

## **CREATING IDENTITY: NARRATIVE ETHICS, INTERSEX INFANTS, AND THE SURGICAL ASSIGNMENT OF GENDER**

Rebekah J. Ross-Fountain

Researching issues related to ambiguous genitalia and the birth of an intersexed infant into a family draws the individual into an intense on-going debate about normalcy and well-being. Intersex refers to the range of conditions that occur naturally and fall outside the usual dimorphic categories of male and female (Fausto-Sterling, 1993, 2000) and designates having “the genital/gonadal/reproductive structures characteristic of both sexes” (Blizzard, 2002) or simply a child’s genetic sex and phenotypic sex do not match the standard male and female designations. The usual indication for an anomaly is the birth of an infant with ambiguous genitalia, although some occurrences are not detected until later. Biologist Anne Fausto-Sterling (2000) estimates the rate of occurrence for all intersex conditions is 1.7%, but the number of infants designated as needing corrective surgery<sup>1</sup> falls between 1 in 1,000 to 1 in 2,000 live births. Delving into the current literature on the intersex requires us to face challenging questions about informed consent, social acceptance, individual voice, family expectations and relationships, family secrets, the language of medicine, and professional ethics. While this literature on the intersexed follows divergent avenues that include medical/scientific descriptions and studies (Bradley, et. al. 1998; Diamond & Kipnis, 1998; Diamond & Sigmundsen, 1997; Minto et. al., 2003; Zucker, 1999) ethical dilemmas in treatment (Blizzard, 2002; Diamond & Kipnis, 1998; Diamond & Sigmundsen, 1997; Dreger, 1998; Zucker, 1999), attempts to understand and articulate gender identity development (Bradley, et. al. 1998; Diamond & Kipnis, 1998; Diamond & Sigmundsen, 1997; Zucker, 1999), the language and naming of the “problem/s” (Dreger, 1998) and protocols of treatment (Blizzard, 2002; Diamond & Kipnis, 1998; Slipjer, Drop, Molenaar, & Keizer-Schrama, 1998), this paper focuses on the calls by ethicists and activists to abandon treatment guidelines that necessitate surgery for non-life-threatening conditions.

We are currently at a point where it may not be clear which direction to precede when encountering “ambiguous genitalia” and that is a difficult obstacle to hurdle when deciding what to do with one’s own child. Couple this issue with all the other “normal” anxieties associated with giving birth and we see why the American Academy of Pediatricians recommends ongoing counseling for families and children in treatment.

Writing and speculating on how to treat intersex infants pushes the parameters for defining sex and gender, disputes social norms, questions the importance of external physical appearance (body image), challenges our understandings of identity development and psychological health models, etc. When analyzing each of these issues, it is tempting to try to narrow one’s scope to the immediate realities of the condition alone. It is not that easy. Living life does not neatly divide into manageable issues and each time we attempt to splinter the reality of intersexed persons into simply the condition in need of treatment, we deny their humanity. When evaluating treatment guidelines we must look at the entirety of a person and the pursuit of a flourishing human life in all its aspects, current and future. Historically, there has been a tendency to view intersex infants by only the appearance of their genitalia and their futures

were weighed by their potential to engage in a heterosexual marriage. This overriding emphasis on the appearance of external genitalia is troubling.

John recalls thinking it was small minded of others to think all his personality was summed up in the presence or absence of a penis. He expressed it thus: “Doctor...said, it’s gonna be tough, you’re going to be picked on, you’re gonna be very alone, you’re not gonna find anybody unless you have vaginal surgery and live as a female. And I thought these people gotta be pretty shallow if that’s the only thing they think I’ve got going for me; that the only reason why people get married and have children and have a productive life is because of what they have between their legs. . . . If that’s all they think of me, that they justify my worth by what I have between my legs, then I gotta be a complete loser.” (Diamond & Sigmundson, 1997)

