

What is the agenda of the intersex patient advocacy movement?

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Today, almost a decade after the Intersex Society of North America was founded, many people still misunderstand what criticisms the intersex patient advocacy movement makes of standard practice, and what reforms we are asking for. I'm pleased to have this opportunity to provide a summary of our recommendations for patient-centered care, and to contrast them with the current state of medical practice.

- Intersexuality is primarily a problem of stigma and trauma, not gender.
- The child is the patient, not the parents.
- Professional mental health care is essential.
- Honest, complete disclosure is good medicine.
- All children should be assigned as male or female, without surgery.

Our program -- which includes diagnosis, sex assignment, peer and professional counseling, and offers cosmetic surgery to patients who are mature enough to make an informed decision -- cannot be characterized as "do nothing."

Intersexuality is primarily about stigma and trauma, not gender

Physicians and other helping professionals, the media, and the general public have typically interpreted intersexuality as being primarily a problem of gender.

At the Intersex Society we understand intersexuality primarily as an issue of stigma and emotional trauma. In our culture, sexual variation which blurs the line between male and female is stigmatized. Intersexuality is so highly stigmatized that, until recently, the phenomenon was little known outside related medical specialties. Thus, the birth of an intersex child is emotionally traumatizing: Parents are traumatized because the birth of a child with sexual ambiguity violates a deeply held world view, and because it elicits parental feelings of shame and guilt. Patients are traumatized because they are made to feel utterly unique, alone, and unacceptable. Not only patients and parents, but doctors as well are traumatized [1].

"After stillbirth, genital anomaly is the most serious problem with a baby, as it threatens the whole fabric of the personality and life of the person. The trauma of discovering a genital anomaly in the labour ward is great for both parents and doctor" [2].

John Hutson, MD

The traditional model of medical management has been based on the idea that patients can be helped to live a "normal" life if only their intersexuality is concealed. Intersexuality could be eliminated through a combination of "spin control" (concealing information about intersexuality) reinforced by early genital surgery and later exogenous hormones [3, 4].

This misplaced focus on gender distorts the perspective of clinicians in many ways that are harmful to patients. Intersex patients have frequently been subjected to repeated genital examinations, which create a feeling of freakishness and unacceptableness [5, 6]. Our criticisms of a misguided model of care have been dismissed by physicians who are unable to see intersex except through the lens of gender. Thus, Johns Hopkins urologist John Gearhart dismisses intersex patient advocates as "zealots," while Great Ormond Street urologist Philip Ransley writes us off as "green wellied loonies" [7, 8].

The child is the patient, not the parents

“This [ambiguous genitalia] is very distressing to the family, and surgery is available to make that appearance more acceptable” [9]
Great Ormond Street urologist Peter Cuckow

Remember that the intersex child, and not the parents, is the patient. Parents do need immediate and ongoing psychological support (both professional and peer support). Clinicians must distinguish between what the parents want and what the child needs. Unlike many other cases in which parents make medical decisions for their children, in intersex conditions the parents’ wishes often conflict with the child’s ultimate best interest. The Constitutional Court of Colombia examined this issue and has required the legal and medical communities to establish a new category of consent, “qualified, persistent informed consent,” intended to force parental decisions to take into account only the child’s interest [10, 11].

Professional mental health care is essential

Intersexuality requires a team approach, including a licensed mental health professional as a central member of the team. Though most clinicians agree that counseling is an important part of management, most clinicians also fail to provide their patients with counseling. In the summer of 2001 medical student Megan Curran surveyed the fifty pediatric endocrine fellowship programs in the U.S. and Canada [12]. These academic programs are teaching the next generation of pediatric endocrinologists, and their practice thus plays a large part in determining the standard of care for decades to come.

We received responses from 27 of the fifty institutions. All of these institutions see some intersex patients, but only 16 said they have a mental health worker available. Only five say they offer counseling after the initial diagnosis. Eleven said that they do or would offer referrals to counseling for intersex adults, but a total of only four actual therapists could be named by the 50 institutions. Some said that after diagnosis and surgical sex assignment, the patients were no longer intersexed. Many commented that psychological support is needed, but not available, or that they were unable to find qualified mental health professionals. One worried that counseling would do more harm than good. We conclude that only a small minority of patients with intersex conditions are provided with professional psychological support during childhood or as adults.

Honest, complete disclosure is good medicine

Families and patients need complete and honest medical information, presented in a comprehensible way. Families must make medical decisions for their children, and they need this information to make considered decisions. Patients need information, presented in age-appropriate fashion, in order to make sense of their condition. One of the goals of medical management of intersex has been to normalize the condition. For intersex, as for many other stigmatized conditions, perhaps the most effective way to accomplish normalization is through peer support rather than concealment [13]. Both parents and patients need accurate information in order to find peer support resources.

Traditional management has aimed at normalization by withholding or misrepresenting information about patient history and diagnosis [14, 15]. Many articulate accounts are available in which patients describe how lack of honest disclosure left them feeling freakish and betrayed [16-18].

