THE COST OF NORMAL: THE SUBJECTIVE EXPERIENCE OF INTERSEXED INDIVIDUALS WHO HAVE UNDERGONE CORRECTIVE GENITAL SURGERY

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ABSTRACT

For nearly 50 years children born with a Disorder of Sexual Development (DSD) were routinely treated with early corrective genital surgery, and their families were encouraged to keep their full conditions secret from them. Many of these patients experienced their treatment as a physical and emotional trauma that has left them with impaired sexual functioning and feelings of shame and violated trust. This was a qualitative study exploring the experience of three individuals who were born with a DSD and who have undergone corrective genital surgery and hormone replacement therapy. Data were analyzed using a grounded theory approach. In spite of their different disorders, and quite different medical treatments, all three subjects described, in an interview, similarities in their experience of their bodies, their dawning sense of difference and shame, particularly as they approached adolescence, and their employment of dissociative strategies to escape their difficult childhood experiences. Each described a family culture of secrecy and silence about their medical conditions. As adults, they describe the effects of trying to “pass” and their efforts to regain a sense of bodily autonomy. All three women reported ongoing struggles to hold on to a positive self-image and to build and maintain positive relationships. This study suggests that growing up with a DSD has added to problems each women had in coming to terms with her sexual identity. It corroborates much of the literature in the field regarding a ‘coming out’ process: all three women described ending their isolation by connecting to an online community, and finding comfort, pride and self-esteem in an intersex identity. Finally, suggestions are
offered for psychotherapists working with individuals with DSD, both survivors and the newly diagnosed, as well as their families.
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CHAPTER I

Introduction to the Study

The Medical Management of Intersexuality*

Since the 1950s the medical management of children born with atypical or ambiguous genitalia has been based upon theories postulated by the century’s foremost sexologist, John Money. Money and colleagues argued that the individual is psychosexually neutral at birth, and that psychosexual development is related to the appearance of the genitals. Additionally, it is essential to an eventual successful psychosexual outcome – i.e., the gender identity matches the gendered body – that the sex assignment be made before the age of two, and that there be no doubt, in the parents or the child, as to the gender assignment (Money, Hampson & Hampson, 1955, Money & Ehrhardt, 1972). With these postulates, Money and his colleagues offered the medical community a seemingly neat answer to an inordinately confusing and anxiety-producing problem: What to tell parents who don’t have an answer (and desperately want one) to

*In their 2006 Consensus Statement on Management of Intersex Disorders, the American Academy of Pediatrics suggested that the term intersexuality or intersex be supplanted by a new nomenclature “disorders of sexual development” (DSD) meant to reduce stigma for patients and their families. As much of the research on this topic was written using the old terms and the subjects in the current study describe themselves with the old terms, intersex and DSD will be used interchangeably throughout this paper.
the question, “is it a boy or a girl?” The stigma faced by children with ambiguous genitalia could be avoided by a definitive gender assignment and surgical alteration of the genitals to approximate the appearance of typical genitalia.

The birth of a child with DSD has come to be regarded by doctors as a psychosocial emergency. A team of specialists is assembled - geneticists, pediatricians, endocrinologists, and pediatric urologists. These doctors, adhering to Money’s theories, work as quickly as possible to sort through the complicated chromosomal, hormonal, gonadal and endocrinological evidence in the small body before them in order to choose a treatment strategy that will offer the best outcome. Delay in this process is considered threatening to the parents’ ability to attach to their child, and to their ability to see their child as unambiguously male or female. To this end, some doctors tell parents that their ambiguous child does indeed have a male or female sex, but that the sex of their child has not finished developing and that the doctors will figure out the correct sex and help the child finish developing; “the message [conveyed to these parents]… is that the trouble lies in the doctor’s ability to determine the gender, not in the baby’s gender per se” (Kessler, 1990 p. 23). Most sex assignments are made within the first 48 hours, and if corrective surgery is indicated, it is performed shortly thereafter.

When faced with the unusual body of an infant with DSD, specialists working in the prevailing medical model have a hierarchy of decisions to make. Ambiguity in sex is sometimes also a physical emergency - it is not in itself a danger but can point to an underlying condition that may be life-threatening to the child. Once a diagnosis is made and any underlying medical issues are stabilized, the doctors consider the chromosomal sex of the infant. If the child’s chromosomes are XX, the child is almost always assigned
female, no matter how masculine the genitalia appear. Here the chief interest is in preserving potential reproductive capabilities. Large clitorises, those that are more than one centimeter in length, are surgically reduced to feminize the body. Vaginas are created or lengthened to accept an average size penis, labia are separated if they are fused, and hormonal therapy is implemented to regulate menses and foster feminine secondary sex characteristics and fertility.

Genetic males, babies with XY chromosomes, must have an “adequate” penis, meaning it must be an adequate length and look like a believable penis. Children with XY chromosomes with a stretched penile length less than 2.5 centimeters are usually assigned female. Their phallus is carved down to resemble a “normal” clitoris, their testes are removed, a vagina is created, and at puberty the child is placed on hormone treatments. If the penile length is judged “adequate”, but is bound down facing backwards (a condition called chordee), or the urethral opening is not in the typical position running through the tip of the penis (a condition called hypospadias), further surgeries will be performed in an effort to make the penis appear more “normal”.

Babies with chromosomes that do not conform to the standard XX or XY configuration are assessed with the same protocols: decisions about gender assignment are made primarily on the basis of phallus length; surgery and hormone treatments bring the child’s body in line with the assigned gender.

The present limits in surgical technology also affect the ultimate gender assignment. It is far more difficult to create a functional, “believable” penis than to create a vaginal cavity. A shared understanding is that surgeons have more success creating “a hole than a pole” (Kessler, 1990). Pushing up against the limits of
technology, doctors rely upon Money’s theory of psychosexual neutrality to guide their decisions. Consequently, most children with DSD are assigned as girls.