The physician’s view of acceptable genitalia was the predominate factor driving surgery. Until recently, the dominant treatment protocol relied on an authoritative approach to medicine of having the physician/s determine the viable gender with parents watching from the sidelines. For nearly fifty years, the birth of an infant with ambiguous genitalia was met with swift gender re-assignment and the accompanying surgery to correct the outward appearance of the genitalia. This practice asserts several tenets, (1) gender identity is malleable, (2) atypical genitals will lead to serious psychopathology, and (3) the complete concealment of the condition and the related events produces the best psychological outcomes (Diamond & Sigmundsen, 1997). The approach trusts that immediate correction to ambiguous genitals and complete acceptance of the gender assignment is the only way to ensure stability for the child and to avoid confusion and stigmatization (Slipjer, Drop, Molenaar, & Keizer-Schrama, 1998). The psychiatrist John Money and his assertions<sup>2</sup> of psychosexual neutrality at birth and gender malleability significantly influenced this dominant treatment protocol. “Corrective” surgery was done immediately, preferably prior to 18 months of age. Complete acceptance of the assigned gender by the parents and the absolute secrecy of any “original” ambiguity were to provide full acceptance of the assigned gender for the patient. Due to this code of secrecy, many adolescents were actually deceived when puberty required additional surgeries and hormone therapy (Diamond & Sigmundsen, 1997).

As a young woman, Sherri Groveman, who has AIS, was told by her doctor that she had “twisted ovaries” and that they had to be removed; in fact, her testes were removed. At the age of twenty, “alone and scared in the stacks of a [medical] library,” she discovered the truth of her condition. Then “the pieces finally fit together. But what fell apart was my relationship with both my family and physicians. It was not learning about chromosomes or testes that caused enduring trauma, it was discovering that I had been told lies.” (Dreger, 1998)

After reading several studies in which individuals were treated under the traditional paradigm, a picture emerges of seeing individuals as labels of “sexual orientation,” “toys of interest,” “acceptable appearance,” and “career desires.” These singular aspects that may be quaint or humorous for a “typical” child in a “typical” family became clinical notes with defining magnitude. What does it mean if a patient likes trucks more than dolls while he/she is six years old? For the average child, it may be a passing interest in childhood play. However, for an intersexed child it may be a monumental issue that is labeled and recorded in the clinician’s paperwork to confirm the gender assignment or to present worry from concerned adults (did we choose the wrong assignment?). The concern with this approach is the absence of the “patient” being the one to define the magnitude and the significance of each point, of each and every act being scrutinized within his/her life. The observers have all the power and their level of comfort takes center stage.

The results for children are these things happen to them and decisions are made on their behalf in order to maintain specific social expectations about sexual dimorphism and narrowly defined gender roles. Adults who adamantly oppose the treatment decisions made for them prior to their ability to voice a concern, a doubt, or straightforward opposition are demanding an end to all surgeries that are not done to save the life of the child. Breaking silence is a recurrent theme for those affected by intersex conditions (Rye, 2000). They reject all the levels of secrecy and denial: familial, medical, and social. And they challenge current debates about gender identity, sexual function, body image, and psychological health (Fausto-Sterling, 2000; Rye, 2000). The intersection of these issues is the multiplicity of lived experiences that ultimately comprise a single person’s life and how that is respected and understood to ultimately be the individual’s narration—a narration that is created and articulated by the individual in coordination with and in spite of familial and social expectations.

Shifts in medical ethics alone concerning informed consent and patients’ rights have challenged many aspects of the traditional treatment methods of the intersexed. Most pediatricians today would see treatment as necessarily involving the voice of the parents and would reject outright lying to patients.

However, activism from intersex adults has taken the challenges to current medical guidelines much further. In the mid-90s, people who wanted to challenge the paternalistic treatment of the intersexed, to end unnecessary surgeries, and break former silences formed the Intersex Society of North America (ISNA) ([www.isna.org](http://www.isna.org)). ISNA maintains that reform has still not gone far enough and that invasive surgery on infants should be halted altogether, whether individual parents prefer it or not.

Their demands are based on important medical, ethical, and psychological points. The surgery is not medically necessary. “[M]edical texts advise . . . ‘of all the conditions responsible for ambiguous genitalia, congenital adrenal hyperplasia is the only one that is life-threatening in the newborn period,’ and even in cases of CAH the ‘ambiguous’ genitalia themselves are not deadly” (Dreger, 1998). Ironically, traditional treatments have regularly led to

psychopathology (Dreger, 1998; Slipjer, Drop, Molenaar, & Keizer-Schrama, 1998). Ethically, a shift must be made to child-centered concerns.

