

# **Jamie's Medical Care: An Ethics Primer for the Clinical Management of Intersex <sup>1</sup>**

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Ira and Karen are confronting a number of difficult decisions at a time when they most likely have not worked through their own disappointments and anxieties about having a child born with mixed gonadal dysgenesis. Of primary importance in this case is that Jamie does not face any immediate health risk attendant to being intersexed. It is, therefore, critical that Jamie's doctors not suggest a false sense of urgency which will cause Ira and Karen to make a hasty decision about genital surgery. Instead, as Ira and Karen acclimate to the diagnosis, they will be in a better position to make a decision which is based on their reasoned assessment of what is in Jamie's best interest.

It should be emphasized that Jamie, and not Ira and Karen, is the patient whose needs are of primary importance. However, Jamie is not able to give consent or otherwise participate in decisions concerning medical care. Thus, prior to Ira and Karen giving permission for any medical or surgical intervention, Jamie's physicians have an ethical obligation to ensure that Ira and Karen are provided with all of the following safeguards:

1. Complete information about Jamie's medical condition;
2. The opportunity to consult further with mental health professionals who are experienced in the clinical management of intersex;
3. Presentation of the alternative of making a tentative gender assignment, reinforced by dressing Jamie in clothing appropriate for such assignment, but delaying or foregoing genital surgery until Jamie's psychosexual orientation can be assessed, and Jamie can be an active participant in any medical decision-making;
4. Information concerning the risks and complications attendant to any surgical intervention, including the possible diminution in sexual sensation resulting from damage to clitoral nerve tissue, as well as later dyspareunia stemming from surgically created scar tissue in the genital region<sup>2</sup>;
5. Disclosure that no comprehensive retrospective studies establish any therapeutic benefit of surgery;

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<sup>1</sup>The author wishes to thank Shane Snowden, incoming chair of the University of California Gay Lesbian Bisexual Transgender and Intersex Association, and Professor Julie Greenberg of the Thomas Jefferson School of Law, whose valuable insights have informed this article.

<sup>2</sup>Schober, J.M: Long-Term Outcome of Feminizing Genitoplasty for Intersex. In P.D.E. Mouriquand (Ed.), *Pediatric Surgery and Urology Long Term Outcomes*. Philadelphia, Penn: W.B. Saunders, 2000.

6. Disclosure that current recommendations for treatment focus on the length of the phallus rather than on psychological outcome studies<sup>3</sup>;
7. Information that several pediatric endocrinologists and urologists have called for a moratorium on infant genital surgery until retrospective studies demonstrate that the benefits of surgery outweigh its potential consequences<sup>4</sup>;
8. Disclosure that the risk of intratubular germ cell neoplasia and other gonadal tumors is minimal in a child whose gonads are left intact prior to the completion of puberty<sup>5</sup>;
9. An explanation that any hormonal imprinting resulting from the gonads has likely already occurred, and that because the gonads will not be active again until later childhood or early puberty their retention will potentially allow Jamie to have a natural source of hormones if Jamie is ultimately reared male; and
10. Assurance that Jamie's ability to receive medical care is not dependent on Ira and Karen's consenting to surgery.

These ten safeguards are consistent with Policy Statement RE9510 "Informed Consent, Parental Permission, and Assent in Pediatric Practice" adopted by the American Academy of Pediatrics. These safeguards are also consistent with two recent decisions of The Constitutional Court of Colombia (SU-337/99, May 12 1999 and T-551/99, Aug 2, 1999) which specifically addressed the issue of parental "proxy" consent to genital surgery on their children. The Columbia Court held that that all information concerning the risks of surgery should be communicated on at least two separate occasions, over the course of several weeks, to ensure that the parents have a complete understanding of the nature and consequences of such surgery. Moreover, the Court deemed it is necessary for the risks of surgery to be summarized in writing. In this case, such written summary will also allow Ira and Karen to weigh their decision at home with the benefit of such information.

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<sup>3</sup> Dreger, A.D.: Ambiguous Sex'-or Ambivalent Medicine? Ethical Issues in the Treatment of Intersexuality, *Hastings Center Report* 28: 3 (1998): 24-36.

<sup>4</sup>See, e.g., Kipnis, K. & Diamond, M: Pediatric Ethics and the Surgical Assignment of Sex. *J. Clin. Ethics*, Vol 9, No. 4, Dec 1998; Wilson, B.E. and Reiner, W.G: Management of Intersex: A Shifting Paradigm. *J. Clin. Ethics*, Vol 9, No. 4, Dec 1998.

<sup>5</sup>Manuel M., Katayama K.P., Jones H.W. Jr: The age of occurrence of gonadal tumors in intersex patients with a Y chromosome. *Am J Obstet Gynecol* 124:293-300, 1976.

While not currently a formal requirement of informed consent, if Ira and Karen had not already been in touch with an appropriate intersex patient support or advocacy group<sup>6</sup>, Jamie's physicians should also have put them in touch with one.<sup>7</sup> Because Ira and Karen have accessed this resource, the support group will ideally connect them with adults who underwent similar surgical procedures as infants, as well as other parents who have been confronted with similar challenges. This will allow them to become informed "consumers" in making decisions about Jamie's medical care.

