

Rhetoric of the Medical Management of Intersexed Children

New insights into "Disease", "Curing", "Illness" and "Healing"

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Introduction

[1] What happens when a child is born, and the attending physicians look to declare, Its a boy! or Its a girl!, but cannot clearly decide? What happens when a girl at 18 still has not reached menarche, and after a bit of research, it is discovered that she has an XY chromosome type? What causes a doctor or a parent to worry about a clitoris that seems too large, or a penis that appears to be smaller than usual? How do we as a society respond to the knowledge that not all people are XY, or XX, but could have both, or neither? What do we do when we hear about men with ovaries, or women with testicles?

[2] These intersexed individuals clearly do not conform to our fundamental assumption that humans have two and only two sexes, and that each particular body clearly conforms to one or the other of these sexes, but not both. One possible response to this awareness is to reassess the assumption of the binary sex paradigm. (Cf. Fausto-Sterling 2000a) In the face of the multiple factors that contribute to the classification and identification of a sexed type, it would be reasonable for us as a society to rethink and problematize the binary paradigm and its self-evidential status institutionalized in our politics, our laws, our practices as social beings.

[3] Another possible response, and indeed the typical response is to enact a corporeal ethic upon the bodies of those who do not conform, in order to require them to display the appropriate markings and behaviors for one or the other sex category. (Cf. Meyer-Bahlburg 1993, 1998; American Academy of Pediatrics [AAP] RE 9958; Money, Hampson and Hampson 1955; Money and Ehrhardt 1972) This is something similar to, but also more than the imposition of gender categories, (Butler 1990, 1993) because the very bodies of the intersexes are under question. A body without a clearly determinable sex must have one made for it: surgically, hormonally, behaviorally, socially. If not, it is diseased (physically deficient or deviant), and as such is ill (cannot be and will not be socially accepted/acceptable). It requires curing (intervention) in order for it to heal (to become acceptable again, to find a place in society). In cases of intersexuality, what is naturally (I use this term wisely) present is represented as somehow unnatural, and must be made more natural in order to be recognized, understood, classified.

[4] In the last 100 years or more (Dreger 1998), the medical profession has turned its powerful professional gaze upon what were once termed hermaphrodites, now named intersexed, in an effort both to determine and understand the underlying causes leading to this diagnosis, as well as to develop a series of medical interventions in response to them. In the United States, but also clearly throughout Europe and to an increasing extent elsewhere in the world, surgical techniques on genitalia and secondary sex characteristic areas of the body, psychosocial research into gender identity and techniques of reinforcing this identity, as well as the availability of hormone replacement/supplement techniques provide for the feasibility of a technological response and intervention in the life of an intersexed individual. This effort can be extensive, and it can be profound. (AAP RE 9958) It operates upon the presumption that intersexed individuals are deviations from a particular norm of sex morphology, and is committed to the belief that medicine can provide the tools whereby the symptoms, if not yet the causes, can be managed so as to allow the intersexed individual a sense of place in the binary sex system. (Cf. also Rosenfield, Lucky and Allen 1980; Glassberg 1980)

[5] Since the foundation in 1993 of the Intersexed Society of North America, there has been a growing public awareness about the experience of intersexed patients who have undergone medical treatment. The testimony of intersexed adults regarding their treatment as children has brought to light a number of criticisms regarding such practices as early surgical intervention and early gender assignment and the means by which it is reinforced (Beh and Diamond 2000; Kipnis and Diamond 1998), not to mention the extremely troubling reports of nearly universal medical paternalism, deflection and deception. (Cf. Dreger 1999; <www.isna.org>) As a result, a growing number of voices have expressed concern about the success of particular practices and the standards by which medical researchers have in the past used to judge success of their interventions. (Fausto-Sterling 2000b; Draft Statement; Alizai et al. 1982; Creighton, Minto and Steele 1998) Many have pointed out the lack of long-term follow-up studies (Chase 1996; Kipnis and Diamond 1998; Creighton and Minto 2001; cf. however Migeon et al., 2002, and the on-going North America Task Force on Intersexuality) and have thereby begun to question whether a patient or parent of a patient, when presented with medical options, can ever be said to be fully informed when giving their consent. (Ford 2001) Even more troubling for medical practitioners, some have begun questioning certain fundamental presumptions guiding current medical treatment. (Reiner 1996; Holmse et al. 1992; Diamond and Sigmundson 1997; more generally, see Diamond et al. 1996; Diamond 1965; contrast, however, Bradley et al. 1998) In particular, the assumption of the psychosexual neutrality of children at birth, first proposed by John Money (besides above, cf. also Money, Hampson and Hampson 1957; Money 1994; Money Potter and Stoll 1969; Money 1975; Money et al. 1981; Money 1983), now of the Psychosocial Research Unit of Johns Hopkins Medical Center, has come under fire, particularly since the publication of the biography of David Reimer, the John/Jane Doe patient whose case became the foundational proof for the success of medicines intervention in cases of intersexuality. (Colapinto 1997, 2001)

