

The New Science of Intersex

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MR. JONES was surprisingly relaxed and jovial considering that he had driven two hours from Bakersfield to Los Angeles to have his thirteen-month-old child examined by half a dozen doctors. No doubt he was sustained by his faith: on his T-shirt was boldly emblazoned “Got Jesus?” The examination rooms are usually crowded in the Intersex Clinic (now the Disorders of Sex Development [DSD] Clinic) at UCLA, where experts from pediatric urology, endocrinology, genetics, and psychiatry gather to assess children with DSD and counsel their parents. I am the psychiatrist attending in the clinic and the most recent addition to what had long been exclusively a pediatric urology clinic. However, given the growing controversies over the past two decades concerning corrective genital surgeries in intersex infants, it had seemed prudent to include a variety of specialists in arriving at a consensus on treatment.

Little Ben was an active, well-nourished baby who had had an unusually tumultuous gender history. After the physical exam was completed and the room cleared out, I got to talk to Mr. Jones privately. The Joneses had been told they had a baby boy when he was delivered at a small, rural hospital. But a few days later they received a panicked call from the hospital: “Your child’s a girl! Take him to UCLA right away for surgery to become a girl!” At least that is how Mr. Jones recalled the shocking answering machine message. Chromosome testing had uncovered that Ben was 46XX: he had the normal number of chromosomes (46), but he had two X sex chromosomes instead of the usual XY chromosomes of males. More detailed genetic testing found that he had an SRY gene on one of the X chromosomes..

SRY (Sex-determining Region of the Y) was only identified two decades ago after a half-century hunt for a gene on the Y chromosome that induced the developing embryo to develop testes rather than ovaries. The reigning hypothesis was that once the testes start to form, they generate all the subsequent hormones that promote the development of male internal and external genitalia. It was thanks to rare patients like Ben that in the 1980’s geneticists were able to isolate SRY. A rare genetic cross-over event during sperm formation can lead to SRY transfer from the Y to the X chromosome, resulting in a baby with penis but XX chromosomes (like Ben) and, conversely, a baby with a vagina but XY chromosomes (and no SRY on the Y chromosome). Such so-called “complete sex reversal” is exceptionally rare among the

DSD. Far more common (perhaps one to two percent of births) are minor anomalies of genital development: hypospadias (a urinary opening somewhere along the shaft of the penis) or an enlarged clitoris due to excess androgens. In between is a spectrum of atypical or “ambiguous” genitalia that for millennia had all been called hermaphroditism.

The mythical Hermaphroditos had all the ideal qualities of man and woman, but in reality it is impossible to have two complete sets of male and female reproductive systems since they develop from the same primordial tissues (except for one parallel system: the seminal duct system versus the Fallopian tubes, uterus, and upper vagina). In the 19th century, microscopic examination of the gonads revealed that most animals with ambiguous genitalia nevertheless had gonads of a testicular or ovarian cell type. Only rarely did they have a mixed gonad or one testis and one ovary—the so-called “true hermaphrodite.” The other “pseudohermaphrodite” cases were deemed to have a true sex (determined histologically or chromosomally) but with anomalous genitals. Determining the true sex in humans had great legal importance since sex is critical to civil rights: men and women have different rights, same-sex marriage was (and largely remains) illegal, and

society wanted to prevent “unnatural alliances” of people of the same sex.

This was all the province of medical specialists until the 1990’s, when a confluence of forces brought intersex people and their surgical treatment to public attention. First, there was the rediscovery of a famous case of surgical sex-reassignment: “John/Joan”—actually Bruce/Brenda/David Reimer. In the

1960’s, the infant Bruce Reimer suffered a surgical accident that burned off his penis during circumcision. John Money, a psychologist at the Johns Hopkins University, had counseled the parents that their child would be a normal girl if they went through with further feminizing surgery. A decade of research on intersex children had convinced Money that an optimal sex should be determined based on potential fertility and genital functionality, and that subsequent surgery, sex hormones, and parental rearing would shape a healthy gender identity, as well as prevent homosexuality. This treatment approach, facilitated through advances in endocrinology and surgery, led to a standard of treatment whereby infants with a large clitoris (greater than 1 cm.) should undergo clitoral reduction and infants with no penis or a “micropenis” (less than 2.5 cm.) should be reassigned female.