In this environment of concerns and tensions between successful gender assignments versus dissatisfied individuals, there are only a handful of studies that evaluate individual treatment cases (Diamond & Sigmundsen, 1997; Migeon, et. al., 2002; Phornphuktkul, 2000; Slipjer, Drop, Molenaar, & Keizer-Schrama, 1998) and just a few of those are long-term studies. Most of the literature ends with an urgent call for long-term studies with extensive follow-up to treatment well into adulthood (Blizzard, 2002; Bradley, et. al. 1998; Diamond & Kipnis, 1998; Diamond & Sigmundsen, 1997; Dreger, 1998; Migeon, et. al., 2002; Phornphuktkul, 2000; Zucker, 1999). One of the existing long-term studies found that nearly forty percent of children treated under the contemporary protocol had developed psychopathology by the age of sixteen (Slipjer, Drop, Molenaar, & Keizer-Schrama, 1998).

The source of the pathology and then the appropriate treatment path is an area of contention among contemporary researchers and physicians. When Drs. Milton Diamond and Kenneth Kipnis challenge current treatments, they point to the lack of long-term studies to support the predominant view, their own ground-breaking follow-up to the Joan/John case, which shattered the prevailing paradigm,<sup>3</sup> and they use the testimonies of many dissatisfied adults to bolster their call for a change in procedures. It is primarily an ethical matter to Diamond and Kipnis and they have three recommendations for change. First, there should be a “general moratorium on such [genital] surgery when it is done without the consent of the patient.” Second, the “moratorium should not be lifted unless and until the medical profession completes comprehensive lookback studies and finds the outcomes of past interventions have been positive.” Third, “efforts [should be] made to undo the effects of past physician deception.” (Diamond & Kipnis, 1998) They accept that a gender will need to be chosen for children, but they do not believe surgery should ensue until the child can articulate an acceptance or rejection of the parents’ and physicians’ best guess. They especially reject the notion that secrecy is healthy.

While many pediatricians will agree that secrecy has had ill effects, they may not be in agreement that the early surgeries should end. Dr. Kenneth Glassberg (1999), a pediatric urologist at Columbia University, cautions that protecting patient autonomy to the point of allowing children “to be considered freaks by their classmates” will lead to poor outcomes. He rejects a complete moratorium on surgery and asserts that forbidding early surgery is “more of an experiment” than performing the operations has been (Glassberg, 1999). Obviously, Glassberg taps into the fear that many parents have about the social rejection of their children.

Pulling these threads together, one must return to the lived voices of individuals whose lives are forever affected by all of these events. Martha Coventry, “a woman who had her ‘enlarged’ clitoris removed by surgeons when she was six, insists that ‘to be lied to as a child about your own body, to have your life as a sexual being so ignored that you are not even given the decency of

an answer to your questions, is to have your heart and soul relentlessly undermined” (Dreger, 1998).

So, the question becomes—should we allow surgical intervention to be the answer for the comfort level of the adults in the life of an intersex infant? Or are the mistakes of the past glaring enough for us to see that social discomfort with differences is not a reason to permanently change children’s bodies. We must stand back for a broader view and attempt to see the consistencies and ambiguities of a person’s whole life in order to navigate through the decisions to be made in infancy. Each of us must ask ourselves how small/large would my penis/clitoris have to be that I would have preferred being assigned the other gender and surgically “corrected”. What would I want to be the overriding factors in determining surgical intervention: size, appearance, ability to feel sensation, viability, health, surgical risks, psychological effects, comfort-level of parents or other family members, comfort-level of future class-mates?

One of the aims of narrative ethics is to honor the unfolding of a particular life in its own context and to allow the individual to be the creator of the story to be told. With this aim in mind, there is not one treatment protocol that should govern all children. At the same time, it is also apparent that this approach would exclude treatment guidelines that require early non-life-saving surgery. A removed clitoris can never be returned and how do we know what the future relationship of any given clitoris will be to its environment, other body parts, possible future partners in pleasure, etc. I realize this assertion runs somewhat counter to contemporary standards that grant parents full medical consent rights for their children, but there have to be safeguards for children that protect them from their own parents’ (or physician’s) level of discomfort for differences. Again, social discomfort for difference is not a morally compelling reason to permanently alter a child’s body.

## NOTES

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<sup>1</sup> This narrower category is the concern of this paper.

<sup>2</sup> His views were significantly shaped by his John/Joan case. The John of the above quote is this John from Money’s case. For a full description of this case, its influence on treatment guidelines, and a further acknowledgment of John’s experience see the works of Diamond and Kipnis and Diamond and Sigmundson.

<sup>3</sup> John rejected his gender assignment as Joan and now successfully lives as a married heterosexual male. This case reveals the inadequacies of relying on a single case study to significantly shape treatment guidelines.

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