilization. This belief has not been tested in court or addressed by statute in California. Furthermore, these treatment goals, while benevolent, may not rise to the level of urgency that would justify permanent restriction of a child’s reproductive freedom. It may be that parental consent is adequate to authorize sterilization when such treatment is urgently necessary to preserve life or health, as in the case of active testicular cancer. It is not at all clear that parental authority to consent to medical procedures includes situations where sterilization is proposed as an elective procedure, where the procedure could be safely postponed until the child can consent, or where less-invasive alternatives are available—situations that are common in intersex cases.

Indeed, some providers may not think of the procedures they are performing as sterilizations when the child’s capacity for fertility does not match the gender assignment. For example, if the child is assigned female, especially if she is older and seems content with that assignment, it may not occur to her doctor or her parents that she would have any use for testes. However, if she has testes that could produce viable sperm (or might gain that capacity through future medical advances), this may be her only route to biological parenthood. In such a situation, there may be difficult choices to

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40. These risks are sometimes significant, but other times are low enough that they may not justify sterilization in infancy. See, e.g., Houk & Lee, supra note 14, at 4507; Carla Murphy et al., Ambiguous Genitalia in the Newborn An Overview and Teaching Tool, 24 J. PEDIATRIC & ADOLESCENT GYNECOLOGY 236, 246 (2011).
41. See Consensus Statement, supra note 5, at 562 (noting that under United States law “[p]arental decisions are deferred to except in situations where potentially life saving treatment is withheld,” without addressing limitations on parental authority to consent to sterilization).
42. Medical providers may be familiar with Title 22, sections 70707.1–70707.9 of the California Code of Regulations, which contains special procedural requirements for sterilization of competent adult women beyond the normal requirements of informed consent, and seems to apply only to procedures which are “for the purpose” of sterilization. However, this statute does not apply to minors and does not address the question of parental consent. See Cal. Med. Ass’n v. Lackner, 124 Cal. App. 3d 28 (Cal. Ct. App. 1981).
44. For example, instead of removing gonads to prevent the emergence of potentially undesired secondary sex characteristics, medication can be used to delay puberty until the child is old enough to participate in the decision.
45. Interestingly, the inability to see sex-discordant fertility as fertility is reflected in the medical literature. See Consensus Statement, supra note 5, at 556–57 (“Available data support male rearing in all patients with micropenis, taking into account . . . the potential for fertility in patients reared male.”). Of course the patient’s potential for fertility is not affected by rearing. The buried
make at puberty involving weighing the risk of cancer and certainty of developing facial hair and other masculinized features against the potential for fertility. However, making these choices prematurely limits the child’s exercise of reproductive freedom as surely as if the child had a more “typical” body.

Finally, some providers may assume that court oversight is not necessary simply because they genuinely believe there is no question that they are acting in the child’s best interest. Although doctors and parents generally have the child’s best interests at heart, this decision will permanently impair the child’s ability to exercise a fundamental right, which differentiates it from other kinds of medical decisions. In the past, some doctors and parents who relied on parental consent alone for elective sterilization of developmentally disabled children were later found liable for violating the child’s fundamental rights, even though such practices were common at the time of sterilization. Elective sterilization of an incompetent person requires additional procedural protections, regardless of the good intentions of caregivers.

IV. HOW MIGHT A CALIFORNIA COURT ANALYZE A MOTION TO AUTHORIZE SURGERY THAT WOULD RESULT IN STERILIZATION OF A CHILD WITH AN INTERSEX CONDITION?

As controversy grows over the medical treatment of children with intersex conditions, doctors and parents may begin to seek court approval of sterilization in order to shield themselves from future liability. A California court’s guiding standard should be the best interest of the child. In its search to find a constitutionally adequate process to govern performing sterilizing procedures on children with intersex conditions who are too young to comprehend the gravity of such a procedure, the court would most likely turn to the existing, well-tested statutory framework for sterilization of conservatees. While the statutory requirements of the California Probate Code only address sterilization of developmentally disabled adults, they represent the will of the legislature in an analogous situation. Further, courts have already found the procedural requirements of the probate code to pass constitutional muster.

Under a judicial remedy fashioned on this model, a person found competent to consent to the procedure him- or herself would not need to meet

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assumption is that a patient with this condition reared female will be infertile because her testes will be removed.