The Reimer case had provided the culminating support for Money’s approach, since Bruce/Brenda was a non-intersex individual who had nevertheless been feminized and had reportedly developed a female gender identity. The reality that emerged when David Reimer went public was far more turbulent and tragic. Little Brenda had constantly rebelled against feminine

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clothes and activities. When she was finally told her true medical history at age fourteen, he reverted back to being a boy. He took the name David, subsequently had penile constructive surgery, and later married a woman. After struggling with depression, his twin brother's suicide, and separation from his wife, David committed suicide in 2004.

The popular press presented the case as a failure not only of Money's psychological theory of gender role, but more broadly of social constructionist approaches to gender, and even feminist studies. Money's theories had indeed been influential for many 1960's feminists. He was the first to make the theoretical distinction between "sex" (the biological aspects of male and female) versus "gender" (the psychological and cultural aspects of masculinity and femininity). The John/Joan case in particular became the most dramatic proof that one is not born a woman but becomes a woman (to paraphrase French feminist Simone de Beauvoir). Money's research was central to the feminist argument that "biology is not destiny": biological sex does not determine psychological traits; on the contrary, gendered behavior is shaped primarily by social factors. Publicity around the rediscovered Reimer case instead pushed the counterargument that biological sex really is determinative of gender role, gendered behavior, and psychological differences between the sexes. The conservative press also used the case to attack certain gay and lesbian studies with this apparent triumph of biological determinism over social constructionism: sexual orientation, like gender, must also be biologically determined.

A second reason for the increased visibility of intersex was the emergence of the intersex advocacy movement in the 1990's. Support groups for intersex patients and their parents had kept a low profile and focused on treatment issues for specific diagnoses like Congenital Adrenal Hyperplasia or Androgen Insensitivity Syndrome, but in 1993 a new type of broader intersex activism arose with the Intersex Society of North America (ISNA) under the leadership of Cheryl Chase. After struggling for decades to find out details of her own diagnosis and treatment (for true hermaphroditism), Chase followed the political tactics of feminist, LGBT, and AIDS activists by pushing for greater public visibility, a broad political umbrella of intersex diagnoses, and direct action protests at medical conferences. More than individual support, ISNA wanted to bring the plight of intersex people to the public and to change surgeons' approach to altering atypical genitalia at the risk of excising erotic sensation. ISNA's tactics evolved over time as it quickly developed allies within medicine (including myself: I was on the board of ISNA and chair of its Medical Advisory Board from 2002 to '05). It developed patient-centered standards of care that encouraged informed consent rather than secrecy and greater caution in early genital surgeries. Chase and other ISNA associates were instrumental in promoting a nomenclature change from "hermaphrodite" to DSD.

With these accomplishments behind it, ISNA dissolved in 2008 to be replaced by a new organization: the Accord Alliance. The transformation was tactical as well. ISNA had long had a rocky experience with other intersex groups. To the right, many among the distinct intersex support groups disliked ISNA's early tactics and the term "intersex," which suggested gender intermediacy or confusion. To the left, more radical identity politics groups promoted that very gender queerness and distrusted ISNA's later alliance with

Fixing Sex: Intersex, Medical Authority, and Lived Experience

by Katrina Karkazis

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the medical profession. The DSD term was especially reviled since it represented further pathologization of intersex rather than its destigmatization as simply a variant of sexual biology and gender identity. This is, of course, the same political tactic used by post-Stonewall gay radicals who rebelled against

earlier homophile activists' attempts to win over the medical profession. Instead, activists like Frank Kameny and Barbara Gittings pressured the American Psychiatric Association to remove homosexuality from its classification of mental disorders in 1973.

