

**INTERSEX(ES) AND ALTERNATIVE STRATEGIES OF HEALING:  
MEDICINE, SOCIAL IMPERATIVES AND COUNTER-COMMUNITIES OF IDENTITY**

BY

**J. DAVID HESTER**

**Published (in German) as "Intersexes and Alternative Strategies of Healing: Medicine, Social Imperatives and Counter-communities of Identity," *Zeitschrift für Ethik in der Medizin* (2004).**

The classification of a child or adult as "intersexed" is an extremely complex process, not only with respect to the use of medical criteria used to make the identification, but especially also with respect to the social consequences faced by both patient and parents. The medical literature recognizes a wide variety of conditions and factors that can contribute to the eventual diagnosis: genetic, chromosomal, hormonal, gonadal, internal and external phenotype and the various congenital and/or pre-natal conditions that can have an impact upon the body of the patient [4; 14]. Additionally, however, psychosocial factors have also played an important role [6; 32; 33; 36; 37; 38]: sex of rearing, sexed identity (both pre- and post-pubescent), and even sex object desire<sup>1</sup> have often impacted decisions about the clarity and success of the classification of an individual as either male or female under the guidance of the "optimal-gender" policy [32; 33]. It is commonplace in the literature to cite the statistic that 1.7 intersex births out of 100 [11], with 1 child out of 1000 or 2000 to present enough genital ambiguity to warrant considering surgical intervention [22].<sup>2</sup> This statistic itself, however, signals the inherent breadth and variation associated with the classification: some cases of intersexuality present physically more obvious "evidence" of sex-morphological discontinuity than others.

---

<sup>1</sup> Vgl. dazu [17], [20] und [22] document and explore the profound impact that the fear of homosexuality has made upon the medical management of intersexed patients.

<sup>2</sup> This statistic has been publicized by the Intersex Society of North America, <[www.isna.org](http://www.isna.org)>

Historical and rhetorical analysis [25] of modern (mid-19<sup>th</sup> century onwards) medical research and response in cases of intersexuality demonstrate the impact of specific social values in determining both classification and goal of intervention. It is in particular these values that have had such a profound impact upon the variability of identification of and response to intersexuality. On the one hand, the fluidity of sexual identity in time and across cultures makes it difficult to ascertain self-evident standards by which to judge when cases of “intersexuality” should be identified and treated. On the other hand, social demands that the individual nonetheless conform to social concepts of sexed identity motivate and drive the intervention and methods of medical treatment. The purpose and justification of medicine’s treatment of these cases center around the issue of successful integration of the intersexed individual into the gender norms of the society into which she or he is born (vgl. dazu [7]; compare, however [16]). It is this concept of “healing” that is operating as the presumed goal of medical intervention. Under these circumstances, dominant communitarian values take supremacy in medical decision-making.

The question we will explore in this essay is the extent to which these circumstances can be justified. Medical intervention in cases of intersexuality premised upon the application of communitarian values approaches the intersexed as deviations in need of treatment. Under this view, “healing” is understood as resulting from employing medical services in order to help the individual conform to community values. This presumes, on the one hand, that untreated individuals cannot successfully “heal”, and on the other, that treated individuals experience medical intervention as a means for “healing”. Are these assumptions justifiable? If not, what alternatives to this notion of “healing” are employed, and by whom? What implications would such alternatives have for the current “optimal gender” policy, and for medicine in general?

In order to answer these questions, we will review the responses of intersexed individuals and their parents available to researchers through internet websites, forums, discussion groups, and first-person published essays. We will consider carefully what is herein termed the “rhetorics of healing” – the discursive and concrete strategies which intersexes themselves employ in their own efforts at “healing”. In this way, we can

---

<sup>3</sup> vgl. ([17], S. 79-109); S. 139-166 gives a detailed history of modern medicine’s early efforts to classify and provide treatment for hermaphroditism; ebenso ([20], S. 29-114)

compare medicine's presumptions of the way these individuals are "supposed" to heal (through medical intervention) with the way intersex individuals themselves describe the healing process. It is hoped that by doing so, we can shed a new light upon current debates regarding the treatment of intersexes,<sup>4</sup> not by addressing the specific issues of determining which means of "curing" represent the best choice,<sup>5</sup> but by considering the more implicit and therefore more fundamental question of how "healing" takes place. In this way we may be able to conceive of new contexts within which medicine's response need not be determined and limited by dominant social values.

### **FRAMEWORKS OF HEALING**

For the purposes of this essay, "intersexuality" is understood simply as those physiological conditions, broadly conceived, that are viewed by either physicians, parents or patients as "deviations" from the sociologically significant norm of an exclusive male-female delineation of sex. These can include endocrinological conditions such as Androgen Insensitivity Syndrome (which results in varying degrees of discontinuity between chromosomal and anatomical/genital sex factors)<sup>6</sup> and

---

<sup>4</sup> In favor of the "optimal gender" policy vgl. [32; 33; 36; 37; 38]. Against the policy's current emphasis upon surgical intervention siehe [8; 15; 30; 45].

<sup>5</sup> The North American Task Force on Intersexuality, founded in 2000 by pediatric urologist Ian Aaronson of the Medical University of South Carolina in Charleston, is the first concerted, systematic effort by the medical community to look at all the clinical data and gather all the information available regarding clinical responses to genital ambiguity and their long-term outcomes. Other efforts are being led by W Reiner of The Johns Hopkins Gender Identity and Psychosexual Disorders Clinic. Another is being led by C Migeon, an endocrinologist and professor of pediatrics at The Johns Hopkins Medical Center; initial results have been published under [34; 35]. Another is focusing on CAH patients, led by S Berenbaum, a psychologist and professor of physiology at Southern Illinois University School of Medicine.

<sup>6</sup> Besides the major works cited in notes 1 and 2, above, which give explanation of this condition vgl. ebenso [5; 10; 47]

Congenital Adrenal Hyperplasia (which can result in genital “virilization” for XX chromosome individuals) (vgl. [19]), to genital variations whose etiologies are not clearly understood (micropenis,<sup>7</sup> clitoromegaly,<sup>8</sup> hypospadias<sup>9</sup>), to chromosomal “anomalities” (Turner (vgl. [6; 43; 53], ebenso [50]) Klinefelter (vgl. [31], ebenso [9; 46]) whose phenotypic and anatomical impact may be apparent, but whose socially recognized gender assignment may not (at first) be under question.

The reason for taking such a broad view of intersexuality is that it will help us to note not only the common experience of “illness” shared by all, an “illness” whose consequences lead to the medical classification of “disease”. It will also help us to note common, if also variable, strategies of “healing” that are undertaken by these individuals and groups. What they all share is an experience of (or classification as) social liminality (“illness”) on the basis of a naturalized assumption of sexed identity premised upon the belief that a human being should be clearly and unambiguously identified as belonging to one of only two sexes: male or female.

Medical strategies to confront the issue of the liminal position of intersex(es) have taken two major forms. The first is through the creation of a rhetorical space (i.e. performative-diagnostic space generated most often through the rhetoric of the attending physicians) wherein an intersexed child is not recognized as a pathology or developmental deviation, or if recognized as such, is nevertheless accepted without recourse to immediate medical intervention. This was historically the predominant, if also at times not unproblematic response by those attending births up to the late 19<sup>th</sup> century in Europe and America. This approach continues to function, to an ever-decreasing extent, even today in mostly non-urban and non-Western settings. Sometimes, this rhetorical space is the result of a lack of knowledge or recognition of intersex(ed) “conditions” by those in attendance. Sometimes it occurs through the

---

<sup>7</sup> Most neonate penises range 2.8 to 4.5 centimeters in stretched length. A micropenis is defined as a phallus “have a stretched length of less than 2.5 standard deviations below the mean for age or stage of development.” ([44], S. 569). That translates to 2.5 centimeters as the minimal accepted length.

<sup>8</sup> Clitoral length of 82 neonates ranged from 0.2 to 0.85 centimeters.

<sup>9</sup> As an indication of underlying intersexed condition, however, the birth rate is closer to 1 in 10,000 (vgl.[2; 42]).

happenstance of the birth and registration of the infant outside the medical system. It can also be the result of the direct rejection by parents of the practice of physicians that seek to create an alternative rhetorical space, namely, a space of trauma and pathology. Regardless of its origins, the effective result is the minimization of the pathological experience of liminality by means of a rhetorical space of “acceptance” of the person for who and what they are, and not for what they ought to become. A process of naturalization generates processes wherein “healing” is not “healing from”, but living comfortably and healthily with oneself as intersex.

Alternatively, liminality is overcome through direct confrontation of forces of social and medical management seeking to eradicate difference. This usually results from the experiences of those who at birth were identified as intersex and upon whom medical management and surgical intervention were agreed upon (by both parents and physicians) and enacted. In reaction, intersexed individuals come together to create a rhetorical space of “healing” that is “healing from”. However, the object and circumstance from out of which “healing” takes place is not their own identities as intersex(es), but the medical practices whose intentions are to bring them into conformity with the binary gender system. By addressing the issues and strategies of illness that intersex(es) face, many intersex(es) come together and develop counter-strategies of healing that often include confronting silence and isolation by seeking out and/or creating communities of support. Liminality is eradicated through the rhetorical strategies of fashioning new facets of identity and through outreach and education. Rhetorics of healing that emphasize truth-telling, seek to overcome isolation, and reject pathological labels and practices that dominate these discourses.