All children should be assigned as male or female, without surgery

We have three objections to early genital surgery. Most importantly, surgery stems from and reinforces the idea that sexual difference is unacceptable. Since surgery does not produce normal genital appearance, nor does it eliminate behavioral differences, the intersex patient is forced to conclude that he or she remains unacceptable [19]. Second, surgery damages sexual sensation, and thereby limits adult quality of life by interfering with development of intimate bonds [20, 21]. Finally, some children grow up to express a gender identity discordant with their assigned sex (that is, in retrospect they were assigned the “wrong sex”) [22-26]. These risks are acknowledged in a statement by the British Association of Pediatric Surgeons which calls for a more conservative approach to surgery [27].

Neonatal sex assignment is a legal and social requirement, but surgery is no prerequisite for legal or social sex assignment. By way of demonstration, even when early surgery is performed, it generally does not occur until the child is 8 to 18 months old, but this does not prevent the child from being assigned a sex much earlier -- shortly after birth. Furthermore, there are many examples of intersex people who grew up without surgery, whose legal and social sex was unimpaired, and who seem to have been very well adjusted [28-30].

We believe that sex should be assigned after a careful examination and diagnosis. The large number of reports of failed sex assignments disproves the traditional belief that sex can be arbitrarily assigned based upon surgical convenience. Sex should therefore be assigned, after a careful medical investigation and diagnosis, based upon the best guess for the most likely gender identity outcome. This guess should be based upon the available data -- that is, what we know about gender identity outcomes in other patients with similar diagnosis and presentation.

Conclusion

All parties to the controversy have acknowledged that determination of optimal care for children with sexual ambiguity is hampered by lack of data. Many of the variables that would need to be assessed are soft, psychosocial variables with complex interdependencies. Experience has shown that hard statistics are rarely attainable for populations with any stigmatized condition, because subjects are motivated to evade investigators or to mislead them. Prospective studies would take decades, and many surgeons discount older data; their belief in the safety and efficacy of their surgery is essentially impervious to data [31, 32].

In the absence of data, our practice should be guided by principle rather than tradition. Relevant principles for intersex include the Hippocratic “first, do no harm,” ethical principles (respect for the intersex patient as a unique human being and facilitation of patient autonomy), and evidence-based medicine principles (secrecy and early surgery are radical interventions with demonstrated risks and no demonstrated benefits, used to treat a condition which is a variation rather than an illness) [33].

Medicine has an important part to play in lessening the pain of living with intersex conditions. That promise cannot be fulfilled until we recognize that a one-size-fits-all program of normalization via shame, secrecy, and early genital surgery places the needs of parents, doctors, and society ahead of the needs of the patient.

“Trust between patients and careproviders may be more important to intersexuals’ welfare than any other goal that is immediately achievable.” [34]

Randy Howe, MD

REFERENCES

1. Sutton, A., 'Lesley': the struggle of a teenager with an intersex disorder to find an identity- its impact on the "I" of the beholder' Case Study D., in *A Stranger in My Own Body*, D. Di Ceglie and D. Freedman, Editors. 1998, Karnac Books: London.
2. Hutson, J.M., *Clitoral hypertrophy and other forms of ambiguous genitalia in the labour ward*. Australian and New Zealand Journal of Obstetrics and Gynaecology, 1992. **32**(3): p. 238-9.
3. American Academy of Pediatrics Section on Urology, *Timing of Elective Surgery on the Genitalia of Male Children with Particular Reference to the Risks, Benefits, and Psychological Effects of Surgery and Anesthesia*. Pediatrics, 1996. **97**(4): p. 590-594. Available from <http://www.aap.org/policy/01306.html>.
4. American Academy of Pediatrics Section on Endocrinology and Section on Urology Committee on Genetics, *Evaluation of the Newborn With Developmental Anomalies of the External Genitalia*. Pediatrics, 2000. **106**(01): p. 138-142. Available from <http://www.aap.org/policy/re9958.html>.
5. Alexander, T., *The Medical Management of Intersexed Children: An Analogue for Childhood Sexual Abuse*. 1997. Available from <http://www.isna.org/articles/analogue.html>.
6. Money, J. and M. Lamacz, *Genital Examination and Exposure Experienced as Nosocomial Sexual Abuse in Childhood*. The Journal of Nervous and Mental Disease, 1987. **175**(12).
7. Toomey, C. 2001. The Worst of Both Worlds. *Sunday Times Magazine*, October 28.
8. Angier, N. 1997. New Debate Over Surgery on Genitals. *New York Times*, 13 May, B7.
9. Murray, J., *Intersex conditions*, in *Woman's Hour*. 2001, BBC: London. Available from http://www.bbc.co.uk/radio4/womanshour/10_12_01/tuesday/info1.shtml.
10. Corte Constitucional de Colombia, *Sentencia T-551/99 [Constitutional Court of Colombia restricts genital surgery on children]*. 1999. Available from <http://www.isna.org/colombia/>.
11. Corte Constitucional de Colombia, *Sentencia SU-337/99 [Constitutional Court of Colombia restricts genital surgery on children]*. 1999. Available from <http://www.isna.org/colombia/>.
12. Curran, M. and C. Chase, *Survey of mental health services for intersex in pediatric endocrinology fellowship programs (unpublished study)*. 2001.
13. Goffman, E., *Stigma: Notes on the management of spoiled identity*. 1963, Englewood Cliffs: Prentice-Hall.
14. Marion, R., *The Curse of the Garcias*. Discover, 2000. **21**(12): p. 42. Available from http://www.discover.com/dec_00/featvital_full.html.