The conceptual and political challenges of intersex have been the third current that has brought it to prominence, especially in academic circles. Psychologist Suzanne Kessler had decried intersex surgeries in 1990, presenting them as forced surgical enforcement of a two-sex system that could not allow intermediacy.* In a subsequent book, *Lessons From the Intersexed* (1998), she concluded that the lesson from ending intersex surgery and instead allowing genital ambiguity to remain unaltered would be the dissolution of gender itself. The idea is as politically inspiring as it is utterly disconnected from the actual experience of intersex people or the heart-wrenching decisions their parents have to make when an intersex child is born. Nevertheless, the intersex cause has been avidly taken up in academic gender studies as the political frontline after feminism, GLB theory, and transgender studies. The paradoxes and internal contradictions to this are dizzying. First, the current interventionist approach was instigated by Money, who promoted the sex/gender distinction and the notion of socially or medically constructed gender in the first place. Second, intersex is about biology and not just identity, as even Organisation Intersex International (which radically promotes eliminating the binary sex system) agrees. Third, much hostility between ISNA and separate intersex support groups was over the perceived gender radicalness of ISNA, despite the fact that ISNA repeatedly stated it favored binary sex determination of infants rather than gender neutral rearing.

In the last two decades, intersex has been a boon for the most disparate theorizing on sex, gender, and sexuality—for both the biological determinists and the social constructionists, those claiming that sex/gender is strictly binary and those advocating its dissolution entirely. Into this intellectual and political maelstrom comes Katrina Karkazis's *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Theoretically savvy and politically engaged, Karkazis is one of the founding board members of the new Accord Alliance. Yet her work is one of the most balanced in the field. It is the product of a decade of research arising out of her 2002 doctoral dissertation in anthropology from Columbia University (*Beyond Treatment: Mapping the Connections among Gender, Genitals, and Sexuality in Recent Controversies over Intersexuality*) and is informed by interviews with intersex adults, parents of intersex children, and physicians in the field. I suspect it is her close connection with intersex patients and their parents that most tempered her analysis.

Karkazis's take on John Money is almost sympathetic compared to most academic and popular critiques that demonize him as either a crazed social constructionist or a rigid biological de-

* "The Medical Construction of Gender: Case Management of Intersexed Infants," in *Signs* 16 (1990).

terminist. She rightly points out that, rather than simplifying sex determination in intersex cases to a single factor, Money repeatedly argued that there were at least seven biological and psychological factors (although he tended to give much more weight to the sex of rearing). A more subtle and perhaps more radical point Money argued was that the great majority of people with intersex conditions grew up to be psychologically healthy and accepted their anatomy and assigned sex if medical interventions were done early and parents were firm in their gender rearing. This contradicted psychoanalytic theory, dominant in the 1950's, which held as a basic tenet that psychosexual anomalies were a predominant cause of psychopathology. Chief among these sexual pathologies was, of course, homosexuality, which for a century had been considered a form of psychosexual hermaphroditism or "sexual inversion" (the term Freud still used in referring to homosexuality in the early 20th century). Money was so optimistic about the role of gender rearing or imprinting that he argued that in cases like John/Joan an "iatrogenically induced homosexuality" could be created by doctors' and parents' psycho-surgical gendering; that is, Joan would eventually be attracted to boys although genetically XY.* In the same vein, Money and Richard Green (later known for *The "Sissy Boy Syndrome" and the Development of Homosexuality*, 1987) wrote in the 1960's that boyhood effeminacy was a "gender-role disorder" and a warning sign of later homosexuality, which could be prevented by proper coaching in masculinity. Finally, Money's extensive experience with intersex cases and their gender manipulation through surgery and hormones led him to strongly endorse sex reassignment treatment for transsexualism. He was instrumental in the establishment of the Gender Identity Clinic at Johns Hopkins in 1966—the first academic transsexual clinic in the country.