In what follows, we will explore more in-depth several examples of the rhetorics of healing. Drawing from resources made available to us through the advent of internet technology,<sup>10</sup> we will turn to the many first-person stories of intersexed individuals and

---

<sup>10</sup> Among those whose information has been helpful for this study, in addition to those mentioned in the references given below, are the following: Intersexed Society of North America <<http://www.isna.org>>, The UK Intersex Association <<http://www.ukia.co.uk>>, Intersex Society of South Africa <[isosa@netactive.co.za](mailto:isosa@netactive.co.za)>, Adrenal Hyperplasia Network <<http://www.anh.org.uk>>, Cares Foundation <<http://www.caresfoundation.org>>, The Magic Foundation

parents of intersexed minors, as well as to the discussion-forums hosted by new communities of intersexed identities. Due directly to the advent of this new form of communication, these individuals and groups have developed an unprecedented level of outreach, education and advocacy previously unavailable to them. We will consider these many examples within the broad framework outlined above, consisting of non-pathological identity on the one hand and anti-pathological identity on the other.

### **RHETORICS OF HEALING: NON-PATHOLOGICAL IDENTITIES**

There is very little direct evidence for or against the success of psychosocial paradigm of the medical management of intersex(es). Long-term studies of the effect of current medical practices including rapid gender assignment, surgical intervention, and routine non-disclosure are only just beginning to be proposed. Evidence for or against the long-term effectiveness of early medical and surgical intervention, despite 50 years of its widely adopted practice, is simply incomplete or non-existent.

On the one hand, this suggests the necessarily tentative and experimental nature of current medical management practices, bringing with it a host of ethical and legal issues concerning how physicians represent the results of their interventions. On the other hand, what little follow-up evidence has been published, both directly related to the results of the “optimal gender” protocol upon the intersexed and indirectly reflecting it by reference to the long-term effects of the surgical procedures, suggests

---

<<http://www.magicfoundation.org>>, CAH Support Group of Australia  
<<http://www.vicnet.net.au/%7Ecahsga/>>, Bodies Like Ours  
<<http://www.bodieslikeours.org>>, Riksföreningen för Adrenogenitalt Syndrom  
<<http://home.bip.net/rf-ags>>, Intersex Support Group International  
<<http://www.isgi.org>>, MRKH Foundation <<http://www.mrkh.net>>, The Turner Society  
<<http://www.tss.org.uk>>, Mixed Gonadal Dysgenesis Support Group  
<<http://www.xyxo.org>>, Klinefelter Syndrome and Associates  
<<http://www.genetic.org/ks>>, Hypospadias Support Group  
<<http://www.hypospadias.co.uk>>

some very real risks for those who are under the management of doctors dedicated to the interventionist paradigm.

This situation has led to the current state of intersex research and medical practice, a state wherein a dawning cultural awareness, fostered by the formation of patient-advocacy groups first established with the advent of the internet, is beginning to question the medical, theoretical and ethical validity of the last 50 years of the dominant modern medical paradigm. Physicians, however, when confronted with arguments for the rejection of the paradigm, often counter with two arguments of their own: First, they employ what argumentation theory terms an argument from silence as evidence of positive surgical and psychosocial outcomes: they have not received negative feedback from the vast majority of their patients, and those from whom they have received complaints represent a vocal minority. Second, they appeal to a presumption that doing nothing with the infants would wreak social and psychological damage for both the patients and their families. While the first argument is currently being addressed by the several long-term studies finally underway in the United States and elsewhere, it is the latter assertion that concerns us here.

The claim that non-medical and non-surgical intervention would result in social and psychological damage is at its heart value judgment premised upon several naturalized presumptions. These include the presumptions that the binary sex-gender system is self-evident, that variations therefrom are pathological deviations in need of repair, that physiological variability of the genitals results in psychosocial stigmatization that patients cannot overcome without medical help, and that it is the role of the physician to ensure psychosocial adjustment through medical and surgical intervention. These presumptions lend their support to the hierarchy of express values that govern medical practice: namely, that physicians and medical practices are to offer means by which “diseased” patients are to be “cured”. The confusion that arises in the case of intersex(ed) patients and their families is one that views “illness” (social stigmatization) as “disease”, and therefore puts the physician in a place wherein “curing” presumes “healing”. In other words, a type of category error can occur when the physician proclaims the birth of an intersexed child as a “psychosocial emergency” and then works upon the patient through medical-surgical means.

Much of the reasoning behind this approach to the issue of intersex(es) is the result of certain histories of medical practices, as well as the history of the medicine and its

social and juridical place in late-modern society (vgl. the often cited work of. [17]). Rather than exploring their historical roots here, I would like to test the presumptions themselves. Taken together, they suggest that those intersexed minors upon whom no medical intervention was practiced would suffer severe psychosocial hardships due to their stigmatized status as gender “deviations”. This is a claim whose benefit is its testability: Is it in fact the case that intersexed people suffer from their condition without medical intervention?

This question has been recently addressed in two key reports, whose conclusions seem to directly contradict this claim and thereby undermine the presumptions supporting it. The first report is an analysis of over eighty examples (published since 1950) of adolescents and adults who grew up with visibly anomalous genitalia ([20], Table 4.3 (pp. 96-100) and Table 4.4 (pp. 102-106). In at least 37 cases, surgical intervention occurred at the request of the adolescent or adult. In all other cases, surgery was not pursued. When surgical intervention did occur, it was not until well after birth. Only two out of 33 cases of those raised as males were reassigned, both voluntarily. Only seven cases out of 51 cases of those raised as female wished to be reassigned as male. In all but one case, the case summaries report that individuals developed into functioning adults, “many of whom have active and apparently satisfactory sex lives.” ([20], p 95). This suggests that immediate surgical intervention upon the birth of the child is neither necessary for successful gender identity development, nor that its absence condemns the individual to a life of difficult psychosocial adjustment.

This conclusion is supported ironically by the research done by John Money, the founder of the current medical paradigm, in his dissertation submitted in 1951 to Harvard University on “hermaphroditism” exploring the lives of 250 intersexed individuals who did not undergo surgery, ten of whom he interviewed in depth. Money’s findings suggested: “One would not have been surprised had the paradox of hermaphroditism been a fertile source of psychosis and neurosis...The evidence, however, shows that the incidence of the so-called functional psychoses in the most ambisexual of the hermaphrodites—those who could not help but be aware that they were sexually equivocal—was extraordinarily low. The incidence of neurotic

psychopathology of the classic types, sufficiently severe and incapacitating to be unmistakable, was also conspicuously low.”<sup>11</sup>

Money’s work was supplemented and enhanced by the further research of John and Jane Hampson at Johns Hopkins. Together over the next six years, they would study an additional 131 intersexed individuals from all age groups, and publish their findings as the basis for what was to become the theory of psychosexual neutrality at birth. The conclusions reached by the Hampsons in a 1961 article were similar to those reached 10 years earlier by Money, “The *surprise* is that so many ambiguous-looking patients were able, *appearance notwithstanding*, to grow up and achieve a rating of psychologically healthy, or perhaps only mildly non-healthy.” ([23], 1428-1429). Contrary to the initial expectations of the report’s authors, intersexed individuals grew up comfortable with their genital ambiguity.

These reports are supported by additional evidence from India [48] and Saudi Arabia (vgl. [51], ebnsa [3]), South Africa [1], Turkey [40], as well as anthropological evidence from the Dominican Republic [27; 28] and elsewhere [24]. In these cultures, varying social responses to intersex(es) occur between them, including noteworthy differences in outcome that cultural values play in assigning gender to these minors. However, what they share is a common conclusion: the lack of surgical intervention upon the genitals does not seem to have negative social effects anticipated by and justifying the modern medical paradigm adopted in the North.

Anecdotal evidence from the intersexed themselves confirms these reports. Such first-hand accounts are infrequent and difficult to find.<sup>12</sup> Nevertheless, when discovered

---

<sup>11</sup> J Money’s dissertation was never published, but is reported on by J Colapinto ([12], S. 233-235), and can be obtained under the title “Hermaphroditism: An Inquiry into the Nature of a Human Paradox” Social Sciences (PhD Dissertation; Cambridge, MA: Harvard University, 1952).