Doctors take charge of the all-important gender assignment and surgeries that make genitals conform to the assigned gender, but essential to Money’s theory was unambiguous rearing in the assigned gender. This, of course, is the domain of the parents. Doctors have often advised parents to remain silent about their child’s condition as he or she matures, and to meet any questions from their child with obfuscation or lies (Dreger, 1998a, Kessler, 1998; Natarajan, 1996). In the effort to help new parents commit entirely to the assigned gender, the parents themselves have not always been informed to the full extent about their child’s condition, or the procedures performed upon the child (Kessler, 1990, 1998).

The DSD Conditions

An estimated one in every hundred children is born with some deviation from typical male and female anatomy. One in every two thousand children undergoes corrective genital surgery for their condition (Blackless et al, 2000). This is similar to rates of birth defects like cystic fibrosis or Down Syndrome (Dreger, 1998b; Fausto-Sterling, 2000). An estimated 100,000 adults with DSD live in the United States alone (Nussbaum, 1999).

Fausto-Sterling (1993) has argued that there are not two, but five sexes: males, females, ferms (female pseudo-hermaphrodites), merms (male pseudo-hermaphrodites) and herms (so-called true hermaphrodites). Female pseudo-hermaphrodites account for about half of the individuals born with ambiguous genitalia (Dreger, 1998b). They have ovaries and an XX chromosomal basis. Their external genitalia appear masculinized
because the child has been exposed to high levels of prenatal androgens. The internal organs appear more typically feminine. A ferm’s atypical genitalia might be caused by a number of factors. A pregnant mother with a tumor on her supradrenal gland might prenatally expose her female child to excessive amounts of androgens. Pregnant women have been given androgenic hormones to prevent miscarriage that have a virilizing effect on their female fetus. Most common, however, is the condition congenital adrenal hyperplasia, or CAH, where the adrenal glands of the fetus produces relatively large amounts of androgens, resulting in the masculinization of the external genitalia.

There are two main causes of male pseudo-hermaphroditism: adrogen insensitive syndrome (AIS), and 5-alpha-reductase (5-AR) deficiency. Again, merm have testes and an XY chromosomal basis, but their external genitalia appear feminine. People with AIS produce testosterone, but they lack a key androgen receptor and their bodies cannot read the testosterone produced. People with the complete form of AIS have bodies that look unambiguously female, but they have no uterus; rather, they have undescended testes and sometimes a short, blind vaginal opening. They are always assigned as girls, if their condition is even detected; sometimes the condition becomes apparent only at puberty when the girl does not begin menstruating. The testes of these girls are often removed because they have a high chance of becoming cancerous. The surgeries are often explained as the removal of their “ovaries.” Partial AIS, where the body can read some amount of testosterone produced, is rated along a continuum from very close to typical male genitalia to entirely feminized genitalia.

Children with 5-AR have a deficiency in an enzyme that breaks down testosterone so it can be read by receptors. When they are born they look like typical girls. At
puberty, however, their undescended testes produce more testosterone and the body no longer needs the enzyme for the testosterone to have an effect on pubertal changes. These apparent girls’ testes descend, their clitorises enlarge, and they develop male secondary sex characteristics, making a startling change from female to male. Five-AR is transmitted genetically and there are relatively large populations of people with the condition in rural Dominican Republic and among the Sambia people of Papua New Guinea (Fausto-Sterling, 2000).

True hermaphroditism is the most rare and least understood phenomenon. The gonads of these individuals contain both ovarian and testicular tissue. Most of these individuals have an XX chromosomal basis, but some are XY, and some have both XX cells and XY cells. Their bodies can look typically male, typically female or something in-between.

Other conditions are also considered under the rubric of intersexuality. Kleinfelter’s Syndrome, where the individual has one Y chromosome and more than one X chromosome, can sometimes result in ambiguous genitalia. Perhaps one in 200 boys are born with the condition of hypospadias, where the urethral opening does not exit through the tip of the penis, but rather somewhere along the shaft of the penis or at the base of the penis in the “female” position. Because it is considered so important for a male to urinate while standing, some of these children will undergo multiple surgeries to “repair” their errant urethras.

The Emergence of a Dissenting Voice

Since 1960, tens of thousands of people have been treated in accordance with this paradigm, and because of the surrounding secrecy, many do not know that they have a
DSD (Nussbaum, 1999, Williams 2002). The prevailing medical paradigm went unchallenged for decades. But in the early 1990’s, and with the emerging technology of the World Wide Web, intersex adults began communicating with one another - forming support groups and protesting the treatment they have received at the hands of medical specialists (Angier, 1996). They claimed that their surgeries were mutilating and harmful, that they destroyed their sexual functioning, and that the shame and silence that surrounded their conditions and surgeries sabotaged their psychological development (Chase, 2002; Coventry, 1999; Devore, 1999). The Intersex Society of North America, (ISNA) founded in 1993 by Cheryl Chase, led the call to end all unnecessary infant surgeries and the attendant silence and shame.

Simultaneously a small but growing group of researchers, academics and doctors began to listen to the stories of adult intersexuals. Advances in our understanding about the effect of prenatal hormones on gender identity (Diamond, 1997, 1998), the outcome of surgery on sexual functioning and sensation (Melton, 2001), and the potential traumatic impact of repeated medical procedures on psychological development (Shopper, 1995) led some researchers in the field to question the hegemony of Money’s theories and the ethics of performing surgeries with questionable outcomes on infants who can not give informed consent (Chase, 1993; Daaboul & Frader, 2001; Marsh, 2006; Reis, 2005).