[6] What has not come under question is the fundamental assumption of the need for medical treatment in the first place. That is, what has not come under question is the impetus informing the desire to make the natural more natural. (Cf. Sedgwick 1990) Let us for the moment accept the current strategies and efforts at reform and postulate a situation where their criticisms are all successfully met. Let us postulate a moment in time when:

[7] all vestiges of physician paternalism have been overcome, and parents and patients are given full and complete explanations of the particular conditions and circumstance facing the intersexed child and/or adult;

[8] surgical standards have been agreed upon such that not just aesthetic outcome and patient survivability standards are met, but also post-surgical complications are at a minimum and patient experience is included as a necessary aspect of determining success;

[9] the complex notion of gender identity is completely understood, universally accepted, and patient outcomes are successful according to these standards;

[10] several long-term studies from research centers from all over the world offer us clear and unambiguous answers regarding best practices.

[11] Let us grant this utopian vision whereby all criticisms raised by current efforts at reform have been met. The question still remains: Is it necessarily the case that an intersexed child under the practices of these perfected guidelines can achieve healing under its practices? Or are the underlying assumptions of the need to intervene in these cases such, that the effort to bring the ambiguously sexed child into conformity with the binary sex paradigm will be undermined by the presumed pathology of the condition? More importantly, how do these assumptions shape the practices of identification, intervention and follow up? What takes place when a child is declared intersexed and is forced to undergo a series of medical interventions, ranging from possible surgery to counseling, from possible hormone treatment to daily reinforcement of gender identity and role, in order to bring him or her into conformity with the natural binary sex system?

[12] Current medical guidelines make use of rhetorical dynamics that create a state where practices of the diagnosis of the "disease" and the procedures used in "curing" lead the patient to a state of "illness" wherein no "healing" can ever be achieved. These practices are informed by an assumption of what constitutes natural sex categories and characteristics, and views medical intervention as part of an effort to render the intersexed body more in conformity with nature. This assumption is inextricably linked to these guidelines and their resultant practices, such that the result would be the same no matter their possible future reform: the intersexed patient is a boundary violation of the binary sex ideology in constant need of surveillance and control. It is the thesis of this article that under these circumstances, healing can never take place for the intersexed patient.

The Current Medical Protocol

[13] In order to pursue our analysis, it is important to review key practices and perspectives informing the current medical practices undertaken in cases of intersexuality.

[14] The modern medical profession since the 19th century has codified and reinforced the notion of the existence of two and only two genders, and has institutionally sought to regulate bodies according to a belief of "one body, one gender". (Dreger 1998, 79-109; Fausto-Sterling 2000b, 1-44: 30-44) While recent studies have suggested the as many as of 1.7 intersexed births per 100 (Blackless, et al. 2000, 151-166), it is the commitment to maintaining the socially presumed standard of two discreet sex categories that drives the medical intervention in these cases.

[15] If a body presents itself as ambiguous, i.e., as violating these normative presumptions, the physician begins a series of tests to determine the underlying condition. (Cf. Hutcheson and Snyder) The process is conducted within a team framework (including, under the best of circumstances, the original referring physician, a pediatric endocrinologist, a pediatric urologist, a geneticist and possibly a psychologist, psychiatrist or a psychoendocrinologist). (AAP RE 9958; Migeon 2001) The team seeks to ascertain the underlying condition leading to genital ambiguity in an effort to identify the body's "true" gender. It will then decide upon the gender assignment and gender of rearing according to the two-sex model.

[16] Gender assignment is determined according to the following guidelines: 1) "Genetic females should always be raised as females, preserving reproductive potential, regardless of how severely the patients are virilized." 2) "In the genetic male, however, the gender of assignment is based on the infant's anatomy, predominantly the size of the phallus." (Both quotes Donahoe et al. 1991, 527; cf. also Riley and Wodehouse 1989, 569-571; Money 1975, 610; AAP RE 9958; Oberfield et al. 1989, 453-454; Hutcheson and Snyder) It is not yet clear how these guidelines relate to the processes of diagnoses that took place prior to assignment. Published guidelines seem to concern themselves more with anatomical appearance and function, than with exploring the relationship between a given condition and eventual psychosocial adjustment. (Tiefer 1994, 363-377; cf. also Reilly and Woodhouse 1989) This makes sense within the model, since the assumption is that eventual gender identity acceptance can be formed through reinforcements such as sex of rearing and clear physiological signals. (Cf. however Reiner 1997, 1044-1045; Hendricks 2000; van Seters and Slob 1988)

[17] During this time physicians generally counsel parents not to assign a sex to the affected newborn, nor to name the child. If asked, the parents are counseled to avoid gender pronouns when referring to the child, using phrases like "our baby", "our child", etc. It is also important to use neutral terms such as baby, gonad and phallus instead of sex-specific terms like boy or testes or ovaries and penis or clitoris. (Migeon 2001; AAP RE9958) Only after the "true sex" has been chosen and the parents told of the results of the investigation is the baby given a name, the birth record filled out, and the surgeries and/or other interventions scheduled. This communicative approach to keep the baby in an unmarked, socially liminal zone is premised upon the intention of the protocol to have all parties send clear signals that will not undermine the certainty of the assignment.