46. See, e.g., Lake v. Arnold, 232 F.3d 360, 374 (3d Cir. 1999) (holding the statute of limitations did not bar a mentally handicapped woman’s claim when she had been sterilized over twenty years earlier with her parent’s consent and prior to any holding that such sterilization was unconstitutional).

47. “This ‘best interests’ standard serves to assure that in the judicial resolution of disputes affecting a child’s well-being, protection of the minor child is the foremost consideration.” Johnson v. Calvert, 851 P.2d 776, 799–800 (Cal. 1993) (Kennard, J., dissenting) (pointing out prevalence of the best interest standard in cases involving child welfare).
other procedural requirements. If a sterilizing procedure is recommended to an older adolescent with an intersex condition, a court could determine that the minor is competent to consent or withhold consent. If the minor is very young or not yet competent to decide, the court would appoint counsel for the minor. In the case of an older pre-pubescent or pubescent child who might be able to express an opinion but is not yet mature enough to offer consent, the court would appoint counsel, take the minor’s opinion into consideration in making a best-interest analysis, and not order the procedure if the minor makes a “knowing objection.”

Counsel for the minor would be obligated to oppose the petition rather than making an independent best-interest determination. Presumably, the parents bringing the petition and the doctors recommending the procedure would present the opposing view. The court would also need to make several findings in order to authorize the sterilization, including that the patient could not make the decision him- or herself in the future, that less-invasive methods are unworkable, that looming scientific advances that could provide new options are unlikely, and that the patient has not knowingly objected to the procedure. There would be an automatic appeal.

Since it was written with developmentally disabled people in mind, there are parts of the statutory scheme that will not apply to the situation of a non-developmentally-disabled child or will not be necessary to meet constitutional requirements of adequate procedural protections. For example, the probate code sections seem to be written with the assumption that birth control is the primary reason for considering sterilization and therefore require a showing that the person is likely to engage in sexual activity in the near future. Prevention of pregnancy may be the primary benefit of a sterilizing procedure as envisioned by the drafters of the statute. However, in the case of a young child with an intersex condition, the anticipated benefits of the sterilizing procedure are different—as noted above, they may include prevention of presumably undesired secondary sex characteristics, improved genital appearance, or reduction of cancer risk. A court considering the underlying purpose of this procedural protection may require a showing that the minor is likely to realize the purported benefits of the medical procedure and that it could not be postponed.

Another section of the statutory model may need clarification in order to adapt it to the situation of children with intersex conditions. Section 1968 reads: “This chapter does not prohibit medical treatment or surgery required for

49. See PROB. § 1954.
50. See PROB. §§ 1957, 1958(h).
52. See PROB. § 1957(a–h).
53. See PROB. § 1962(b).
54. See PROB. § 1958(c).
other medical reasons and in which sterilization is an unavoidable or medically probable consequence, but is not the object of the treatment or surgery.” One way to read this section is that procedural protections are not necessary if prevention of pregnancy is not the object of the treatment, as is generally the case with intersex conditions. Another way to read it is that the procedural protections are required, but that the court shall not prevent medically necessary treatment even where all of the showings generally required for sterilization cannot be made. The first reading of section 1968, however, would essentially defeat the entire statutory scheme. It would frequently be possible to work around procedural requirements by coming up with some medical benefit of sterilization—prevention of menstrual cramps, for example—and claiming that it was the object of treatment. Thus, the second reading is the correct one. If medical treatment that would unavoidably result in sterilization is required, obviously it could be a decisive factor in a best-interest analysis. However, given the weighty constitutional interests at stake, an incompetent patient should have court oversight to ensure that such treatment truly is required and that the balance has been properly struck in the best-interests analysis. This reading is aligned with leading California cases regarding involuntary sterilization and it should apply whether the patient is a child or a developmentally disabled adult.

**CONCLUSION**

While there is a shameful history of eugenics in its past, California can rightly be proud of the leadership role it has played in defining and protecting the privacy rights of some of its most vulnerable citizens—minors and developmentally disabled adults. However, there remains an overlooked group of extremely vulnerable children in our midst, children born with atypical sex anatomy who remain subject to involuntary sterilization. California has already recognized that minors’ privacy rights trump parental authority when lifelong limitation of reproductive freedom is on the line. We have a well-developed and time-tested procedural framework for protecting both the reproductive rights and the best interests of incompetent patients who may benefit from sterilization. Adapting this framework to fit the situation of children with intersex conditions would protect them while also shielding their doctors and parents from future liability. Our history, and our humanity, demand no less of us.