The medical historian Alice Dreger (1998a, 1999) outlines the ethical issues inherent in the acceptance of the standard medical protocol. Under the Money protocol, decisions about gender assignment were based upon inherently conservative, sexist and heterosexist assumptions (Dreger, 1998a). The criteria for assignment were different for
individuals with XX chromosomes, with the importance placed upon reproductive functioning, than for individuals with XY chromosomes, where the assignment is based upon the adequate functioning of the phallus. Babies with XY basis, who do not possess an “adequate” penis, are assigned as girls. Their testes are removed, destroying their reproductive functioning. Babies assigned as girls often had their clitorises reduced, impairing their sexual functioning. Additionally, the surgically created vaginas were not required to function like a “real” vagina; they do not self-lubricate, and they are not required to have the same sensitivity as a vagina or to change shape when stimulated. The only requirement doctors demanded is that the surgically created or enhanced cavity be able to accommodate an average-sized male penis. Successful sexual outcome was defined not as ability to achieve orgasm but as ability to achieve successful vaginal penetration.

Intersex activists argued that there is no data to suggest that the standard protocol actually works (Chase, 2002; Diamond, 1999; Dreger, 1999). Researchers in the field had been lamenting the lack of follow-up data for decades, but the data that did exist up to this point was primarily concerned with surgical outcomes – if the surgery has produced a cosmetically attractive result – rather than sexual functioning and psychosocial outcomes.

However, in the early and mid 2000s, studies began to emerge from a group of researchers working out of University College London Hospital that told a much different story about how successful the early and repeated surgeries were. In study after study (Creighton 2001, 2004; Creighton & Minto, 2001a, 2001b; Creighton, Minto & Steele 2001a, 2001b; Creighton, Minto & Woodhouse 2001; Crouch, Liao, Woodhouse,
Conway & Creighton, 2008; Crouch, Minto, Laio, Woodhouse & Creighton, 2004), people with a DSD who had undergone childhood surgery to normalize their genitals reported less satisfaction about their bodies, poorer orgasmic response, difficulty accepting vaginal penetration during sex, pain during sex, and poor clitoral and vaginal sensitivity compared to control groups. This new data galvanized the movement within academia that was responding to intersex activists, accelerating a call from doctors and surgeons to change the protocol (Karkazis, 2008).

There was, of course, ample anecdotal evidence that the medical protocol did not work. Personal stories continue to emerge in the popular press (they are also beginning to emerge in the professional literature) that attest to the posttraumatic and physical scarring of the surgeries and the psychological damage of the secrecy and lies.

Additionally, critics argued that the standard medical paradigm violated the basic medical ethics of informed consent, truth telling, beneficence and autonomy (Dreger, 1999). Parents are not told about the theoretical basis of the approach or the paucity of long-term follow-up evidence attesting to the success of surgeries. Children are deceived about their diagnoses and their surgeries. Activists point out that these infant genital surgeries are cosmetic, not life-saving, and therefore performing the surgeries without informed consent violates the infant’s autonomy. Only one DSD condition, the salt wasting form of CAH, points to an underlying life-threatening condition, and even then, the atypical genitals are not in and of themselves dangerous. The social psychologist Suzanne Kessler notes “genital ambiguity is ‘corrected’ not because it is threatening to the infant’s life but because it is threatening to the infant’s culture” (1990, p. 24).
Finally, the emerging narratives from adult intersexuals provide evidence that surgery and silence actually harm the patient.

An important development leading to the intensification of the controversy surrounding Money’s theories and infant genital surgeries has been the stunning reversal of the famous John/Joan case. “John” was a normal XY child who, after a circumcision accident at 7 months old that destroyed his penis, was reassigned and raised as a girl. John Money offered the successful female gender identity of the child, now “Joan,” as evidence of psychosexual neutrality and the predominance of rearing in determining gender identity. The argument was made all the more convincing because “Joan” was an identical twin, and her brother provided a perfect control in this “experiment in nature” (Money & Ehrhardt, 1972).

This case received enormous attention when it first was published, and it cemented Money’s theories and reputation. But in 1997, a competing researcher, Milton Diamond, found that “Joan,” who had been “lost to follow up” for years, had in fact never been comfortable as a girl, and at puberty had requested surgical re-assignment to be a male. He was now living as man, married to a woman, and was the adoptive father to her children. Diamond published his findings (Diamond & Sigmondson, 1997), striking a blow against Money’s theory of psychosocial neutrality, and a blow for his own theories about the effect of pre-natal androgens on the brain. Even more damning was the popular attention the case received. “John’s” story was published first in Rolling Stone, (Colapinto, 1997) and then as a book (Colapinto, 2000), and “John” himself did a national tour of talk shows and book signings, describing the misery of a childhood full of doctor appointments, hormone treatments, secrecy, psychiatrists, self-loathing and
fantasies of suicide. Tragically, David Reimer, the real “John,” did commit suicide on May 4, 2004. The publicity surrounding the case helped to quicken the pace at which DSD specialists are willing to accept the alternative treatment protocol promoted by ISNA - namely, a halt to all medically unnecessary surgeries, full disclosure to parents and children, and the provision of supportive psychological counseling to the families affected by DSD conditions.

*Psychological and Emotional Sequelae of Surgery and Silence*

The sociologist Sharon Preves (1999) has conducted a qualitative study interviewing 41 North American adults who were born with DSD conditions. She asked them about their subjective experiences with particular emphasis on how they learned of their intersexuality, experiences with medical intervention, issues of identity development, and the challenges of being intersexed as well as their responses to those challenges. She found that efforts to destigmatize intersexual bodies by erasing, through surgery, physical differences, actually increased individuals sense of stigma and deviance. In particular, “being encouraged to keep silent about their differences and surgical alterations only served to enforce feelings of isolation, stigma and shame” (p.55).