[18] Indeed, the implementation of communicative practices is recommended from the very beginning. The most important moment of communication is seen as the initial consultation with the parents, wherein the physicians are to approach them by stating that the child really does have a gendered identity, but that the genitals and gonads are incomplete, and the "true sex" of the child has to be more clearly investigated. Accordingly, the physician is directed to state that the gender of the child is not yet "finished", and their procedures will help to "correct" and "complete" this development. Integrity of the gender identity system and the determination of the gender are thereby maintained in the hands of the physicians, and consistency of this message plays a key role in the assignment process.

[19] This fundamental commitment is the driving force behind all future follow-up consultations, often resulting in extraordinary paternalistic avoidance of candid and forthright communication with the patient regarding her/his condition. "[A]ccurate patho-physiological explanations are not appropriate and medical honesty at any price is of no benefit to the patient." (Forest 1981) "Discretion" became a fundamental aspect of the guidelines, since the guidelines depended upon clear, congruent and consistent messages being sent to the parents and the child so as not to create confusion. (Peris 1960: 156-166; Slijper et al. 1994, 10-11, 14; Lee and Mazur 1980, 156-163) Success of the adoption of the gender assignment is premised upon the intersexed individual not knowing they are intersexed. Truth telling within this protocol is seen as threatening its very success, (Natarajan 1996) since it would mean informing the patient that her/his gender was ever in question.

[20] In sum, the intersexed patient is identified as such only after the physician is confused about the external phenotype, a confusion premised upon an (institutional) commitment (since the 19th century) to a binary system of clearly differentiated gender/genital markings. Commitment to this binary system is reinforced through approaches taken by the physician, under guidance of the medical protocol, that describe the patient as having a true but developmentally incomplete sex which will be helped along by the intervention of the physician. In order to maintain the clarity of the binary gender system, gender assignment must be accompanied by consistent signals, and the patient must never be aware of the possibility of ambiguity or difference.

The Rhetorics of Medical Management

[21] With this background in view, I wish to turn an analysis of how notions of "disease", "illness", and curing are constructed in the protocol through certain acts of naming, disciplining, evading and constructing. For the purposes of this paper, "illness" is not just the process of identifying and diagnosing a medical condition for the sake of eliminating a "diseased" or "unhealthy" state. It is, instead, the whole plethora of relationships at work when patients, physicians, technicians, families come together and isolate the patient as a pathology, set the person apart in an effort to prevent social contagion.

[22] "Disease" is therefore just one aspect of "illness", and to be pronounced "diseased" is a rhetorically performative activity (label), based upon certain medical guidelines with greater or lesser degree of risk, signifying a change in responsibilities and activities at work between all the players.

[23] Let us consider more closely, building upon what we have already discussed, the ways in which the ideas of disease, curing and illness interact and intersect in the practices of physicians, parents and patients with respect to the intersex(es).

[24] **The Rhetoric of Disease:** When is a newborn, an intersexed newborn, in need of immediate clinical and surgical intervention? A straightforward answer to this question has not been developed. While several conditions have been identified as leading to intersexuality, and while tests are available to discern the particular etiology of a given condition, they are only performed after the physician has already declared the child to be intersexed. It is only once the physician declares the child's genitalia ambiguous that the underlying condition is confirmed.

[25] This is, of course, typical, since the "art" of diagnosis and treatment proceeds along similar lines: symptoms are described or are witnessed, and the underlying condition for them is identified by tests that help to confirm an initial diagnosis. The question regarding the identification of intersexed children as such, is what symptoms do physicians initially rely upon? How does a physician first come to "recognize" the genitalia as "ambiguous"?

[26] While scales of "normal" clitoral (Riley and Rosenbloom 1980; Oberfield et al. 1989; Sane and Pescovitz 1992) and penis lengths (Flatau et al. 1975; Donahoe et al. 1991) for newborn children have been developed, literature is replete with subjective phrases such as "ambiguous genitalia", "expected size", "appears small", "judged on the basis of...in relation to the size of the patient", none of which are defined or specified any further than this. (Kessler 1998,) Of course, it may be that in such cases the "ambiguity" would be "obvious" to any observer. Nevertheless, this does beg the question of just how "ambiguous" ambiguity is allowed to be before labeling the child intersexed and commencing with the prescribed interventions. One of the reasons for this murkiness is that there is no medical standard of gender assignment and genital appearance that isn't also entangled with cultural, and even personal, aesthetic notions of how the genitals should "properly" look and function.