Clearly, intersex conditions have long been intertwined with issues of sex, gender, and sexuality. So it is not surprising that journalists and academics have focused on these sexy aspects of intersex. However, Karkazis also highlights the broader medical challenges facing intersex patients and their parents. The reason the DSD clinic at UCLA has four specialists is because some of the intersex conditions involve multiple organ systems, higher risk of cancer, and a lifetime of hormone replacement. Some of the known genetic intersex syndromes also include cognitive deficits or mental retardation. For the parents, concerns about genitals and sexuality often take a second place to deeper worries about their child's survival and general quality of life. As one mother expressed it to me, she was fearful of being inadequate to care for a child with a chronic illness requiring periodic injections—just like juvenile diabetes.

Groups like INSA have repeatedly emphasized that intersex activism is not about starting a gender revolution but about a health care revolt: better information for patients and parents, psychological support, and greater patient agency in decisions about genital surgery. This last issue has gotten the most attention and is truly grueling for the parents of an intersex infant who, of course, cannot participate in the decision making process. In some cases surgery is essential: for example, when the urinary or rectal outlet is blocked. On the other hand, given several decades of expe-

* John Money and Anke Ehrhardt, *Man & Woman, Boy & Girl: Differentiation and Dimorphism of Gender Identity from Conception to Maturity* (Baltimore: Johns Hopkins Univ. Press, 1972).

rience with particular conditions, sex reassignment would no longer be advisable in certain cases: for example, traumatic ablation of the penis (David Reimer's case), or 46XY micropenis. Experience has shown that female assignment is in conflict with the child's future gender identity, making a bad situation only more tragic. That leaves the many cases where there is no definite diagnosis or inadequate long-term follow-up studies to guide parents and doctors. Does an enlarged clitoris need to be reduced for the mental and functional wellbeing of a child? Does a severe case of hypospadias need to be corrected in infancy? I have spoken with men with hypospadias who had early surgery and were dissatisfied with the results and, conversely, those who did not have early interventions only to later deal with urinary tract disorders requiring multiple traumatic surgeries as an adolescent and adult. Both individuals blamed their parents for their action or inaction. That is the wrenching dilemma for parents: having to sort through complex biomedical information and woefully inadequate science to make a crucial decision for their child.

I have seen many parents struggle in good faith with these decisions about biomedical interventions, trying to be as objective as they can. However, their overall level of education and their personal, cultural, and religious beliefs about gender and sexuality inevitably color the decision-making process. One family may not be able to countenance the gender confusion of a girl with a penile-like clitoris, another is happy to imagine rearing a gender-bending girl. Mr. Jones was understandably anxious about his son Ben. The medical team had already recommended a course of testosterone treatment to see if his penis would grow, and then surgery to pull down the testes into the scrotum. He understood that the latter was important to reduce the risk of testicular cancer in adulthood, but that the hormone treatment was cosmetic—just to make the penis grow a little. He was thrilled by the penile growth after the first testosterone treatment since he was concerned about his son's future fertility and sexuality. If he was concerned that Ben's XX chromosomes might lead to an attraction to men, Mr. Jones did not express it that morning. He just wanted to be reassured that Ben would have the confidence to be sexual with girls and one day have children. He was confused in thinking that Ben lacked the "gene for semen," so he was relieved to learn that Ben would probably produce sperm, but with a reduced count. Although he repeatedly exclaimed, "It's in God's hands," he was clearly taking responsibility and relying on modern medicine to shape his son's body and future sexuality. Only time will tell whether Ben lives up to those expectations, is satisfied with his treatment, or shares his father's faith, but I believe Mr. Jones acted in good conscience for the health and happiness of his son.

I cannot predict whether the treatment plan we recommended will help Ben feel secure about his body, his gender, and his sexuality as he grows into adulthood, but I do believe that the spirit of openness, information, and support that the intersex movement has inaugurated should do much to reduce the shame and isolation of many people with intersex conditions. Ben is growing up in a completely different cultural era than a fifty-year-old Latino man I saw recently for his first consultation concerning his small, partially feminized genitalia. He had avoided any medical examinations his whole adult life and had never been intimate with anyone out of excruciating shame. Let us hope that intersex people can finally come out of the closet of stigma to be able to receive the treatment they want and freely choose their gender and sexuality. ≡