One of the most consistent themes Preves encountered centered on a lack of full disclosure. Many interviewees report a history of searching for information about their medical conditions, terrified of what they might find. Overwhelmingly, though, the experience of not knowing is described as far worse than knowing. In one instance a woman was told by a geneticist “I’m obliged to tell you that certain details of your condition have not been divulged to you, but I cannot tell you what they are because they would upset you too much.’ So she’s telling us we don’t know everything, but she can’t
tell us what it is because it is too horrible” (p.57). Others find that knowing is not as painful as discovering you have been lied to. This sentiment is voiced in a separate essay by Sherri A. Groveman (1999), who describes finding out that she has AIS: “It is disorienting when you have always considered yourself female to learn that you have XY chromosomes and once had testes. It is equally disorienting when you have always considered yourself loved and cared for to discover that your parents and doctors have lied and left you to your own devices to discover this truth” (p. 26).

Feelings of shame were most intense in those individuals who endured repeated medical examinations or treatments. They spoke of feeling “monstrous, Other, freakish” (p. 56). Here Preves notes that, although the prevailing medical treatment is intended to minimize or erase differences, the constant, unwavering attention from medical practitioners on their genitals served to emphasize differences for these people. “Faye” describes how her operation highlighted her sense of shame: “If they would do this to me, it must be that I am unacceptable as I am. The point is the emotional damage you do by telling someone that ‘You’re so fucking ugly that we couldn’t send you home to your parents the way you were’” (p. 58). Surgeries are far from perfect, and often intense follow-up procedures have been required. Further measures that attempt to “normalize” the genitals, like the use of manual vaginal dilation in combination with vaginoplasty, or catheterization of urethras that have been occluded by scar tissue, are physically painful and experienced as humiliating and degrading.

Preves also describes a process where her participants cope with the stigma of difference through “‘coming out’ rather than assimilating to the norm” (p. 61). Her participants describe gaining empowerment, and begin to experience their intersexuality
as a positive aspect of self through acknowledging their differences to themselves and others, joining support groups, and developing pride in their identities.

It was John Money himself who published one of the first records of the negative psychological effects on intersexed people of corrective genital surgery and medical follow-up (Money & Lamacz, 1987). The researchers interviewed and reviewed the patient charts of two intersexual women who had gone through the standard protocol at the Johns Hopkins psychohormonal research unit. In addition to several surgeries and intensive hormonal treatments, these women had gone through multiple genital and/or rectal exams as children, often in the presence of several male doctors and students, as well as repeated sessions of medical photography. Both developed a severe aversion to hospitals and genital procedures in childhood, and an avoidance of follow-up medical care. Money and Lamacz explain the phobia and the subjective experience of physical examinations as sexual abuse as a kind of displacement, “Genital exposure becomes a convenient focus of aversion … It is the entire syndrome [Intersexuality] against which the child’s aversion is directed. It is the syndrome that stigmatizes her as a freak – a sexual freak.” (p. 720). But the first-hand account of one of these women conveys the terrifying power of the hospital experience, and of being under the medical gaze:

“Well, I would be laying there with just a sheet over me and in would come about 10 doctors, and the sheet would come off, and they all would be feeling around and discussing how much I had progressed, or this or that…That was scary, I was petrified. I’ve had nightmares about this… I think it is abuse more or less when you are younger and you just don’t know what’s going on. And you are very shy. I mean just because the doctors have on white coats or whatever, you don’t know they are doctors. They are just strangers…But the killer was that last guy who took all those pictures … They don’t even take them that way for Playboy. I mean in every which position. My face was red raw for about 2 hours.” (p. 717)
This fear and confusion about, and the effects of, an invasive medical gaze pervades the narratives of people who have undergone corrective treatments and the attendant follow-up. “John” from the John/Joan case recalls thinking “Leave me be and then I’ll be fine…it’s bizarre. My genitals are not bothering me, I don’t know why it’s bothering you so much… They [the doctors and psychiatrists] kept making me feel like a freak” (Diamond & Sigmondson, 1997, p. 301).

The very nature of intersex conditions, the fact that intersex conditions concern the genitals, seems to compel a kind of fascinated gaze that, even while it takes in the genitals, ignores the whole person attached to those genitals. Certainly, intersex narratives repeatedly describe the experience of being treated as a body part, and the prevailing treatment seems to be far more invested in the cosmetic appearance of that body part than in the psychological functioning of the person in possession of that body part. The psychologist Nina Williams (2002) describes an analysis with “Kristin,” a woman who suspects that she may be intersexed. Williams discusses a countertransference configuration in which she, the analyst, unconsciously re-enacts the role of a caretaker who is focused on “Kristin’s” unusual genitalia, rather than her trauma. Williams equates this empathic failure in the analysis with a similar failure in her patient’s medical experience and family life.

As more research emerges on the psychological functioning of adults who were treated under the standard protocol, it becomes painfully clear just what kind of cost the treatment has exacted. In a fairly recent German study (Schützmann, Brinkmann, Schacht, & Richter-Appelt, 2007), adults with disorders of sexual development endorsed
symptoms of psychological distress, self-harming behaviors and suicidal tendencies comparable to a group of women with histories of physical and sexual abuse.

Looking Toward the Future

The study and treatment of DSD has seen a tremendous evolution in the past 20 years, and especially within the past decade. As activists put pressure on the medical establishment to listen to patient narratives, academics and researchers have responded with improved follow-up studies that empirically validate those stories (Karkazis, 2008). Thanks in large part to the work of ISNA and the varied and passionate group of activists, patients, and scholars who have raised voices of protest against a model of care that was neither humane nor effective, the American Academy of Pediatrics published their “Consensus Statement on Management of Intersex Disorders” in 2006. This document, and subsequent standard of care, incorporates many of the recommendations that ISNA and like-minded members of the Intersex community have been advocating for years: a more cautious approach to surgery with an emphasis on functioning rather than cosmetic appearance, improved patient-centered care, including psychosocial support and ongoing open communication with patients and their families, and a new nomenclature targeted at replacing language that is stigmatizing and overly focused on gender and genitalia. Thus, what was called ‘Intersex’ is now ‘Disorders of Sex Development’.