[27] It should therefore come as no surprise that expectations on the part of physicians have a profound affect on their judgment. For example, the presence of the phallus can outweigh all other indicators in the initial gender assignment. (Cf. Kessler 1998, 44-46) Of course, this difficulty is related to whether one sees a "small penis" or a "large clitoris". The problem is, such a judgment is itself dependent upon preconceived notions of how a "penis" or a "clitoris" is "supposed" to look. A "penis" (even a severely hypospadiac one) is what a "boy" has, the gender of whom is what the physician is supposed to be determining in the first place. A "clitoris" is what a "girl" has, even if it is enlarged and accompanies fused "labia".

[28] In other words, the end determines the beginning. The gender you assign the child determines how you will view the child's ambiguity, and how you will proceed with the "necessary" corrections. Once a physician decides the signs of ambiguity are "confused", because the objects are not fulfilling their preordained and necessary role of clear, male/female marking, the physician then goes on to decide which of the two genders the genitals can measure up to fulfilling best. If it is decided the phallus is "too small" to be a boy, the child becomes a girl whose clitoris is "too big" and in need of cliteroplastic correction. Same goes with a "girl" whose fused labia and phallus are inappropriately sized/formed, who is then "fixed" so she can later be allowed to procreate. A hypospadiac boy, on the other hand, must undergo phalloplastic surgery so that he can later stand to pee. Clearly intersexuality is not a medical issue, but has always been predominantly a cultural issue that medicine has attempted to control by bringing to the issue of gender identity its tools of medical management. (Cf. Dreger 1998, 167-201)

[29] It does not seem to occur in the literature that the genitals are just what they are and don't need fixing at all. It has recently been argued that differences exhibited in the so-called gender-ambiguous body are well within the range of statistical probability of variation, and should thereby be seen as entirely normal. (McCullough 1999) Recent proposals propose that male and female not be seen as polar points along a spectrum, but that the multiplicity of factors contributing to gendered identities and morphologies should cause us to view each manifestation gender as a point in a multidimensional space. (Fausto-Sterling 2000a) Under this new paradigm, the variety of sex phenotypes presented at birth to the physician would signal, not the need to correct the genital structure, but only the need to test to identify specific health risk factors. Set against this proposed model, the full force of the current model of clinical intervention seeking to reinforce a binary gender system comes to the fore: it is simply a socially- and culturally-driven mandate performed and reinforced through medical disciplinary practices that are premised upon unquestioned assumptions about gender identify and formation.

[30] That the medical protocol and the medical representation of intersex(es) constrains and predetermines the choices available to the parents, is elided in the literature. Usually, articles speak of the parent's "discomfort" and "confusion", of the parent's "demand" for intervention and rectification, thereby representing the intervention as parent-driven and the medical intervention as a response to this demand. It is clear, however, from published studies (Tversky and Kahneman 1981; Marteau 1989), and even the AAP protocol itself (RE 9958), that physicians and medical policy makers do indeed recognize the power of the physician in interacting with parents. Emphasizing the importance of framing the description for the parents, this framing impacts upon not only the reception of the information, but the eventual decision outcome. The physician is taught to choose terms wisely, to educate the parents so that they accept the logic of the protocol and the physician-team's recommendations. Interestingly, the success of this approach, however, depends upon a variety of factors, including the level of parental education, which seems to impact upon the effectiveness of the physicians persuasive logic. (Nussbaum 2000 mentions the difficulties physicians face with certain not very sophisticated parents.) Nevertheless, it is reported by physicians that the parents, when presented with the option of surgical intervention, almost uniformly choose to pursue this route. (Hendricks 1993) It is the presentation of surgery as a solution to a problem carefully taught the parents by their physician that leads the parents to agree. (cf. Dreger 2002)

[31] In contrast, sociologist Suzanne Kessler has assembled data of the way parents view their intersexed children in their own words. The letters from parents containing their initial reaction to their children consistently describe their children as "perfect" and "perfectly healthy". Some of them kept using these terms, even while describing their children's genital anomalies and the procedures physician's prescribed for "correction". (Kessler 1998, 93) Other parents described how physicians altered their perception of their children, stating "we had no idea there was anything wrong", or "no one ever expressed feelings there was something 'wrong' with him", or that the physicians, not the parents, had some question as to the gender of the child. (Kessler 1998, 94) When parents did show concern for their child's state, it was more to do with the potential health issues (regarding CAH, in particular) and medical treatment options than with gender identity and genital appearance: Which hormones and how often? What do the surgical procedures do? What kind of follow up is necessary? How healthy will the child be? It is also clear that when the genitals and the procedures upon them were mentioned, the discussions about them were shaped by the rhetoric of the psychosexual guidelines and physicians, with little or no mention, for example, about the experiences of the child undergoing such operations. (Kessler 1998, 96-97)

[32] Given that, historically, intersexed children and adults were not a problem until medically defined as such (Dreger 1998, 15-78); legally, the problem of intersexuality was a question of inheritance and suffrage (Fausto-Sterling, 30-36); and clinically, underreporting of intersexed conditions continues to occur, it seems a reasonable hypothesis that, without the intervention of the physician and the rhetoric of pathology, the parent might not feel the pressing need to confront issues of gender ideal conformity. The child's body is held under suspicion first and foremost in and by the medical approach.