<sup>12</sup> Among those I have been able to identify and access include: “Bobby-Jo” <[http://www.medhelp.org/www/ais/stories/bobby\\_jo.htm](http://www.medhelp.org/www/ais/stories/bobby_jo.htm)>, “Tony” <<http://home.vicnet.net.au/~aissg/Tony.htm>>, “A Berdache’s Odyssey” <[http://members.tripod.com/~Berdache\\_Two/](http://members.tripod.com/~Berdache_Two/)>, “Swati’s Story” <<http://www.medhelp.org/www/ais/stories/swati.htm>>, “Intersex Babies: Controversy Over Operating to Change Ambiguous Genitalia,” ABC News (19 April 2002),

they all reflect a similarity in certain features of their experience: some degree of awareness of difference with their peers, but no traumatological relationship to their own bodies<sup>13</sup>: “But of course it bothered me that the periods had never started. I just told myself that it would never happen now and hey what the hell I didn’t care...I was saving a ton of \$\$ on pads and tampons and being “sick” once a month like so many girls. Besides, I was just going to stay single and I still didn’t want kids anyhow. I truly felt ‘blessed’ by not having this monthly curse and thought of myself as a very unique special girl. And I had just accepted the fact that in my mind I just never developed “downstairs” and my insides they were still like a little girls, OK so what I can live with that!”<sup>14</sup>

A curiosity about this difference usually leads to an awakening experience (through television, internet searches, eventual medical diagnosis) wherein their identity as an “intersex” becomes known to them; this in turn leads to a confirmation of intuitive experiences, and offers them an identity that confirms their own sense uniqueness. As one put it, after reading a newspaper article on intersexes (a term she had never heard before): “I just remember being like...Oh my God, I think this is me. I was overjoyed to know what I was.”<sup>15</sup>

And when asked if they would pursue surgical interventions upon their genitalia, the majority of them reject the idea.<sup>16</sup> “Of course I was teased about my body when I was growing up, as is the experience of most children, but that is no reason to alter one’s body. A couple of my lovers have teased me tenderly about my androgynous body,

---

<[http://abcnews.go.com/sections/2020DailyNews/2020\\_intersex\\_020419.html](http://abcnews.go.com/sections/2020DailyNews/2020_intersex_020419.html)>. See also the essays in the collection edited by Alice Dreger [13; 18; 29]

<sup>13</sup> All reported teasing from peers and negative reactions by others (from rejection by potential lovers, to incestual rape), but none of them reflect a traumatology of their own body and person stemming from their genital ambiguity.

<sup>14</sup> “Bobby Jo’s Story”, an autobiography of an adult CAIS “female”, available at <[http://www.medhelp.org/www/ais/stories/bobby\\_jo.htm](http://www.medhelp.org/www/ais/stories/bobby_jo.htm)>

<sup>15</sup> “Viloria”, quoted in “Intersex Babies,” ABC News: 20/20

<sup>16</sup> “Bobby-Jo”(CAIS “female”) was eventually accepted surgery to remove her undescended testicles, “Tony” (PAIS “male”) opted to undergo a mastectomy, abdominoplasty and phalloplasty.

and used to be embarrassed about the way my clitoris stuck out – it didn't hide behind my labia like I thought it should – but again that is no reason to surgically alter it. As an adult I have grown to like my body the way it is. I like the fact that we are each unique individuals, which necessitates a wide variety of body shapes, sizes, and colors. I certainly don't feel the medical establishment has the right to determine which of our bodies are socially acceptable." ([29], p 100).

Unquestioning acceptance of intersexed bodies as normal and natural seems to be a powerful means of "healing". As these examples indicate, intersex(es) whose bodies diverge from the gender ideal nevertheless find "health" through integration into the community and acceptance of their own bodies simply as individual variations on sex-gender. Their experiences share an important common trait together: they are "healthy" with respect to their sense of gendered/sexed selves. The absence of experiencing a rhetoric of pathology, as practiced by the medical practitioners under the modern medical paradigm and reinforced through medical intervention, avoids the creation of a space from out of which the intersex(es) "must" be "healed". Psychosocial liminality is neither rhetorically generated nor reinforced through the institutional imposition of gender categories by medical means. Rather, the intersex(es) find identity and place within community, and may or may not choose to turn to medicine in order to address specific features of their individual bodies.

### **RHETORICS OF HEALING: COUNTER-CULTURAL COMMUNITIES OF IDENTITY**

Those who have undergone treatment under the medical management protocol have taken another route toward the development of a context of healing. In contrast to those whose intersexuality was not discovered or, for whatever reason, was not medically addressed, those who have undergone treatment are placed in a context that requires them to "heal from". Some suggestive lessons regarding the development of rhetorics of healing arise from out of this different context.

On the one hand, it is certainly the case that each condition, due to both the nature of the condition and the ways in which the condition is typically and traditionally treated by the medical community, generates a unique context from out of which the intersexed patient seeks to "heal". On the other hand, the many first-person accounts

now available to the researcher describe several strategies of healing in common among the various conditions. Foremost among them, as we shall see in what is to follow, is the participation in newly-formed communities of shared experience and valuing-practices that provide intersex(es) with a space through which they overcome their isolation, in which they begin to validate experiences, and from out of which they seek to reach out to others.

*Androgen Insensitivity Syndrome* (AIS – a person with XY chromosomes whose cells cannot “read” testosterone and therefore develop a typically “female” phenotype) patient narratives share a similar structural pattern of medical intervention, familial response, and patient experience.<sup>17</sup> According to the descriptions by AIS adults, at a young age the patient is brought to the doctor, a series of tests is run whose outcome is not shared, “hernia” operations are scheduled for the removal of “faulty ovaries” or sometimes “appendix”. In some cases, the reason for the intervention is due to amenorrhea; in other cases it is “discovered” through a series of accidental (biology lab karyotype) and no-so-accidental factors (determined effort by the patient to research medical reports and records). With the approach of puberty, the individual is put on hormone replacement therapy (HRT) and is told about not being able to have children (adoption as an option is usually mentioned). The individual often feels odd due to the sometimes obvious differences in their bodies to those of their peers and/or siblings

---

<sup>17</sup> The following analysis is based upon a collection of 71 first-person accounts in English and German culled from the material made available from the following websites: Androgen Insensitivity Syndrome Support Group <<http://www.medhelp.org/www/ais>>, AIS Support Group Australia Inc. <<http://home.vicnet.net.au/~aissg/>>, XY-Frauen <<http://www.xy-frauen.de/>>, Arbeitsgruppe Gegen Gewalt in der Paediatric und Gynaekologie <<http://www.postgender.de/>>. Additional accounts can be found in articles addressing the question of the medical management of intersex(es), for example at <<http://mosaic.echonyc.com/~onissues/su98coventry.html>>, <<http://www.qis.net/~triea/diane.html>> and <<http://www.nerve.com/dispatches/levay/intersex/intersex.asp>>. The lowest reported age of the group of authors was reported to be 18, the highest over 65, with an average age of between 30-35, and a median age of between 35-40.

(taller body, no body hair, and for post-operative Complete-Androgen Insensitivity Syndrome [CAIS] individuals secondary sex characteristics developing only as a result of HRT), but is rarely told the truth about their condition, and even more rarely given referrals to support groups or counseling. “At about 26 I went to see my doctor about some totally unrelated problem and thought I’d ask her one of the questions that had been niggling at me – whether I should be having smears...To this she replied, “No you have no womb, therefore no cervix. You were born with testes but it was decided as you had normal external female genitalia that you would grow up as a girl”. She must have seen the mortified look on my face then and she added, “Yes, you are one of them.”<sup>18</sup> “There was really no support from my family at all when I was told I would never have kids (happened in a cold hospital room one late summer day in my 16<sup>th</sup> year). Dr. blurted out the news to me and walked out. No counseling, no after care, just the bare facts.”<sup>19</sup>

Many patients recount episodes of display to interns and other doctors, and/or of photographic sessions. Periods of depression are often described, and symptoms of trauma related to these experiences of display are often described. “I was then placed on a table [with] a paper gown, feet in stirrups, probed and prodded with God knows what in my genital area, breasts examined, finger up my rectum, with three other interns and a nurse watching, asking questions as if I wasn’t even there. Each intern touched my genitals. They took pictures. I was crying and nobody cared or stopped what they were doing. I begged them to stop and they just said “oh that doesn’t hurt that much” and “We’ll be done in a minute honey.”<sup>20</sup>

What surrounds the AIS individuals, as patients, is a practice of isolation, evasion and deflection in a paternalistic effort to shield them from the truth. The concerted practiced of secrecy, however, takes its toll. “I was taken to the doctor and within days, surgery was scheduled, for what I was told, a hernia repair. When I awoke from

---

<sup>18</sup> “Elaine’s Story”, e1-e2: e1, available at <http://www.medhelp.org/www/ais/stories/elaine.htm>

<sup>19</sup> “Carmel’s Story”, e1, available at <http://www.medhelp.org/www/ais/stories/carmel.htm>

<sup>20</sup> “Jeanne’s Story,” e1, available at <http://www.medhelp.org/www/ais/stories/jeanne.htm>

surgery, my parents were standing next to the bed. I lifted up the sheet and saw two identical incisions, one on the left, one on the right. I said to my parents, “Why do I have two scars?” My mother, without missing a beat, said, “They also removed your appendix.” I didn’t know it at the time, but 32 years of lies and shame had just begun.”<sup>21</sup> As one individual succinctly put it: “Although the doctors has claimed that knowing the truth would make me self-destructive, it was not knowing what had been done to me – and why – that made me want to die.”<sup>22</sup>

The AIS narratives that are available for review are usually part of a community of support that has published information on the Internet. As with all other groups we will be considering here, the similarity of the rhetorics of healing can perhaps best be explained by reference to the rhetorical constraints shaped by this context. Nevertheless, it is interesting to note that virtually all narratives describe a remarkably similar moment of revelation that is cathartic for the AIS individual. This moment involves a process of healing that usually takes two steps. First is the uncompromised discovery of the truth of their condition that reveals the extent to which secrecy and isolation has been an intentional and extended practice by both parents and physicians. Second is the relief of discovering that they are not alone, neither in the condition, nor in their experience. As one of person put it, exemplifying the sentiments of many: “Three days ago and as part of my ongoing search for the truth about me (my condition) a miracle happened to me, I found the support group and a place with loads of information. No more *pieces* of information. I fell as if I was finally [sic] given the permission after 29 years of darkness, to step out of my prison to the light.”<sup>23</sup>

The result is a rhetoric that underscores the importance of truth for these patients who have been surrounded by secrecy and paternalism, as well as the need for community.