However, there is not yet any evidence that The American Academy of Pediatrics Consensus Statement has been adapted into widespread use, and ISNA’s now defunct website notes “no institution has fully implemented them. There are no mechanisms in place to foster implementation nor to evaluate to what extent these changes improve health care experiences and outcomes for persons and families affected by DSDs.”
ISNA has shut down its website, ostensibly because its aims were achieved with the publishing of the Consensus Statement. However, the loss of ISNA has had far-flung implications for the adult with a DSD who may be looking for help or for a community to join. That person no longer has a single centralized place to get information, find the latest research, review doctors, join forums, and connect with other people who have struggled with concerns similar to their own. While newborn infants with a DSD may hopefully have better outcomes than those treated under the Money protocol, the adult survivor has lost an important connection, outlet and voice.

As we move forward in an ostensibly more patient-centered climate for people with DSDs, mental health practitioners can be essential to providing competent, compassionate and enlightened care. The goal of this care is threefold: to offer to adult intersex survivors a place to heal from the trauma they have endured, to support individuals and families struggling to manage the physical challenges of a DSD, and to foster the development of a positive integrated identity within the unique body affected by a DSD.
CHAPTER II

The Current Study

Rationale and Purpose

Over the past half century, there has been scant attention paid in the professional medical and psychological literature to the subjective experiences of individuals with DSD who have undergone some combination of corrective surgeries and hormone replacement therapy. Very few ethnographic studies exist (e.g., Preves, 1999) that address intersexuals’ subjective experiences of their medical treatment. The medical community had a fifty-year investment in a treatment paradigm that may have traumatized thousands of people in the United States alone, yet in fifty years there is yet to be published any systematic, comprehensive large-scale outcome data as to these individuals’ psychosexual functioning that might legitimate or invalidate that paradigm. Until the early 2000s the medical industry had been reluctant to listen to the voices and stories of people who had undergone treatment and were now petitioning for the elimination of all medically non-essential infant surgeries and an end to the surrounding secrecy (e.g., Glassberg, 1998).
Chase (2002) suggested that the medical industry’s resistance to listening to intersex voices was multi-layered: 1) to accept the ISNA agenda would require the debunking of conservative and sexist assumptions about gender and the gendered body; 2) it would force physicians to look at the possibility that they have actually inflicted harm upon those they were trying to help; and 3) eliminating medically unnecessary surgeries would limit pediatric urologists’ ability to continue their technologically dazzling work.

An additional reason for the resistance can be summed up in a story told by Cheryl Chase at an ISNA fundraiser (NYC, Sept. 22, 2002): while sharing a cab ride to the airport with a prominent pediatric urologist, after each of them had delivered a speech at a medical conference on the topic of early corrective surgeries on intersexed infants, she turned to him and asked pointedly why he (and his colleagues) refused to take ISNA’s views seriously. He responded, “When I make decisions, I don’t want to be swayed by emotion.” This statement implies that intersexuals are somehow irrational or hysterical. In spite of their fringe status as “zealots” (Angier, 1996), ISNA and other intersex activists have made great strides in telling their stories in the popular media, and over time pediatricians, endocrinologists and pediatric urologists have begun to advocate an end to medically unnecessary surgeries (Schober, 1998). Following the publication of the American Academy of Pediatrics 2006 Consensus Statement, ISNA shut down its operation and funneled its resources into a new organization called Accord Alliance charged with promoting the changes listed in the Consensus Statement. ISNA explicitly states on its now defunct website that it felt the need to distance future progress toward
better DSD care from the biases and assumptions that healthcare professionals and families still hold about ISNA.

Chase (2000) speaks of the importance of providing “a counterpoint to the mountains of professional medical literature that neglect intersex experience” (p. 137). This present study, an exploratory, qualitative investigation, is an attempt to add to the scant professional literature, to provide the subjective experience of people with intersexual conditions who have undergone corrective surgery in a systematic and scholarly format. Chase also noted “There is no research effort to improve erotic functioning for adult intersex people whose genitals have been cut, nor are there psychotherapists who specialize in working with adult intersex clients trying to heal from the trauma of medical intervention” (p. 137). This study will add to our existing knowledge and understanding of the kinds of issues with which individuals with DSD struggle, and may foster further inquiry into the ways that psychology as a profession can assist people who come to psychotherapy for help with these issues.

Method

Participants

The participants were three adults with genital anomalies who have undergone some combination of corrective genital surgery and hormone replacement therapy. Participants were recruited through my contact with two intersex activism and support groups – ISNA, and Bodies Like Ours.

I had originally hoped to enlist at least eight participants. I had read over and over again about researchers’ difficulty in finding people willing to submit to various protocols. This is a group of people that typically experiences “science” and “medicine”
as invasive, abusive, prurient and traumatizing. Even knowing this did not adequately prepare me for the struggle it took to find the three generous women who eventually consented to participate in this study. I began recruitment in the Winter of 2003 and finally gave up on trying to find anyone else in the Spring of 2006. I attempted to gather subjects through personal contacts I had made through working with Suzanne Kessler, through a lecture I had participated in at Albert Einstein Medical College and while attending a conference on legal issues concerning and confronting people with intersex conditions. Finally, Betsy Driver graciously agreed to post a description of this study on her website, Bodies Like Ours.

Over the course of two and half years I received only three legitimate offers from people willing to participate, but I was the recipient of a variety of crank offers, including a handful of pornographic emails from people offering to reveal various parts of their bodies to me. By far, the largest number of emails of interest (24 emails) came from other researchers inquiring if I could help them find subjects willing to participate in their research.

*Interview Protocol*

With professional consultation, I developed a questionnaire (Appendix A) to collect data through a standardized but flexible schedule of inquiry. I attempted to make sure that all pertinent topics were covered, but in an open-ended fashion that also allowed for a relaxed, conversational interview.