Beyond ensuring that the requirements of informed consent have been satisfied, Jamie's physicians also have an ethical responsibility to confront their own biases concerning the management of this case, particularly if they subscribe to a phallogentric paradigm of medical treatment. Such paradigm specifies that a male gender assignment will only be made if the newborn has a phallus which physicians believe will later be capable of intromission, generally interpreted to mean a stretched penile length in infancy of greater than 2.5 centimeters.<sup>8</sup> Any child unable to satisfy this standard is reflexively assigned female regardless of medicine's present inability to create a vagina free of surgical complications.<sup>9</sup> Moreover, while sexual functioning is the primary consideration for a male gender assignment, in making a female assignment such paradigm elevates the potential for fertility over how satisfactorily the surgically created vagina will function, or whether the child's capacity for orgasm will be impaired by surgery.<sup>10</sup> Overall, female gender assignments predominate, despite evidence that males with micropenis can enjoy a high quality of sexual functioning, while female assignments for such individuals may be unsatisfactory.<sup>11</sup>

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<sup>6</sup> In this case the parents can be referred to the Intersex Society of North America whose web address is [www.isna.org](http://www.isna.org), as well as to the XY/XO Support Group whose website is located at <http://www.geocities.com/xyxous>, and to the Ambiguous Genitalia Support Network, <http://www.jps.net/agsn>, a support group founded by the mother of a child born with ambiguous genitalia.

<sup>7</sup> American Academy of Pediatrics Policy Statement RE9958 "Evaluation of the Newborn With Developmental Anomalies of the External Genitalia" (hereinafter "Policy Statement RE9958") acknowledges "[M]ost genetic and endocrine centers are able to refer families to appropriate support groups."

<sup>8</sup> RE 9958 states "The size of the phallus and its potential to develop at puberty into a sexually functional penis are of paramount importance when one is considering male sex of rearing." See also Kessler, S: The Medical Construction of Gender: Case Management of Intersexed Infants. *Signs: Journal of Women in Culture and Society*, 16(1) (1990):3-26.

<sup>9</sup> Bailez, M.M., P Gearhart, P., Migeon, C. and Rock, J.: Vaginal Reconstruction After Initial Construction of the External Genitalia in Girls with Salt-Wasting Adrenal Hyperplasia. *J. of Urology* 148 (1992): 680-84; Schober, J.M., Long-Term Outcome of Feminizing Genitoplasty for Intersex.

<sup>10</sup> RE 9958 states "The presence of a capacious, low-lying vagina is advantageous if assignment as a female is being considered, but this alone is not of critical importance. A small, high-lying vagina presents more of a surgical challenge but this may be justified when such children are likely to be fertile."

<sup>11</sup> An outcome study of twenty adult males with micropenis who were actually reared male (without surgical intervention) but who would have been assigned female under the present standard of practice, reveals a satisfactory outcome. While six experienced teasing about their small penises, all of them reported

While the physicians in this case may be primarily concerned with Jamie's ability to achieve peer acceptance, the surgery is, by definition, cosmetic because it is not undertaken for Jamie's physical health. Interestingly, if Jamie had been born with a large nose, a medical recommendation of infant prophylactic rhinoplasty would be heretical, even if it could be shown that such surgery would prevent the child from later being teased in school. Yet Jamie's physicians' assurances (without benefit of supporting empirical data) that surgery offers psychological benefits to the patient and his or her parents, reinforces a cultural mandate at the expense of allowing Jamie to decide independently whether the such conformity is worth the risk of impaired sexual functioning. A recommendation favoring genital surgery also ignores the possibility that any attendant psychological benefit may be more than offset by the clear communication to Jamie that there was something shameful about Jamie's genitals in their natural state. Such shame is reinforced if, as is common medical practice, the truth about Jamie's being intersexed, and having been born with ambiguous genitalia, is withheld from Jamie in later childhood and adolescence.

Overall, it must be acknowledged that Ira and Karen are looking to Jamie's physicians for guidance at a time when they may be highly motivated to "normalize" their child's genital appearance in the short term without due regard for the long-term impact which their decision will have. Thus, it is incumbent upon Jamie's physicians to encourage Ira and Karen to seek counseling to sort out these various considerations. Moreover, to the extent Ira and Karen cannot agree on whether to forego surgical intervention, counseling may also help them reach consensus on whether to authorize such procedures. However, if following counseling they still cannot agree on how to proceed, it is imperative that Jamie's physicians not "take sides" with either parent. In such instance, because there is no immediate health risk to their patient, and because the requisite parental permission has not been obtained, Jamie's doctors should not perform surgery. Instead, the parent favoring surgical intervention can obtain, if appropriate, a court order mandating surgery. Such judicial intervention will protect the physician against potential liability to the parent who opposes such operation.

Regardless of the decision Ira and Karen make, Jamie's physicians have a wonderful opportunity to educate them about intersex and help them to develop a sufficient level of comfort with the diagnosis to allow them, in turn, to help Jamie cope with the challenges of being intersexed. Far more than by surgical intervention, the outcome in this case will be directly impacted by how well Jamie's physicians can work in tandem with Ira and Karen to assist them in communicating their love for, and acceptance of, their child.

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feeling male, and all had erections and orgasms. Nine had sexual intercourse satisfactory to themselves and their partners, seven were married or cohabiting, and still others were sexually active. Reilly, J.M. and Woodhouse, C.R.J. "Small penis and the male sexual role," *The Journal of Urology* 142 (1989): 569-572. Colapinto, J: The true story of John/Joan, *Rolling Stone* December (1997): 54.

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