[33] It is due the representation of the body as non-normal, as (re-)presenting a problem, that the physician-surgeon can offer skills to fix the problem, a rhetorical context in which the parents and patient are caught beneath the full force of clinical disciplining management. Even under circumstances wherein a parent-driven initiative is taken to render the body surgically normalized, it is the rhetorical power of the label of not normal, ambiguous, , disordered that contributes to the conviction to fix the body of the child. What becomes clear in this murky area of "defining the intersexed" is that rhetoric of identification and representation by the literature and protocol, not to mention the individual physician, focuses its full rhetorical force to pathologize the body of the child and renders its state emergent and in need of fixing.

[34] **Rhetoric of Curing:** Once the physician is convinced of the ambiguity of the genitals, has instructed the parents to recognize it, runs the tests and determines the gender to be assigned to the child, how does the physician justify the necessity of the surgery? After all, it is not that genital operations are at all necessary to meet the medical challenges (as distinct from the psychosocial challenges) confronting the patient.

[35] In order to justify surgery, the literature draws from a variety of inventional techniques, which could be summarized as a rhetoric of tragedy. Terms such as "necessary", "must", "demand" and "require" become part of the discourse of physicians when describing these operations. (Kessler 1998, 32) The psychosexual management guidelines suggest that without the surgery, neither the parents nor the child will accept the gender assignment, since the genitals would not clearly display the appropriate and distinctive markings. The parents might reject the child.

[36] Fear of teasing and the assumption of childhood trauma resulting from it, figures large in the literature, without any specific documentation regarding the experience of intersexed children who have not undergone surgery. The "locker room" test in particular plays a vital role for judging the adequacy of size and shape of the "penis". (Mureau et al. 1995; cf. E Lee 1994; Kessler 1998, 70; Kipnis and Diamond 1998, 403)

[37] The medical reports on these surgeries use terms such as "disfiguring and embarrassing" (Gross, Randolph and Crigler 1966), "deformed", "offensive", "troublesome" (Randolph, Hung and Rathlev 1981), "ungainly" (Newman, Randolph and Anderson 1992), "unsightly" (Kogan, Smey and Levitt 1983) when discussing "clitorises" deemed "grossly enlarged" (Gross, Randolph and Crigler 1966). When describing "micropenises", the language is not as dramatic, but can nevertheless verge on the tragic: a child with such a "heartbreaking" condition "must" be raised as "females", they are "doomed to life as a male without a penis". (Newman, Randolph and Anderson 1992, 650) A "small" penis must be constantly reaffirmed in its adequacy to fulfill masculinity. After testosterone treatments [HCG] are administered on the child, physicians look for a reaffirmation "of his allegiance to all things masculine." (Newman, Randolph and Anderson 1992, 645) Parents are reported as having "encouraged more appropriate male behavior". (Guthrie, Smith and Graham 1973, 250)

[38] In the tragic atmosphere of an intersex diagnosis, surgeries become a necessity. In fact, so committed to intervention, surgeons have been known to perform genitoplasty upon children without prior authorization, in addition to other surgical procedures being performed at the time. (Wilson and Reiner 1999, 119) There are available to the surgeon a wide range of genitoplastic techniques available: cliteroplastic and phalloplastic surgeries for the phallus (its reduction, resection, elimination, or, in the case of a hypospadiac penis, reconstruction), vaginoplasties to help construct and elongate the vagina, labioplasties to "improve" and "naturalize" the look of the labia majora. (For an excellent summary, cf. Fausto-Sterling 2000b, 56-63) Consistently, each current surgical technique is described as producing "normal" looking genitals (no matter which era the report comes from), and techniques are represented as vastly improved from those that had been favorable in previous years. (For examples of a rhetoric of progress", cf. Kessler 1998, 74; compare Chase 1998) The report success rates are 100%, with results routinely categorized as "excellent", "acceptable", resulting in achieving a "satisfactory cosmetic result", "normal or near normal anatomic appearance", obtaining vaginal openings "adequate for sexual intercourse", achieving "excellent results" in hypospadiac repairs, and almost always the surgeries result in "minimal complications." (Fausto-Sterling 2000b, Table 4.1-3) The protocol demands the surgeries as necessary, the surgeons report ever improving "excellent" results.