The interview schedule was developed through an extensive review of the literature, as well as a careful reading of various support group websites. After compiling an initial questionnaire, I solicited feedback from the founders of intersex support groups,
colleagues conducting psychotherapy with intersexed patients, and colleagues conducting research in this field. I incorporated this feedback into the final schedule after a final review of the literature. Additionally, I conducted a pilot interview with an intersexed volunteer who gave feedback about the questionnaire protocol and the experience of responding to the interview questions. This feedback was incorporated into the final interview protocol.

The questionnaire addressed five main topic areas: (1) the nature of the participants’ intersex condition; (2) the treatment of that condition and the participant’s experience of that treatment; (3) the way that the participant’s condition was understood and managed by his or her family; (4) the effect that the condition and its treatment has had on the participant’s important relationships to self and others; and (5) how the interviewee experienced the interview. Finally, basic demographic information was gathered, including age, sex, sex of rearing, occupation, ethnic and religious background, and educational history.

Procedure

Because of the potentially traumatic nature of the material that may have arisen, it was my intention, while conducting this study, to remain as flexible and sensitive to the needs of each participant as possible. All efforts were made to let the participants control their experience of the interview through choice of location, time, and their willingness or unwillingness to answer any particular question.

Each interview was held in or near a different city along the Eastern seaboard of the United States. Each of the three participants chose their location for the interview. I met Kara in a relatively quiet room in a café, Julie in a sitting area of a mid-range chain
hotel, and Linda in the living room of her brother’s vacant apartment. Kara’s interview lasted the longest, at 6 hours, 47 minutes, Julie’s interview lasted 5 hours, 21 minutes, and Linda’s interview took 97 minutes.

Prior to recruitment, and again, prior to the interview, it was carefully explained to the participant that she was not required to answer any question that made her uncomfortable, and if at any time she wanted to stop the interview, or the tape recording, she could. In addition, prior to the initiation of the interview, a consent form was presented outlining these options, as well as participants’ rights, in writing. A copy of the consent was given to the participant, and I held a signed copy. This copy was not linked with interview data, so as to preserve the participants’ anonymity. Demographic data was obtained but no identifying information was recorded.

Interviews followed a semi-structured format. They were audio taped and subsequently transcribed by this researcher.

Protection of Participants

Participants were recruited through avenues that assumed that a potential participant had a certain level of comfort telling her story. It was not the intention of this project to interview people who were telling their experience to another person for the first time (or even the tenth time). Recruitment focused exclusively on people who were comfortably “out” in the intersex community and who had experience relating their story. Every effort (previously described) was made to assure that participants understood the kinds of questions that they would be asked, what they could expect from the interview process, and what controls were in place so that they could feel comfortable and in control of the interview process.
Nonetheless, the very subject of the study was expected to bring up potentially upsetting feelings even in people relatively comfortable relating their experiences. The investigator, a trained clinician, was available to help interviewees with any emerging feelings that they found distressing. Appropriate professional referrals were available if needed; however, none were needed.

_Treatment of Data_

_Qualitative methodology._

This study examines intersexual individuals’ subjective experience of their medical treatment through the use of a qualitative, exploratory method of research. Qualitative methods of research have different goals and make use of different types of data collection and analysis than traditional quantitative methods. Because the essential aim of qualitative methodologies is hypothesis generation rather than hypothesis testing (McCracken, 1988), they are ideally suited to a newly researched area of study where there is scant consensus as to what questions should be asked.

Qualitative methodologies have long been used in social science research such as anthropological ethnography, and have been used in the field of psychology to study areas characterized by complexity and ambiguity (Mahrer, 1988). Qualitative research grew out of “grounded theory,” which seeks to develop a research method “grounded” in the phenomenon being investigated (Strauss & Corbin, 1990). It assumes that the researcher is not an (impossibly) objective observer, but is a subjective participant, embedded in the very phenomenon being observed. The investigator therefore is the primary tool in data collection, and a potentially enriching part of the data itself (McCracken, 1988). To this end, data is analyzed as it is collected and new questions
arise as overarching themes emerge and are folded back into the investigation (Strauss & Corbin, 1990).

Dreger (1998b) describes her own work as lying within the realm of “narrative ethics,” i.e., medical ethical philosophies that take into account the stories of patients. She “seek[s] to draw historical and sociological lessons from these [patients’ autobiographical] accounts and, moreover, to understand the way in which narratives of suffering carry with them ethical obligation – obligations on the part of sufferers to tell their stories, and obligations on the part of others to listen with the storyteller and to recognize the community (and the communal obligations) of the culture in which these narratives are created” (p. 169). My hope was that this project could serve a similar function.

Data analysis.

Transcriptions of audiotaped interviews were analyzed using established methods (McCracken, 1988). Each individual transcript was examined and analyzed repeatedly – moving from the specific to the general: the focus was first on each response by itself, then within the context of the entire interview to get a sense of recurrent ideas. Finally, individual interviews were compared with one another, as well as reconsidered in light of the relevant literature, to identify corroborating and contradictory themes (Strauss and Corbin, 1990).
CHAPTER III

Results

Participants and Their Experiences

Three participants agreed to be interviewed, each with a different background and a very different DSD. Because their experiences and conditions were so different and their stories are so rich and filled with so much feeling, I have decided to offer what I hope is a clear description of the life experience of each woman, in her own words, before exploring common and divergent threads of narrative later in my discussion.

I have organized each synopsis around the basic topics within the interview schedule. The narrative data has been roughly organized in the following order: the nature of the DSD and the participants’ experience of their bodies; the medical treatment of the condition and the participants’ experience of that treatment; the ways in which their families handled their condition; how the participants’ experience has affected them in their relationships; and, finally, the participants’ experience of the interview itself.

I have changed and/or obscured essential identifying information for each woman in an effort to protect the participants’ anonymity (Gabbard, 1997, 2006).
Linda

Linda is a white woman in her mid 40’s who was raised as a girl. She was born with the salt wasting form of Congenital Adrenal Hyperplasia. She works as a teacher and considers herself a “patient advocate” as well. She graduated from college. Although she was raised in a liberal western religion and considers herself spiritually active, she no longer actively participates in organized religion.