---

<sup>21</sup> “Renee” e1-e4: e1, available at <<http://home.vicnet.net.au/aissg/renee.htm>>

<sup>22</sup> “Angela”, quoted in M Coventry, “The Tyranny of the Esthetic: Surgery’s Most Intimate Violation,” OTI Online, available at <<http://mosaic.echonyc.com/~onissues/su98coventry.html>>

<sup>23</sup> “Angel’s Story” e1-e2, e2, available at <<http://www.medhelp.org/www/ais/sotries/angel.htm>>

Interestingly, few AIS patients, in their narratives, question directly the wisdom of surgical intervention *per se*, and often do not often reflect a motive for addressing this particular aspect of the medical management paradigm. This despite difficulties finding optimal HRT dosages, and despite learning that estimates suggests that testicles in cases of CAIS patients can become cancerous only 2-5% of the time (although estimates vary) (vgl. [41]). More often come expressions of sadness about childlessness, reflections of difficult relationships with parents<sup>24</sup> as a result of discovering the truth, and a disappointment, if not outright confusion and even outrage at the paternalism of physicians. It is also evident that the role of parents have a profound impact upon both the depth of “illness” experienced (in cases of total and continuing denial, this can be quite overwhelming, but also in the case of parents who are supportive and forthright, the confidence and strength to heal becomes significantly enhanced), as well as supportive lovers and friends who validate the identity and value of the AIS person. In general, what is at stake in most, if not all of the narratives available is a rhetoric of truth telling that seeks to undo the implicit pathology of their condition orchestrated through medical and familial silence and paternalism. As one very succinctly put it: “I think the most vital thing a parent can do for a child with AIS is to be open and not pass on their terror of discovery. Children deserve the truth because it is their truth and it can be revealed in sensible and caring ways. Parents ought to defend their children against the doctors, too, and be assertive. It is very hard to forget being let down by your parents.”<sup>25</sup>

This truth telling becomes a shared communal value whose consequences extend to the sharing of life experiences in an effort to reach out to others just discovering their condition.

---

<sup>24</sup> Few stories from the perspective of the parents of AIS children are available. Among those available on-line which are easily located can be found at MedHelp.org <<http://www.medhelp.org/www/ais/stories>> and include: “Toni’s Story” .../toni.htm, “Virginia’s Story” .../Virginia.htm, “Veronica’s Story” .../veronica.htm, “Trust Me – I’m a Patient” .../WAVE.HTM, “Niel’s Story” .../neil.htm, “Deb’s Story” .../deb.htm, and “Gayle’s Story” .../gayle.htm.

<sup>25</sup> “Ann’s Story”, e1-e2: e2, available at <<http://www.medhelp.org/www/ais/stories/ann.htm>>

It is the nature of *Congenital Adrenal Hyperplasia* (CAH – an endocrinological condition wherein cortisone cannot be properly treated by the body, so as to cause the adrenal glands to produce higher quantities, thereby causing a “virilization” of the body; often accompanied by salt-wasting propensity that can be deadly), as a potentially deadly endocrinological condition, that discussions available to the researcher are dominated by parents of children with CAH.<sup>26</sup> Given these conditions, the rhetorics of healing that arise out of and give shape to these discussions are primarily didactic: Parents tend to discuss all the issues necessary for understanding the condition of their child(ren), including the type of CAH, discussions of test results, various treatment options including advantages and disadvantages of growth hormones, types of drugs and dosages, how to handle and prepare for adrenal crises. Sometimes it is clear from the discussion that the parent has been upset by the ways in which specific endocrinologist and/or pediatricians have handled their child(ren)’s

---

<sup>26</sup> The resources available to the researcher tend for CAH to be dominated by the genre of discussion forums, due primarily to the emergent nature of the condition. Unlike AIS, the parents of CAH patients also tend to dominate the discussion boards. There are very few first-person narrative accounts by those with CAH. Such stories can be found at: CAH Our Voices Our Stories Stories <<http://cahourstories.net>>, ISNA “Presented at Robert Wood Johnson Medical School” <<http://www.isna.org/library/whelanjan2002.html>>, “Kira” (one of the earliest posted 1<sup>st</sup>-person narratives on the Internet) <<http://www.qis.net/~triea/kira.html>>, CAH Support Group <<http://www.cah.org.uk>> under “CAH Stories”, Adrenal Hyperplasia Network “Becky Roche’s Experience of CAH” <<http://www.ahn.org.uk>> under “Personal Stories”, and the CAH Organization of Texas <<http://www.tdh.state.tx.us/newborn/Cahoot.htm>>. Extensive discussions of over 2200 combined postings by parents, patients, and even young adults with CAH (as of February 2003) can be found in forums sponsored by Congenital Adrenal Hyperplasia.org<<http://www.congenitaladrenalhyperplasia.org>>, Bodies Like Ours <<http://www.bodieslikeours.org>>, CAH Support Group under “Messages”, and Yahoo! Groups “Congenital Adrenal Hyperplasia” <[http://groups.yahoo.com/group/adrenal\\_hyperplasia](http://groups.yahoo.com/group/adrenal_hyperplasia)>.

case, and are seeking connection with others to obtain information and comfort, share experiences, and obtain recommendations.

Under these and similar circumstances, the rhetoric of parental forums assumes a close connection between “healing” and curative procedures, supported by a community-building effort to reach out to and be available to other parents with CAH children.

Interestingly, it appears that a majority of parents seem to accept the necessity of surgical intervention to reconstruct the genitals. This issue has come increasingly under fire from a number of different quarters, including adult CAH individuals and those with clitoromegaly (“enlargement” of the clitoris).<sup>27</sup> Depending upon the context of the particular forum and its discussion history, it appears that parents are aware of the terms of the current debate, and often it is clear that physicians have discussed surgical options with them, with the parents choosing to go ahead with the procedure.

Being essentially an endocrinological syndrome, it is not immediately clear why CAH “females” require surgical intervention upon their genitals as a necessary part of their treatment program. But this is nevertheless presumed to be the case among the physician community. It should therefore come as no surprise that initial discussions about surgical options are predetermined by the rhetoric of the physicians. Parents tend to accept the physician’s assessment as to the surgery’s necessity, and if found to be so, tend to agree with the physician regarding the need for early intervention. At which point, the parents embrace the physician’s assurances that techniques in clitoral recession will result in a “normal” child. “At the age of two, Dr...recommended that we have her genitalia surgically repaired, although hers was not extremely severe. He referred us to a Pediatric Urologist at Children’s,... He was wonderful, and the surgery was very successful. He performed a clitoral reduction and also made sure her bladder

---

<sup>27</sup> The most widely published and broadly adopted proposal concerning surgical management originated with the Intersexed Society of North America. Cf. “ISNA’s Recommendations for Treatment” at <http://www.isna.org/library/recommendations.html>

and other internal organs were in the correct places. Kendall did great, and we were home in just a few days! She now looks like a perfect little girl!”<sup>28</sup>

Once the surgical option comes under question by others, the opponents of surgery struggle to overcome two clear presumptions. The first is the presumption that the parents, along with the physician, have the right to make medical choices on behalf of the infant, even in such cases as clitoroplasty where the permanence of its effects collides with the non-medical basis for it. This presumption is being addressed through ethical discussions regarding patient consent.

The second, and for our study the more important presumption surgical opponents must confront is the connection between “curing” and “healing” that creates a rhetorical space wherein medical practices and intervention presume a “healing” outcome. This is the more difficult of the two, not only because very little follow-up research has been done, but also because it works against a deeply naturalized presumption regarding the “progressive” practices of medicine: “Another major bone of contention we have with surgeons is the lack of follow-up. Very rarely do they ever make an effort to follow-up with infants they cut when they become adults. This lack of follow-up is nothing short of unethical because it shouldn’t be just about genitals that look good enough for the child to “pass”, it should be 100% about whether they function when the child becomes a sexually active adult. That may not happen for decades. One of the reasons the surgeons will tell you that they don’t have follow-up studies is because they change the method every few years. By doing that, they effectively render any follow-up studies useless because they say that method is no longer being done and it causes a lack of control group protocols necessary in good research.”<sup>29</sup>

---

<sup>28</sup> A. Thomsson, “Kendall’s Story” *The Cahoot 3* (Winter 2002), available at <http://www.tdh.state.tx.us/newborn/Cahoot3.htm#Kendall's%20Story>.