15. Natarajan, A., *Medical Ethics and Truth-Telling in the Case of Androgen Insensitivity Syndrome*. Canadian Medical Association Journal, 1996. **154**(4): p. 568-570. Available from <http://www.cma.ca/cmaj/vol-154/0568e.htm>.
16. Kemp, B.D., et al., *Sex, Lies and Androgen Insensitivity Syndrome*. Canadian Medical Association Journal, 1996. **154**(12): p. 1829-1833. Available from <http://www.cma.ca/cmaj/vol-154/1829e.htm>.
17. Groveman, S.A. 2001. Lifting the Curse (letter). *Discover*, March. Available from http://www.discover.com/mar_01/letters.html.
18. Anonymous, *Once a Dark Secret*. BMJ (British Medical Journal), 1994. **308**(19 February): p. 542. Available from <http://www.medhelp.org/www/ais/articles/ONCE.HTM>.
19. Alizai, N.K., et al., *Feminizing genitoplasty for congenital adrenal hyperplasia: What happens at puberty?* Journal of Urology, 1999. **161**(5): p. 1588-91.
20. Creighton, S.M., C.L. Minto, and S.J. Steele, *Objective cosmetic and anatomical outcomes at adolescence of feminising surgery for ambiguous genitalia done in childhood*. The Lancet, 2001. **358**(9276): p. 124-5.
21. Creighton, S. and C. Minto, *Managing intersex: Most vaginal surgery in childhood should be deferred (Editorial)*. BMJ, 2001(323): p. 1264-1265. Available from <http://www.bmj.com/cgi/content/full/323/7324/1264>.
22. Colapinto, J., *As Nature Made Him : The Boy Who Was Raised As a Girl*. 2000, New York: Harper Collins. 304.
23. Reiner, W.G., *Assignment of sex in neonates with ambiguous genitalia*. Current Opinions in Pediatrics, 1999. **11**(4): p. 363-5.
24. Phornphutkul, C., A. Fausto-Sterling, and P.A. Gruppuso, *Gender Self-Reassignment in an XY Adolescent Female Born With Ambiguous Genitalia*. Pediatrics, 2000. **106**(1): p. 135-137. Available from http://www.findarticles.com/cf_0/m0950/1_106/63602518/p1/article.jhtml?term=hermaproditism.
25. Money, J., H. Devore, and B.F. Norman, *Gender identity and gender transposition: Longitudinal outcome study of 32 male hermaphrodites assigned as girls*. Journal of Sex and Marital Therapy, 1986. **12**(3): p. 165-181.
26. Meyer-Bahlburg, H., et al., *Gender change from female to male in classical congenital adrenal hyperplasia*. Hormones and Behavior, 1996. **30**: p. 319-322.
27. British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia, *Statement of the British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia*. 2001. Available from <http://www.baps.org.uk/documents/Intersex%20statement.htm>.
28. Reilly, J.M. and C.R.J. Woodhouse, *Small Penis and the Male Sexual Role*. Journal of Urology, 1989. **142**: p. 569-571.

29. Dreger, A.D., *Hermaphrodites and the Medical Invention of Sex*. 1998, Cambridge: Harvard University Press.
30. Dreger, A., *Intersex in the Age of Ethics*. 1999, Frederick Maryland: University Publishing Group.
31. Dreger, A.D. 2001. Real Trouble. *ISNA News*, May, 2-3. Available from <http://isna.org/newsletter/may2001/may2001.html>.
32. Kipnis, K. and M. Diamond, *Pediatric ethics and the surgical assignment of sex*. *Journal of Clinical Ethics*, 1998. **9**(4): p. 398-410. Available from <http://www.afn.org/~sfcommed/pedethics.htm>.
33. Dreger, A.D., "Ambiguous Sex" -- or Ambivalent Medicine? *Ethical Issues in the Medical Treatment of Intersexuality*. *Hastings Center Report*, 1998. **28**(3): p. 24-35. Available from <http://www.isna.org/articles/dregerart.html>.
34. Howe, E.G., *Intersexuality: What should careproviders do now?*, in *Intersex in the Age of Ethics*, A.D. Dreger, Editor. 1999, University Publishing Group: Hagerstown Maryland. p. 211-223.