Linda’s condition and her experience of her body.

Linda can’t remember a time when she didn’t feel her body was different in some way. Born with CAH, she was frequently at doctors’ visits, but most often she went to her endocrinologist:

I remember I went to the endocrinologist and I knew that he would check me. I know that there were concerns always. You know, even when I was probably five, I was really short, I was very heavy. And my earliest concern, is remembering that I thought I was a midget. I was always kind of the shortest, roundest kid in my class. And didn’t understand until later that that was the medicine and that wasn’t the hyperplasia. That was what their treatment was, and they just didn’t understand. And…I don’t know, I think it was probably part of the genital checks. And I-- I mean, I don’t remember anything specific that young, but I do remember being aware and like wanting to see my mother’s body, so that I could see that I was just like her.

She reports that her condition was explained to her as, “Just that I had these glands in my body that didn’t work. And then I took medicine, which helped them work.” She understood her condition in the simple but meaningful terms of early childhood:

Well, I understood I took medicine every day. I understood that I went to a doctor in that my brother and sister didn’t go to. And I… I know that there - I mean I didn’t think that there was anything particularly different, it was the way I experienced my childhood. I know there was a lot of concern when I had fevers and was sick.
She describes her evolving experience of her body first as a young child,

I didn’t like it. I didn’t like being short. I just didn’t-- I just didn’t look like everybody else - never mind the genitals - but you know the rest of me just didn’t look like my brothers or my sisters, or friends. And I think taking medicine, for kids, is a really big thing. Your body works, but it doesn’t work good enough that you can’t not take anything. And especially when you have siblings that don’t have to do it. You know, it’s… You’re just kind of aware that you’re not-- You’re just not as performing as everybody else.

Then as she grew into adolescence:

You know, it kind of depends on like what age you’re talking about. But I don’t think I ever liked my body. I didn’t like that I was boyish, I didn’t like that I was flat-chested… I didn’t… I wasn’t ever, like, proud of anything…As I became sexual and sexually active, I guess I had thought up to a point that my body was only about pain. And then you know I realized it was about pleasure too. But that came with a lot of heaviness. You know that-- the physical sensation of being excited. Just, uhm- - You know, it wasn’t that I felt like great about that, or, you know, what a blossoming. It was a lot of trepidation. By the time I was a teenager, I mean, I knew that my body wasn’t the same. So, I mean, I-- You know, it’s just a difficult position. And I think those years and times of being awkward as you’re kissing for the first time and all that is like really difficult for—I mean it’s exciting—but those steps of being naked and being touched by somebody else, I think it brings on panic in the pleasure, but when you have a body that you know is different, there’s just a lot of fear in there too.

*Linda’s medical and psychological treatment.*

Linda underwent a surgery as a newborn that was described in her medical records as a “circumcision.” Neither she nor her parents know exactly what the procedure was beyond, “I have no idea; they must have taken skin from around the top of it.” She was also treated with medication for her salt-wasting. Although she underwent frequent genital exams throughout her early childhood, her genitals were not a focus for her until the age of eight:

When I was eight there was something that happened at a day camp. And I guess we were all changing in the same room, and it was the first time that I noticed that that my genitals didn’t look like ... I don’t know if I was aroused, or what. I just kind of remember this, this, this scene. And I waited until October. I didn’t wait. I was-- You know, I wanted to ask my mom, uhm Why did I look different? And by the
time I got to October, and like held it in all that time, finally I just remember trying
to find a place to approach her. By the time I did approach her, you know it was kind
of in this huge, uhm… (crying) You know, just a lot of tears, and uhm… When I
think back, to like that moment, I think if my mom had said to me, everyone’s
different, you know, nobody looks the same. But instead, I was pretty quickly
scheduled for surgery. I mean that’s the only surgery that I know really what they
did. They did a clitoral recession. I think they probably did a vaginoplasty at that
point because I didn’t have to have one done later.

Her doctors and her parents explained the cosmetic procedure as “Just that we’ll
make you look more like a little girl.” She describes the experience:

The operation was done over Christmas vacation. In fact, I think it was done
Christmas day at ____ Hospital … Well, because I wouldn’t miss a lot of school, is
why they chose that. Uhm. But that in itself, being at even ____ Hospital is very
quiet on Christmas. There being kind of this skeletal staff at the hospital, it’s very
quiet. It was kind of only the most severe kids were there. And I had a semi-private
room, and the little boy next to me, and I think he was like five, uhm, it was
explained to me that he had to have a circumcision. Now I don’t know, in looking
back, I don’t know if that’s what it was or whether he maybe had hypospadias or
something. But he was having some sort of an operation too. And I remember him
like screaming. So you know, I think there were all sorts of things that kind of
compounded the memory. And as a result, Christmas has always been this really
bizarre time for me that I try to overcelebrate and like put up as much glitter as
possible. I’ve finally gotten a hold on it. But you know for years I just never
understood the connection… Well, I mean I healed from that, and I remember that
taking a while.

Later Linda herself became concerned when other girls around her got their
periods, “And I had now been lying about having my period. Not only didn’t I have my
period, I didn’t have breasts, I didn’t have a waist. And I knew that my vagina was too
small. I mean, I just, I knew. And I could only put the tip of my pinkie in. I mean and
that hurt.” By the time she was 15 and still had not begun menstruating she went in for
another surgery, a laparoscopy, to make sure her internal structures were all in place and
attached together. She describes what should have been a minimally invasive procedure
done through her abdomen:
And I remember that he didn’t, uh, he didn’t examine me before the laparoscopy. And I remember I was really, really sore. My vagina was really sore. So, and my understanding was that that was not how they were going to be viewing me, with that test. But I don’t know whether they tried, I don’t know whether they did. But I still remember that, trying to urinate for that first day and being incredibly swollen. I mean, my mom knew that I was really sore. I mean I had trouble, I couldn’t urinate at first, I was really inflamed. So. And then it just, I mean it hurt terribly. So I don’t know what they did then. But I remember having the discussion with him after, it was in his office, and him saying, you know—and that I knew right away—everything was attached, everything was there; and they weren’t sure why I hadn’t gotten my period yet, but that I would. But it was at that time that they starting talking to me about having my vagina enlarged. And how we would do that. And he said that they could do a surgery and, uhm, do that. And he said, And while we’re doing that, we really ought to get rid of your clitoris, it’s really too, really big.