<sup>29</sup> B. Driver, founder of “Bodies Like Ours”, an outreach group dedicated to halting genital surgery upon infants, posting a response to a father who was about to take his 8-month-old daughter to a pediatric urologist; “My Latest Essay (It’s Exceptionally Long This Time)” (November 20, 2002) <http://www.congenitaladrenalhyperplasia.com/mb/index.php?msg=0008930076&forum=controversy>.

If and when CAH “females” talk about their surgery experiences, however, these comments tend to reject the connection between “curing” practices of surgical genital reconstruction and the presumption that “health” was thereby attained. This literature shows similarities to AIS in the experience of secrecy and shame: “It was never talked about while I was growing up, I guess my parents expected me to deal with my ambiguous genitals on my own. I also suppose I fell within the mark of what a clit can look like before it is chopped. ...I was totally left to my own devices to “understand” my differences and therefore I developed a lot of shame around my genitals and sexuality in general. It wasn’t until recently that I could talk with anyone about being IS and then I confronted my dad about it. He finally admitted that he always knew that I was larger “down there” (his words) but just figured that “my mother” would have talked to me about “it.” Of course my mom never said anything when I asked her as a child about my genitals. I always felt that if nobody was talking about it that it must be really bad that I had a big clit. Don’t get me wrong; I’m not sorry for what god gave me. What I am upset about, was the silence and secrecy that both my parents and the doctors fostered around my IS. As you and others probably know, it creates a lot of shame for the child. It would have been so much more healthy for me if there was honest communication around this topic from an early age.”<sup>30</sup>

However, for those who underwent surgery, the trauma of procedure and its aftermath figures much larger than for AIS patients. The reason for this are simple: the object of surgical intervention is typically the phallus, an object whose sole function is sexual stimulation, and those sharing their stories do so because their surgeries have been a dismal failure. They question the necessity of the surgical intervention, they question the standards upon which to judge surgical outcomes, they express anger at the loss of sensation or the presence of pain, and they express betrayal at the loss of control of their bodies due to the involuntary act of intervention. “My vagina is about the size of a pencil which surgeons had been trying to “fix” since birth. I was also born with an enlarged clitoris which seemed to bother all around me. The surgeons had talked my mother into letting them reduce the size of the clitoris. They reduced the size

---

<sup>30</sup> Victoria, “I Heard That,” (August 21, 2002), available at <<http://www.bodieslikeours.org/forums/showthread.php?s=6c4474060c5052df793debf2b1e2e3d3&threadid=100>>.

once but it continued to grow because through out my life I refused to take my medicine. I had my final surgery which removed my clitoris at the age of seven-teen. That was back in 1987 when you would think that these barbaric surgeries would not have been preformed [sic]...”

“I had learned a long time ago that my parents and health care professionals did not want to hear what I had to say or thought. I can not [sic] tell you how many times I had heard phrases like these when I would protest any kind of treatment. I would be told “We are doing this to save your life” or “We are doing this to make you normal”. These phrases are not reassuring or comforting. These phrases tend to tell a child that you do not care what they think and what others want to do to your body is right.”<sup>31</sup>

The rhetoric of healing that arises from CAH patients, particularly CAH “females”, includes the priority of truth-telling about the fallout of early genital surgeries, and the catharsis of discovering a community of those with similar experiences. However, it also often includes an express commitment to participate in direct confrontation with the medical community, as well as to outreach and counseling with parents of CAH children so as to undermine the presumption of the need for genital surgery. “The belief that early surgery fixes the problems of intersexed people is wrong. It only makes the problem disappear in the eyes of the parents and the doctors and shifts the entire burden onto the child. The child knows something is not right but no one is willing to say anything. As one women posted on a CAH (congenital adrenal hyperplasia) message board, “It’s as if there was an elephant in the living room but no one would talk about it.” [54]<sup>32</sup>

CAH patients having undergone surgery embrace a rhetorics of truth-telling in a context that seeks to find a perspective counter to the pathologizing tendencies of medical approaches.

Hypospadias (the meatus of the “penis” is located elsewhere other than on the tip of the glans) and *chordee* (downward curvature of the “penis”, sometimes accompanied by twisting) patients express a much broader range of experience with and relationship

---

<sup>31</sup> “Danette’s Story,” e1-e4: e1-e2, available at <<http://www.cahourstories.net/danette.html>>.

<sup>32</sup> Available at <<http://www.isna.org/library/shelanjan2002.html>>.

to the medical and broader community.<sup>33</sup> This is due, in no small part, to two important factors: On the one hand, the frequency of surgeries that a hypospadiac male undergoes when this route is once chosen.<sup>34</sup> This gives them frequent opportunity to interact with the medical profession, particularly urologists, typically extending into adulthood. As adults, they are far more prone to sober evaluation of surgical outcomes and to discuss the benefits of the surgical options from the perspective of a patient-centered assessment.

On the other hand, the cultural importance ascribed to the penis places them under a sense of incredible pressure either to seek out solutions to perceived problems with their genitals, or to determinedly accept their difference as a natural variation. Under the circumstances of social pressure hypospadiac males tend to suffer greatly from embarrassment about their genitals, esp. in the locker room (60.3% Hypospadiac Males [HM] v. 24.1% Control Group [CG]), with physicians, (37.8% HM v. 13.7% CG) and with partners (41.0% HM v. 7.0% CG).<sup>35</sup> They tend to fear public bathrooms, and mention frequently their difficulties with urinating, employing the standard “standing to

---

<sup>33</sup> The following discussion is based on 11 first-person narratives (including one by a parent) located at <<http://www.hypospadias.net>>, 11 first-person narratives (2 of which are duplicates of hypospadias.net) at <<http://www.the-penis.com/hypospadias>>, 56 original postings and their responses by the first internet forum on hypospadias now archived at <<http://www.the-penis.com/hypomessages>>, 3500+ postings on Mums With Hypospadias Kids (481 members as of February 2003) located at <<http://egroups.yahoo.com/>>, 2600+ messages at the Hypospadias Support Group for Parents and Patients (398 members as of February 2003) also located at <<http://egroups.yahoo.com/>>. Cf. also <http://www.hypospadiashelp.fsnet.co.uk> for more personal stories and responses.

<sup>34</sup> Johns Hopkins reports from a follow up study that 39 hypospadias 46,XY patients show a statistical mean of 5.8 surgeries; (vgl. auch [34]).

<sup>35</sup> These conclusions are based upon the results of the second of two major surveys of hypospadiac males who were members of the Hypospadiac Association of America internet forums. It took place between July-August 2001. 183 men with hypospadias responded, and results were compared to a control group of 1890 males from the general population. Available at <<http://www.hypospadias.net>>.

pee” as a naturalized goal of normalcy. Fear of intimacy (35.3% HM v. 6.5% CG), disgust with penis (23.7% HM v. 4.9% CG), and depression (36.5% HM v. 8.9% CG) is also frequently mentioned. In most cases, these fears and embarrassments are only exacerbated by surgery, whose negative outcomes tend eventually to bring the hypospadiac male to the point of accepting their current status, if not actively avoiding further surgeries for fear of worsening results.<sup>36</sup>

Nevertheless, discussions tend to be nuanced: mild hypospadias is only operated on less than half of the time, and outcomes are shared, including frank discussions of failures (fistulae, strictures, hair growth from graft, loss of sensation, multiple repairs, shortening of the shaft), the value of early surgery vs. later, the psychological effects. “The slit is on the underside of my penis starting near the top of the head and is about an inch long and about an inch below the slit is a small hole making it look like an exclamation mark... At seventeen I had my mom take me to a urologist because I wanted to have a more “normal” looking penis. The doctor told me I needed to have some scar tissue removed and to make my erections less tight. I never had any pain or problems with erections and I told the doctor this but he seemed to think it was a problem so I had this corrective surgery. Honestly I don’t notice much of a difference...”<sup>37</sup>

---

<sup>36</sup> It is worth noting that 89% of those with “mild” hypospadias (urethral opening at upper 1/3 of the shaft) responding to the survey said they were not planning to have further surgery. 34% of these gave the reason that they were happy with the result, while 31% said they were afraid more surgery would make matters worse. 80% of those with “moderate/severe” hypospadias (middle/lower 2/3 of the shaft) responding to the survey said they were not planning to have further surgery. Of this group, 16% said they were happy with the results, while 51% feared further surgery would make it worse. Only 24.1% of “mild” hypospadias respondents underwent surgery, with an average of 2.2 surgeries performed. In contrast, 85.7% of “moderate/severe” hypospadias respondents underwent surgery, with an average of 3.1 surgeries for “moderate” cases and 5.1 surgeries for “severe” cases.