[39] Three issues confront us here. First, as already noted, in spite of the thousands of genital surgeries performed on intersexed children over the last five decades, no meta-analyses of surgical outcomes have been offered to date. What few follow-up studies have been reported show a vastly different picture than that of the surgeons. Of 129 adults reporting outcomes in six follow-up studies (Mulaikai, Migeon and Rock 1987; Allen, Hardy and

Churchill 1982; Slijper et al. 1994; Sotiropoulos et al. 1976; Newman, Randolph and Anderson 1992; Hendren and Atala 1995; Mininberg 1982) on vaginoplastic surgeries, well over half reported complications. One follow-up report on twelve cliteroplastic surgeries showed only five cases reported erectile function and sexual gratification. (Sotiropoulos 1976, 601) Another reported ambivalence toward sexual activity as well as sexual inhibition. (Mininberg 1982, 355) A recent report out of London showed sexual dysfunction common in CAIS individuals, with global mean scores worse than the population average, especially for sexual activity, non-communication with partner about sexual activity, and difficulty with vaginal penetration. (Minto and Creighton) Another showed that 33% of those who underwent cliteroplastic surgery in their sample had never been sexually active and scored significantly abnormal for difficulty with orgasm in comparison with their subjects who had not undergone surgery. (Minto, Creighton and Woodhouse 2001) The results for phalloplasty on hypospadiac penises were mixed: these "men" experienced their first sexual encounter at the same age as "normal" "males", and showed no significant difference in "sexual behavior or functioning". But, they were a lot more timid about seeking out sexual contacts, this timidity growing with the number of surgical procedures performed. (Fausto-Sterling 2000b, 86) This would suggest that the claim for success is unsubstantiated.

[40] Second, as also noted, no standards for success have been agreed upon and are frequently the observations of the physician surgeon with respect to observable, that is, cosmetic outcomes. (Draft Statement, Clitoral Surgery Follow Up Data) Summarizing reports on vaginoplasties on 314 individuals, Fausto-Sterling found only 2/3 of the studies gave specific criteria for success, but these did not agree upon the criteria among them. Reductive cliteroplasties fared worse, with two of the nine surveyed reports offering no criteria for "success", or four focusing upon cosmetic results only, and only one emphasizing psychological and long-term follow-up. (Fausto-Sterling 2000b, Table 4.1; Kessler 1998, 53-54)

[41] Third, depending on the condition, from 30% - 80% of children receiving genital surgery undergo more than one procedure, many from upwards of three to five. (Fausto-Sterling 2000b, 86) Fausto-Sterling found high frequencies of complications for vaginoplasty leading to additional surgeries, occasionally a call for postoperative psychological follow up to help patients accept the surgery, and, in general, poor success rates (the highest reported 65% "satisfactory introitus and vagina"). Almost half of the "boys" who underwent phalloplastic surgery between 1985-1992 had to undergo secondary operations to repair the results of the first surgeries. (cf. also Kessler 1998, 71)

[42] These results have been confirmed and elaborated by a recent study coming out of Johns Hopkins. In spite of assurances from the literature given to parents that for gender-assigned males 23 surgeries represent the maximum number of operations and that some patients may need touch up surgery for gender-assigned females, (Migeon et al. 2001) the latest reports from a follow up study 39 hypospadias 46,XY patients show a statistical mean of 5.8 surgeries for men, and a statistical mean of 2.1 for women. Men rated their body image scores higher than the observer-physicians, but neither group was entirely satisfied. Reasons for dissatisfaction were overwhelmingly the unusual appearance of genitalia (71%), with dissatisfaction of gentiosexual function being attributed to surgical complications. Physicians and women rated better cosmetic outcome of feminizing genitoplasty than the men, but did not differ from them in the satisfaction with sexual functioning (somewhat unsatisfied) or body image (somewhat satisfied). Like men, the appearance of their genitalia was the greatest single factor contributing to their dissatisfaction with body image. (Migeon 2002) In total, almost half of all participants reported dissatisfaction with their body image, and two-third were dissatisfied with their sexual functioning.

[43] It is important to note, the subjective declaration of surgical success by urologists notwithstanding, the same techniques for adult transgendered patients are not reported as so successful. (Green 1995) Anecdotal reports from the transgendered community reflect a large number of transsexuals opting out of genital surgery altogether, and those that do

undergo genitoplasty and succeed in "passing" cosmetically, report scarring, numbing, residual pain, the need for repeated dilation or catheterization (for MTF), and sometimes difficulty with maintaining hormonal therapy without unwanted side-effects. (Cf. Califia 1997, 192, 207-209) Surgeons operating on adult transsexuals provide a much different picture of the results, a more nuanced rhetoric seeking to generate more "realistic" expectations regarding surgical outcomes. (Kessler 1998, 73)

[44] It is unclear how much of this is communicated to the parents or patients, nor how well medical information about these procedures, their long-term impact, and the underlying medical conditions they are intended to address are shared. Some recent studies have suggested that under certain circumstances parents are not given consistent information to help them understand the circumstances that they are confronting, (Abramsky 2001; Biesecker 2001) and only half of adult patients according to a follow up study were well informed of their condition and medical history and satisfied with their knowledge. (Migeon 2002) It is these factors that contribute greatly to the argument that informed consent simply cannot and does not take place in decision-making regarding the body of the infant.

[45] Even if it is the case that full disclosure of what few results we have of any meta-analysis and/or long-term study, or if it were the case that the results agreed upon measures of success and could demonstrate it, nevertheless the context of genitoplastic surgery is a context of erasure of difference in an effort to construct "normalcy. Between the declaration of "ambiguous" genitals, the authoritative assignment of gender, the rhetoric of tragedy surrounding the condition of the child, the "necessity" of surgical intervention, the frequency of secondary surgical procedures, and the commitment of the protocol to force the child into culturally, not medically grounded concepts of gender, medical management places and keeps the intersexed child in a state of continued medical management. "Curing" creates and maintains a state of "illness".

[46] **Rhetoric of Illness:** The surgery is declared "successful", and the child and parents go home ready to live "normal" lives according to the gender identity "discovered" and "constructed". But what, exactly, does "success" mean? We mentioned earlier the difficulty with which medical standards can be found and applied to the surgical outcomes. We have also mentioned questions regarding the standards by which to determine successful gender assignment. (Cf. Holmes 1995) Alongside these basic, but also obvious issues confronting the protocol, there is something more subtle to consider: the paradox at the heart of the protocol.

[47] Specifically, I wish to refer to the rhetorical effect of current medical management that blurs the distinction between the "natural" and the "constructed". It proceeds first by taking the "natural" gender indicators on the body of the newborn and turning them into a problem. It holds the body under judgment of suspicion, and expresses this suspicion in a way that suggests that the body has not completed its development: the gender is "there", only it is "hidden". Insofar as the gender is indeed "there", the body has been rejected in its typical role of "natural" foundation for gender identity. The medical protocol demands that the body conform to a preset agenda. What is "natural" has been rejected. The solution? To "construct" a body through surgical techniques and hormone replacement. But it is this "constructed" body that reflects the "true" gender. It is this "constructed" body that is described as "natural".

[48] The body of the intersex(es) is thereby placed in a very strange zone. It is, for all intents and purposes, a cyborg body, a construction of organic and technological components that are supposed to represent more naturally the authentic gender. The success of the protocol depends upon the intersexed child and the parents ignoring all the artificiality the body displays and accepting it as "natural". It is dependent upon a denial of the daily experiences of encountering its own artificiality, experiences intensified each and every time the protocol and its procedures are employed (secondary surgeries, dilation, catheterization, hormone injections/ingestion, follow up consultations, therapy sessions). It requires for its success that the patient and parents to adopt an Orwellian doublethink.

[49] Within such constraints the success of the protocol, whatever its criteria for success are, is severely undermined. Indeed, it is fatally flawed, as it suggests that even if the patient accepts her/his assigned gender, s/he does so in spite of the trauma s/he undergoes when facing the abnormal normality of the medically managed body. Indeed, psychoanalytic literature confirms this: patients experience their treatment as trauma and the source of longstanding psychological damage. (Shopper 1995; Money and Lamacz 1987) One report found that genital surgeries in childhood influenced patient fantasies of injury and sexual difference. (Rosenblitt 1991) Another reported that the universal source of pain among intersexed adults was their experience at the hands of physicians. (Preves 1999) Still another reported a normally outgoing and active child, after having been assigned her gender and undergoing surgery because shy and withdrawn and lodged vehement protests against her hormonal treatments administered later. (Keppel and Osofsky 1985) Even advocates for the protocol noted that parents were reluctant to bring the child back for outpatient check-ups due to having to confront the condition they were trying to forget. (Slijper 1994)

[50] Unfortunately, normalizing procedures like cosmetic genital surgeries sometimes inadvertently [sic] make parents and children feel unnecessary shame. Many adults I know with intersex conditions feel that their parents decision to change their genitals for cosmetic reasons means that their parents saw them as freaks, even though that is not what their parents intended. (Dreger 2002)

[51] These clinical observations are echoed throughout the published, anecdotal first-hand reports of intersexed patients having undergone genital surgery and gender reassignment. Uniformly, they reflect symptomatology of trauma related to the medical management. First-person accounts in *Chrysalis*, reproduced and expanded in Dreger shows a consistency of themes: isolation and a sense of "monstrosity", anger at the deception and silence they repeatedly confronted, shame at the hands of physicians who put them on display, humiliation at the stigmatization experienced by repeated medical interventions (Alexandra 1997), pain from surgical scarring and physical therapy (Melson 2001), little sex drive, few experiences of orgasm. (Alizai et al. 1999) Other first-person testimonials relate similar messages.