<sup>37</sup> David, “Living with Hypospadias: a Personal Account,” available at <http://www.hypspadias.net/stories/david.htm>.

I underwent four surgeries as a child to repair the problem, and they seemed to work well for about 12 years. My penis was shaped normally, could achieve erection, and appeared “normal” as compared to others. As I reached sexual maturity, the growth of my penis caused the surgically repaired skin of the base of my penis to tear, revealing several fistulae, or holes, from the base of the penis into a free urethral opening...I was embarrassed to tell my parents, and went until 17 years old avoiding women because if I was ever in a situation of ejaculation, some semen would shoot out the bottom as well as the tip. I felt women would feel I was a freak. After many years of humiliation, I finally set up an appointment with a urologist. He performed surgery on me in order to repair the shaft leakage...[I]t held for a year and then the skin died and I am now back at stage one.”<sup>38</sup>

In general very little regret is expressed about the attempt, although outcomes are described forthrightly.

Mild and severe cases of hypospadias are much more frequently operated upon, with far fewer positive outcomes (physical, sexual, emotion). These cases tend toward greater levels of depression (47% Moderate/Severe [M/S] v. 32.5% Mild [Mi]), poor self-esteem [57.5% M/S v. 41.4% Mi] and poor experience with medical intervention (61% M/S report dissatisfaction with penile appearance after surgery vs. 39.3% Mi). In either and both cases, however, adults talking about adult decisions have a different perspective than adults talking about decisions made for them in childhood. The latter often mention similar experiences of trauma at the hands of physicians that both AIS and CAH patients mention, particularly with respect to sense of shame, powerlessness, isolation, humiliation and the lack of forthright discussion from parents and physicians. This is particularly the case for hypospadiac individuals operated upon as pre-teen minors. As another poster summed his experience up: “Surgery at age six was traumatic. Fortunately, much of the detail has faded from my memory, but I remember extreme embarrassment about the entire ordeal. I’m sure that much of the embarrassment stems from the way my parents handled things (though they meant no harm, they had little information from small-town doctors and therefore did not make

---

<sup>38</sup> No Name, “Another Personal Account,” available at <<http://www.the-penis.com/hypospadias>>, under “Personal accounts of hypospadias from visitors to this site.”

the wisest decisions). I remember my parents privately telling my teacher about the surgery and encouraging the teacher to lie to the class and say I was having surgery on my arm. Obviously, the full truth would not have been appropriate, but it sent a signal to me that it was something of which to be ashamed. I also remember lying in bed in the hospital after surgery (I was in the hospital for several days) on my back with my legs propped up in some sort of contraption so I couldn't damage the sutures. I was completely naked underneath, except for a blanket draped over the contraption, exposed to nurses, relatives or anyone who walked into the room. I felt vulnerable and somewhat violated in that position. I also remember the catheter and my refusal to obey the nurse and just "let it go" and pee while I was lying in bed. Primarily, I remember the DRAMATIC change in appearance once I finally got to see the finished product after surgery (I can imagine the surgeon could have said something like, "it ain't pretty, but it works"). That caused a sense of confusion, shame, and even a sense of loss for what I no longer had. To a large extent, those feelings remain with me 20 years later."<sup>39</sup>

The discussion among parents reflects concerns about decisions regarding surgery and its recovery, the desire to find others to consult with about their experiences, post-surgical care, reasons and causes for this congenital condition – topics one would expect to find from those whose children might enter into the surgical unit. A characteristic of these discussions not often found in other forums of parents with intersexed minors is the number of postings and discussions related to the high frequency surgeries their children undergo in order to repair previous surgeries. "[A]fter all the failed operations Hayden has been through, i have found it really hard 2 say anything positive in the group 2 others that r looking 4 a bit of hope. And the fact that every time i read the mail in the group and think about what my son has been through in the 4 years of his live brings me 2 tears every time"<sup>40</sup>

His surgery began at 5 months, we were told that it had succesfully [sic] been corrected with a single stage op that took close to 4 hours. Things looked good for a

---

<sup>39</sup> No Name, "My Story," available at <http://www.hypospadias.net/stories/anonymous1.htm>.

<sup>40</sup> Message 2495, mumswithhypospadiaskids eGroup, available at <http://egroups.yahoo.com/groups/mumswithhypospadiaskids>.

couple of weeks, but unfortunately a fistula occurred [sic] and surgery was rescheduled [sic] for another 5 months down the track. The procedure was repeated and again the result not good. We have since had another 5 ops to no avail, we have had full hypospadias surgery 3 times, a repair to the urethra [sic], due to him being born with a double urethra which [sic] they didn't [sic] pick up until [sic] op no.5, dilations of the urethra [sic]. [H]e recently had a supra pubic catheter in for just over 2 months, following surgery [sic] on the 2nd Feb, this year. We are at our wits' ends not knowing how many more ops are needed as the surgeon is unable to give us an explanation as to why the surgery has been so unsuccessful. Maybe they will get it right next time, let's hope so anyway."<sup>41</sup>

"We were told the same thing about 2 months ago after my 11 year old [sic] son's 6<sup>th</sup> operation. All I could think about is why did we let him go through all the operations for the end result like this. My son's father and I have decided no more operations. Enough is enough."<sup>42</sup>

Parents facing these circumstances describe frustration, worry and confusion at the frequency of repairs. They often seek out resources that can direct them to recommended surgeons, discuss next stages, and describe their own version of "case studies" of physicians and physician rhetoric. They rarely employ a rhetoric of "healing from", but rather express trauma about the failures of medical intervention.

Hypospadiac males, like those of others we have considered, report the healing propensities of discovering they are not alone and no longer isolated in the experience of confusion and shame they may feel about their genitals. Finding partners who accept them, as well as the contribution of support and candor from parents, tend to play a very important role in their self-esteem and sense of healing. "What you need is an open honest relationship with a partner where you explain to them exactly what you have before or as any serious relationship starts... In fact you can learn to enjoy the difference in exploring your capabilities together. Now, there will always be a proportion of women who will then run away from you too embarrassed to discuss it.

---

<sup>41</sup> Message 48, mumswithhypospadiaskids eGroup, available at <http://egroups.yahoo.com/groups/mumswithhypospadiaskids>

<sup>42</sup> Message 3004, Hypospadias Support Group eGroup, available at <http://egroups.yahoo.com/groups/hypospadias>

That's their problem not yours...I told my future wife about it very early in our relationship (after about 4 weeks) and although she was mildly interested, it made no difference to our relationship and we have been married for over thirty years."<sup>43</sup>

"..I've worried off and on about a cock that is different than it was "supposed to be", but once I became sexually active as a gay man in my early 30's I realized that the differences weren't particularly important to me or my partners."<sup>44</sup>

Eventually, also, some begin speaking of a coming to terms with their difference (often through counseling), even going so far as to actively downplay the importance ascribed to the penis in the culture, esp. with respect to their whole person. When a rhetorics of healing is employed, "healing from" includes overcoming social stigma, recounting the numerous surgeries and their repairs, coming to terms with their relationship to their hypospadias, and a commitment to truth-telling that includes candor about experiences (sexual and medical) and sharing information.

*Klinefelter* (XXY chromosome) and *Turner* (XY/XO chromosome) individuals,<sup>45</sup> each facing quite distinct symptomatology and origins, nevertheless share a similar rhetorics in their narratives: insofar as the medical community provides information

---

<sup>43</sup> No Name, "Living with Hypospadias – My Story," available at <<http://www.the-penis.com/hypospadias>>, under "Personal accounts of hypospadias from visitors to this site."

<sup>44</sup> No Name, "From a Gay Man," available at <<http://www.the-penis.com/hypospadias>>, under "Personal accounts of hypospadias from visitors to this site."

<sup>45</sup> Among the first-person accounts available, the following were used for the ensuing discussion: D. Brager, "I'm Not Fat, I'm Deformed: Klinefelter's Syndrome & Me" (1997) <<http://www.geocities.com/WestHollywood/Castro/4998/klinefl.htm>>, Anonymous, "Klinefelter's Syndrome: A Personal Reflection" at <<http://www.isgi.org/isgi/Klinefelter.html>>, S Poirier, "My Story" at <<http://host.cnwl.igs.net/~destined/page3.html>>, "Living with Klinefelters'" at <<http://klinefeltersyndrome.org/stefan.htm>>. The Turner Syndrome Forum (280 members, 4000+ postings) at <http://egroups.yahoo.com/group/turnersyndromeforum> and the AAKIS Forum (212 members, 10,000+ postings as of February 2003) at <http://egroups.yahoo.com/group/AAKSIS> were also used.

and support for the families and patients to identify and understand their respective conditions, the individual finds healing *through* medical knowledge and options. This is case both with Klinefelter “boys”, whose symptoms often do not become recognizable until adolescence, and with Turner “girls”, whose condition can more often be recognized at birth, though almost half are not diagnosed until later.<sup>46</sup> Full disclosure to and active participation of these patients in the management of the symptoms of their condition allow them and their families the chance to gain a sense of control and insight.

As with all other groups we have looked at, isolation makes a profound impact upon the experience of the person, both before (knowing they were somehow “different”) and after (“Are there others like me?”). Coming into contact with communities of support provides them with a sense of belonging and understanding.

For both, the difficulty can be with reconciling their experiences and sense of difference with the expectations of those around them. Surgeries (including operations on ears, webbed shoulders) and growth hormones to render Turner minors more “normal”, and mastectomies and HRT to help Klinefelter adolescents develop a more masculine appearance, are frequently proposed options. The potential pathological implications of “normalizing” approaches can have their negative effects: “Adult individuals with Klinefelter variations often report undesirable psychological side effects from HRT. Over time, many untreated persons with Klinefelter accommodate themselves to the reality of their unique body structure and mourn the loss of their feminine identity. For those who decide to have either the mastectomy, HRT, or both, psychological counseling [sic] is highly desirable, but typically is not offered. The removal of breast tissue in males can be as traumatic as the loss of a breast is to

---

<sup>46</sup> For more information regarding patient-oriented outreach and support available through the internet, in addition to that given above, visit the Turner Syndrome Society webpage at <<http://www.turner-syndrome-us.org>>, Turner Syndrome Support Society webpage at <<http://www.turner.org.uk>>, The Turner Center of the Psychiatric Hospital Aarhus in Denmark <<http://www.aaa.dk/TURNER/ENGELSK/INDEX.HTM>>, and Deutsche Ulrich-Turner-Syndrom Vereinigung e.V at <<http://www.turner-syndrom-de>>. See also the very helpful person page “Tim’s Turner Syndrome Page” at <<http://www.iland.net/~tdluke/trnrs.html>>.

females, yet the mastectomy is typically treated as no more than cosmetic surgery and no more significant than a haircut. Often what seems desirable to make the body conform to a typical male appearance is deeply regretted later."<sup>47</sup>

For both, the knowledge (or discovery) of the condition, the responsibility shared in the medical decision-making processes, and the sharing of experiences in order to break out of the sense of isolation, become important rhetorical moments of healing that can bring with it a powerful acceptance of the uniqueness of their experiences and identities. As one Klinefelter post stated: "I also have come to grips with the term INTERSEXUAL. At first I resented it. Now, I am proud of who I am, where I have been, and what I am doing..."<sup>48</sup>

### **HEALING, CURING AND NEW APPROACHES**

These examples do not represent all intersex(es) and intersex(es) experiences and discussions. Indeed, given the wide varieties of forms intersexuality takes, including those forms that we did not specifically address (5alpha-reductase deficiency, vaginal agenesis, gonadal dysgenesis, among many others), it should not be surprising that each condition would shape unique rhetorical worlds, values, experiences and group dynamics. Nevertheless, despite these differences, they also share certain common themes.

Through the stories and perspectives shared by intersex(es) it becomes clear that their respective conditions become subjects of discovery that bring them together with others sharing similar experiences. The expression of relief from the sense of isolation often gives way to the joy that occurs when patients discover others similar to them. This discovery leads to community-building exercises: the sharing of individual histories, the creation of a community of identity, often also the explicit or implied commitment to outreach in an effort to find others undergoing similar experiences. At times the values of the community derived from these exercises in community building

---

<sup>47</sup> No Name, "Klinefelter's – A Personal Reflection," available at <<http://www.isgi.org/isgi/Klinefleter.html>>.

<sup>48</sup> Message 8, livingwithklinefelter eGroup.

are shared with others, sometime developing to the point of their express advocacy before the public and the medical profession.

These communities, depending upon their strength and level of group formation, provide support by giving the intersex(es) a non-pathologized identity and place from out of which they can confront, educate, or simply recover from the isolation encountered in and through dominant and pathologizing community norms.

The initial research provided here is not the end, but the beginning of the kind of approaches to help understand the strategies that intersex(es) take in order to heal. For some, “healing” is a mundane affair, the result of simply living at peace with oneself, when oneself was never problematized to begin with. Distinctions and differences were noted, but not pathologized and marked for necessary “corrective” intervention.

For others, “healing” takes place through recovery from social and medical rhetorics of pathology and their resultant practices. Bodies were seen as in need of correction, procedures were brought upon them to “normalize” them, and recovery is sought from these very procedures. Sometimes the object of recovery is a whole rhetorical world and practices of procedures imposed without consent, procedures left unexplained, of discussions that did not tell the whole truth. Sometimes the object of recovery is simply the fallout from the practices themselves, whether wanted or unwanted. But regardless of the object of recovery, the community of individuals with whom one can share common experiences, validate shared values, chain out common visions, practice forms of truth-telling unprecedented in the lives of its members: the creation of communities of identity marks the most significant catalyst for healing in the rhetorics of these members.

What can we learn from these examples about the nature of “healing” and the relationship between “healing” and “curing”? Among many lessons that may be derived, I would like to offer the following for consideration that may have the greatest relevance for the medical treatment of intersex(es).

1. In many cases of intersexuality, doctors do not necessarily provide the means for healing, and do so mainly in cases where the intersexed patient comes to them as an adult to work with them as partners in determining causes and discussing desired outcomes. In cases of Turner and Klinefelter individuals, physicians clearly can be a means for helping the patient understand their condition and help the patient navigate their medical circumstances successfully. It is possible that this

happens, because these patients are never questioned regarding their gender, nor are their genitals the focus of attention. But for other groups, including CAH and clitoromegaly, AIS, hypospadias, the physician-patient relationship is often reported as compromised through the pathologization of the (inter)sexed body and the medical attention upon the genitalia. For these patients, “healing” takes place in spite of, indeed in recovery from, medical intervention.

2. All patients speak of an “Aha!” experience upon discovery of others like themselves. Isolation and liminality are experiences that are described as ever present in growing up as intersex(es), in varying degrees of intensity. It is only upon recognition that they are not alone that relief is expressed and healing can begin to take place.
3. What this suggests is that the role of liminality and its relationship to medical decision-making must be more directly addressed. The phenomenon of liminality through *disease* has already and often been discussed. When a healthy person becomes sick, and thereby risks certain social status or position through isolation, it is the physician who seeks to bring about a state of health. The physician provides a “cure” for the “disease”, thereby addressing individual needs despite (or even in confrontation with) broader socio-communal reactions to the individual. In the case of patients whose very existence is social liminality, however, the community demands from the physician that they be altered to conform to communal norms. However, as one physician has pointed out, “Medicine does not usually accept the views of society if they are in conflict with the needs of the individual. But we seem to need a categorical statement about a person’s sexuality.” The experiences we have described and summarized here give evidence of the results of an approach that insists the individual be made to conform to social norms. By viewing liminality itself as a “disease” in need of “curing”, doctors have created rhetorical worlds around patients that reinforce their “illness” and prevent “healing”.

It is only by recognizing the validity of difference, accepting the variability of genitals, and demanding the right to bodily integrity and subject autonomy, that these particular communities of healing have been formed. They have been formed through the pain they experience at the hands of the community, family, physicians. They seek to recover through a rhetorics of healing that brings them together to share, learn, create

and support new identities to confront the forces of liminality and isolation on the one hand, and the forces of conformity demanding their erasure on the other.

Without taking a particular position on the question of the “success” or “failure” of surgical intervention upon intersexed minors (and what the standards might be for determining such), what becomes clear is that a deeper issue is at stake: If alternative strategies of “healing” can be shown to exist, then physicians and parents might better explore such strategies and the spaces of freedom and safety they allow from within which *all* parties can work together to view the *responses to* intersexuality, and not the condition itself, as pathological.

## LITERATURE

1. Aaronson I (1985) True Hermaphroditism. A Review of 41 Cases with Observations on Testicular Histology and Function. *British Journal of Urology* 57: 775-779
2. Aarskog D (1971) Intersex Conditions Masquerading as Simple Hypospadias. *Birth Defects Original Articles Series* 7: 122-130
3. Al-Attia H (1996) Gender Identity and Role in a Pedigree of Arabs with Intersex due to 5 Alpha Reductase-2 Deficiency. *Psychoneuroendocrinology* 21: 651-657
4. Allen T (1976) Disorders of Sexual Differentiation. *Urology* 7 Supp.: 1-32
5. Amrhein J, Klingensmith G, Walsh P, McKusick V, Migeon C (1977) Partial Androgen Insensitivity: the Reifenstein Syndrome Revisited. *New England Journal of Medicine* 297: 350-356
6. American Academy of Pediatrics Committee on Genetics (1995) Health Supervision for Children with Turner Syndrome. *Pediatrics* 96: 1166-73 [[Medline](#)]
7. American Academy of Pediatrics RE9958 (2000) Evaluation of the Newborn With Developmental Anomalies of the External Genitalia. *Policy Statement* 106
8. Beh H, Diamond M (2000) An Emerging Ethical and Medical Dilemma: Should Physicians Perform Sex Assignment Surgery on Infants with Ambiguous Genitalia? *Michigan Journal of Gender and Law* 7: 1-63
9. Bender B, Harmon R, Linden M (1995) Psychosocial Adaptation of 39 Adolescents with Sex Chromosome Abnormalities. *Pediatrics* 96 (Pt. 1): 302-308