[52] Parental reports, rare-to-non-existent in medical literature, also support this conclusion. Assembled by sociologist Wendy Kessler, parents reflect traumatological symptoms. They report the initial fear and sense of helplessness and confusion at being told their healthy newborn is intersexed. Time and again parents talk about preparing for the time when they can talk to their child, and defend their decisions on the basis of ignorance or obligation. (Kessler 1998, 90) One report from a mother speaks of how her 18-month old intersexed child stopped pulling out her own eyelashes and biting her nails only after the mother stopped all efforts at dilating her vagina. Another reports that her child who is scared of her "tube". Still others relate how the child who has to squeeze urine out of a diverticulum each time he pees, because of the damage he suffered at the hands of a pediatric urologist. One letter told of a five year old who says, "I hate my dong, I wish I was born a girl," after two surgeries to "correct" his hypospadias. (Kessler 1998, 61-64)

[53] These reports, by both intersexed patients and their parents, prompted one scholar to suggest that the experiences of those undergoing medical management are directly reflective of similar seculars of childhood sexual abuse. These include similar experiences of shame and embarrassment, secrecy and silence, misinformation, dissociation and body estrangement, and betrayal trauma. (Alexander 1997) These experiences have been confirmed, especially trauma, in one of the few psychological case studies to be published on the intersexed. (Williams 2002)

[54] The difficulty with referring to these testimonials is that for physicians anecdotal reports do not carry the weight of clinical trials and follow-up studies. Only recently have long-term studies been published that include evaluation of psychological function. The results of these studies suggest that the current protocol is not, in fact, helping the patients accept and feel comfortable with themselves. One study found 40% of those who under-

went treatment had developed psychopathology by age 16. (Slijper et al. 1998) The Johns Hopkins study also indicates that while gender assignment has been generally "successful" for those participating in the follow-up study, over half of the individuals have reported psychosocial difficulties related to their bodies, and worse results regarding sexual comfort. (Migeon 2002, Discussion: Sexual Orientation)

[55] Interestingly, the authors of these reports indicate that many chose not to participate, and offer as a possible reason the rejection of, and anger with, the protocol and the physician-managers under whose care they were treated. (Migeon et al. 2002)

[56] The conclusion to be drawn from these various sources is that the "curative" procedures and interventions designed to help the intersexed children "heal" have, instead, made them feel "ill" at ease - with themselves, their physicians, their society. Upon the body of the intersex(es) are carved the markings of a gender ideal strictly for the purposes of bringing comfort to others, regardless of the consequences to the child upon whom the burden of conformity is shifted. The result is a constraint upon the child to become complicit in the attempt at erasure of abnormality, an attempt that seeks to convince the patient and parents that the medically managed body is normal. The result is, the child cannot be anything other than ill.

Conclusions

[57] Our study brings about new insights to the discussion of the reform of current medical management policies of the intersex(es), insights not yet considered by ethicists, policy makers, or gender theorists: that the intersex is rendered through medical management a rhetorical, not physiological state of pathology in need of repair. It reveals that the current practices meant to address their existence do so at the expense of the healing they to bring about.

[58] With respect to the current ethical criticisms advocating a halt to surgical intervention: if through surgical and cloning techniques genitals can be fashioned that function without trauma or loss of sensation; if disclosure and "informed consent" are fully enacted: the medical approach of management and intervention cannot succeed, because its rhetoric requires a commitment on the part of the intersexed individual (and parents, friends, colleagues, playmates) to accept the erasure of their intersexuality as normal. As long as the bodies of the intersex(es) are viewed and rhetorically represented as incomplete, faulty or insufficient, as long as the modern medical industrial complex presents itself as the means for identifying the true sex and surgically altering the body of the patient to normalize it, only the body of the medically intervened will be considered and represented as fixed. The paradox of the rhetoric of the medical management of the intersex(es) is simply this: only the surgically altered and rhetorically subsumed body becomes the standard by which to judge an intersexed patient normal.

[59] Current ethical models do nothing to relieve this problem. At the heart of the current ethical critique lies a continued presumption of gender binarism from which the intersexed child deviates. While laudatory for asserting the autonomy of the patient and for indicating that the surgeries are for the comfort of the parent and doctor alone, the pragmatism of the appeal continues to allow for the presumption that intersexed children are not normal. The body is rendered suspect, the disease is presented to the parents in terms of deviation and pathology, medical research and intervention is presented as the cure, the intended audience is parents and observers, the result is conformity.

[60] But the patient suffers the debilitating consequences for deviation from culturally and medically mandated normativity.

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