10. Berthezene F, Fores M, Grimaud J, Claustrat B, Mornex R (1976) Leydig-cell Agenesis: A Cause of Male Pseudohermaphroditism. *New England Journal of Medicine* 295: 969-972
11. Blackless M, Charuvastra A, Derrtyck A, Fausto-Sterling A, Lauzanne K, Lee E (2000) How Sexually Dimorphic are We? Review and Synthesis. *American Journal of Human Biology* 12: 151-166
12. Colapinto J (2001) *As Nature Made Him: The Boy Who Was Raised as a Girl*. HarperCollins, New York
13. Cameron D (1999) Caught Between: An Essay on Intersexuality. In: Dreger A (ed) *Intersex in the Age of Ethics*. University Publishing Group, Hagerstown, MD, pp 90-96
14. Conte F, Grumbach M (1989) Pathogenesis, Classification, Diagnosis, and Treatment of Anomalies of Sex. In: L. De Groot (ed) *Endocrinology*. Saunders, New York, NY, pp 1810-1847
15. Creighton S, Minto C, Steele S (2001) Objective Cosmetic and Anatomical Outcomes at Adolescence of Feminising Surgery for Ambiguous Genitalia Done in Childhood. *Lancet* 358: 124-125
16. Draft Statement of the British Association of Paediatric Surgeons Working Group on the Surgical Management of Children Born with Ambiguous Genitalia (2001)
17. Dreger A (1998) *Hermaphrodites and the Medical Invention of Sex*. Harvard University Press, Cambridge, MA
18. Dreger A, Chase C (1999) A Mother's Care: An Interview with 'Sue' and 'Margaret' In: Dreger A (ed) *Intersex in the Age of Ethics*. University Publishing Group, Hagerstown, MD, pp 83-89
19. Dupont B, Oberfield S, Smithwick E, Lee T, Levine L (1977) Close Genetic Linkage between HLA and Congenital Adrenal Hyperplasia (21-hydroxylase deficiency). *Lancet* 2: 1309-1312
20. Fausto-Sterling A (2000) *Sexing the Body: Gender Politics and the Construction of Sexuality*. Basic Books, New York
21. Fausto-Sterling A (2000) The Five Sexes, Revisited. *Sciences* July, 2000
22. Federman D (1987) Psychosexual Adjustment in Congenital Adrenal Hyperplasia. *New England Journal of Medicine* 316: 209-210

23. Hampson JL, Hampson JG (1961) The Ontogenesis of Sexual Behavior in Man. In: Young W, Corner G (eds) Sex and Internal Secretions. Williams and Wilkins, Baltimore, MD, pp 1401-1432
24. Herdt G (1996) Third Sex, Third Gender: Beyond Sexual Dimorphism in Culture and History. Zone Books, New York
25. Hester JD (2003) Rhetoric of the Medical Management of Intersexed Children: New Insights into 'Disease', 'Illness', 'Curing' and 'Healing'. *Genders* 38.
26. Imperato-McGinley J, Guerrero L, Gautier T, Petersen RE (1974) Steroid 5 $\alpha$ -reductase Deficiency in Man: An Inherited Form of Male Pseudohermaphroditism. *Science* 186: 1213-1215
27. Imperato-McGinley J, Peterson RE (1977) Male Pseudohermaphroditism: The Complexities of Male Phenotypic Development. *American Journal of Medicine* 61: 251-272
28. Imperato-McGinley J, Gautier T, Petersen RE, Sturla E (1979) Androgens and the Evolution of Male-Gender Identity Among Male Pseudohermaphrodites with 5 $\alpha$ -reductase Deficiency. *New England Journal of Medicine* 300: 1233-1237
29. Kim (1999) As Is. In: Dreger A (ed) *Intersex in the Age of Ethics*. University Publishing Group, Hagerstown, MD, pp 99-100
30. Kipnis K, Diamond M (1998) Pediatric Ethics and the Surgical Assignment of Sex. *Journal of Clinical Ethics* 9: 398-410
31. Klinefelter H Jr, Reifenstein E Jr, Albright F (1942) Syndrome Characterized by Gynecomastia Aspermatogenesis without a-Leydigism and Increased Excretion of Follicle-stimulating Hormone. *Journal of Clinical Endocrinology and Metabolism* 2: 615-624
32. Meyer-Bahlburg HFL (1993) Gender Identity Development in Intersex Patients. *Child and Adolescent Psychiatric Clinic North America* 2: 501-512
33. Meyer-Bahlburg HF (1998) Gender Assignment in Intersexuality. *Journal of the Psychology of Human Sex* 10: 1-21
34. Migeon C, Wisniewski A, Gerahart J, Meyer-Bahlberg H, Rock J, Brown T, Cassela S, Maret A, Ngal K, Money J, Berkovitz G (2002) Ambiguous Genitalia with Perineoscrotal Hypospadias in 46,XY Individuals: Long-Term Medical, Surgical, and Psychosexual Outcome. *Pediatrics* 110: e31

35. Migeon C, Wisniewski A, Brown T, Rock J, Meyer-Bahlberg H, Money J, Berkovitz G (2002) 46,XY Intersex Individuals: Phenotypic and Etiologic Classification, Knowledge of Condition, and Satisfaction with Knowledge in Adulthood. *Pediatrics* 110: e32
36. Money J, Hampson JG, Hampson JL (1955) Hermaphroditism: Recommendations Concerning Assignment of Sex, Change of Sex, and Psychological Management. *Bulletin of Johns Hopkins Hospital* 97: 284-300
37. Money J, Hampson JG, Hampson JL (1957) Imprinting and the Establishment of Gender Role. *Archives of Neurology and Psychiatry* 77: 333-336
38. Money J, Ehrhardt A (1972) *Man & Woman, Boy & Girl*. The Johns Hopkins University Press, Baltimore
39. Oberfield S, Mondok A, Sharivar F, Klein J, Levine L (1989) Clitoral Size in Full-Term Infants. *American Journal of Perinatology* 6: 453-454
40. Ölzer G, Mungan N, Yüksel B, Yildizdas D, Satar M, Tuncer R (2000) Evaluation of Patients with Congenital Adrenal Hyperplasia" *Annals of Medical Sciences* 9; also available at <<http://ams.cu.edu.tr/September2000Vol9No3/guler.html>>
41. Quigley C, De Bellis A, Marschke KB, el-Awady MK, Wilson EM, French FS (1995) Androgen Receptor Defects: Historical, Clinical and Molecular Perspectives. *Endocrine Reviews* 16: 271-321
42. Rajfer J, Walsh P (1976) The Incidence of Intersexuality in Patients with Hypospadias and Cryptorchidism. *Journal of Urology* 116: 769-770
43. Ranke MB, Saenger P (2001) Turner's Syndrome. *Lancet* 358: 309-314
44. Reilly J, Wodehouse C (1989) Small Penis and the Male Sexual Role. *Journal of Urology* 142: 569-571
45. Reiner W (2002) Gender Identity and Sex Assignment: A Reappraisal for the 21<sup>st</sup> Century. *Advances in Experimental Medicine and Biology* 511: 175-197
46. Robinson A, Lubs H, Nielsen J (1979) Summary of Clinical Findings: Profiles of Children with 47,XXY, 47,XXX and 47,XYY Karyotypes. *Birth Defects Original Article Series* 15: 261-266
47. Schwartz M, Imperato-McGinley J, Peterson R, Cooper G, Morris P, MacGillivray M, Hensle T (1981) Male Pseudohermaphroditism Secondary to an Abnormality in Leydig Cell Differentiation. *Journal of Clinical Endocrinology and Metabolism* 53: 123-127

48. Sridhar GR (1999) Socio-psychological Aspects of Artificial Sex Change. *Journal of the Association of Physicians of India* 47: 1217-1218
49. Sridhar GR (2001) Intersex Experience with Indian Endocrinologists. *British Journal of Medicine* e5, available at <<http://bmj.com/cgi/eletters/323/7324/1264>>
50. Starke M, Albertsson Wikland K, Moller A (2003) Parents' Descriptions of Development and Problems associated with Infants with Turner Syndrome: A Retrospective Study. *Journal of Paediatric and Child Health* 39: 293-298
51. Taha S (1994) Male Pseudohermaphroditism: Factors Determining the Gender of Rearing in Saudi Arabia. *Urology* 43: 370-374
52. Toomey C (2001) Hidden Genders. *The Weekend Australian* (8-9 December 2001): e1-5. Reprinted at <[http://home.vicnet.net.au/~aissg/hiddenj\\_genders.htm](http://home.vicnet.net.au/~aissg/hiddenj_genders.htm)>
53. Turner HH (1930) A Syndrome of Infantilism, Congenital Webbed Neck, and Cubitus Valgus. *Endocrinology* 28: 566
54. Whelan J (2002) Presented at Robert Wood Johnson Medical School. Intersex Panel for Sex Week: e1-4