This time her mother responded with more deliberation:

And I can remember like walking down these steps with my mother, kind of shell shocked, and saying, We don’t have to go back to him, do we? And she said, No, no, we don’t. You know, my mother, one thing that she can remember in all this is that any time they really talked about doing something with my clitoris it concerned her. Because she knew that that was about pleasure, regardless of what it looked like. And we ended up finding a guy at _____ Hospital who then said to me, Did they talk to you about the dilation at all? And I’m like, What is that? So he explained the process. But even if you had this, you have to keep yourself open and you have to stretch yourself. And there was the possibility that you could do the stretching without the surgery. And that we could try that first before the surgery.

Linda describes how she was prepared for her surgeries:

I was only included if there was an event like we’ve decided that there should be surgery, or… I mean later, when I was starting to get to be a preteen and I was voicing concerns, they started to include me. But I don’t think with very clear information. You know, it was never kind of discussed like what would be done. I don’t remember discussion about it; I just kind of remember being prefaced for events.

And the implicit messages about having to keep it all secret:

I was a really good, compliant little kid. (chokes up.) Uhm. And knew that I was this huge concern and tried to not be like more of a concern. But yeah it was all kind of mysterious and you know you shouldn’t talk about it. And I remember them saying don’t say anything to anybody. You know, when I was eight, don’t tell anybody at school. You know, just don’t tell anybody. I don’t think I asked a lot of questions, because I knew my questions didn’t make people comfortable.
Linda did end up using dilation, with more or less success. It was successful in that she did not feel the need to go in for further vaginoplasty:

[The dilators] were kind of these black tools that came in - they weren’t even in a box, they were like in a box that was meant for something else. And you know, I had to have KY jelly and I had a nurse that helped me through it. But you know, long and painful, and uhm… You know, I think that I thought, Well, isn’t that the goal? To have something in your vagina so it feels good? And I remember that not feeling good at all. You know, and still very difficult to become sexually active. So I definitely knew by then that things were not, NOT normal. I mean I was really determined to have sex. You know the markers of where you become a woman I mean, it’s your period, it’s breasts, it’s, uhm, being attracted to men, uhm…It’s having sex and I was really determined to do that. I was probably… I was 16, so, I did (dilation) probably for maybe six months, maybe nine months. And it was on and off. I mean, at some point... At first it was like, I’m going to do this. I mean it’s a long process and it hurts. Then I, like I had sex, which was terrible and incredibly painful. And just said, oh this is what all girls do. I was probably close to hemorrhaging, but of course I won’t have said anything to my mother. And I don’t--I remember times being sexually active and having it being difficult and painful, or, in some case, not at all. But it didn’t occur to me to like start the dilation again. I mean, I might have done it once. But once I got into my twenties, and I kind of programmed my life to make sure I didn’t-- I wasn’t without company for very long. I really kind of flew from relationship to relationship, always.

Linda explains her medication regimen:

I don’t know if I had hormone therapy when I was in my adolescence. I take Prednisone. So it’s a replacement. The Prednisone I understand controls the suppression. But I don’t know that I was ever given hormones per se. Because you have this salt-wasting component, and then you have this creation of all this androgen. So in a normal person, a normal female, the androgen is processed into estrogen. And then, you know everybody gets a little androgen, but I get so much that it really all just has to be suppressed. I’m very-- You know, it’s not a good medicine to take. It does a lot of damage to your bones. So over the years, I’ve just taken less and less and less. I’ve ended up in crises because I was taking so little. But I just know that the less I can take, the better I’ll be. And then I take something for the salt-wasting--the Florinef. And then I also had a thyroid condition that came out—I was probably in my late twenties---so I take Synthroid for that.

Linda can’t remember having medical photography, but she does remember the confusing feelings that came up for her when she knew she was going to the doctor and she was going to be looked at:
It’s funny, I can admit now it was—in a really not good way—it was sexually exciting. Because I knew someone was like going to be looking. I don’t remember if there was a lot of touching, but I do remember there was some spreading. Well, I mean, [it’s not good] to be sexually excited about going to the doctor. It wasn’t about going to the doctor, it was about, it was a part of my body that if you touched, there was a reaction. And I remember thinking like I shouldn’t - I was scared if I got a clitoral erection, that they would, you know - That that would not be, not be a good thing. But I don’t remember minding it.

But going to the doctor could also be special:

And it’s funny because my endocrinologist wasn’t the one who gave me shots, it was my pediatrician in ______ that would do that. So I can remember that I always knew if I was going to this doctor, I wasn’t getting shots. So there’s kind of a benefit there. It was - he was a really kind man, his name was ______; he’s still up at _____ Hospital. He had a really nice assistant. I can still remember like walking down one of the ramps and the smell. You know, it still a very distinctive hospital smell. You know… It was just… something in those hallways. But it was always kind of a special occasion. My mom and I would come in, and we would do… Going to the city was always… I can remember most the time I was dressed up, or I had… So I don’t really remember minding it.

Linda explains the impact of her medical treatment on her sexual functioning:

I have always been able to feel pleasure. I-- And in that there’s a lot of pain. Which for a really long time I just counted to that kind of pleasure and pain thing? I didn’t realize the pain I was experiencing was really more than was acceptable to anyone. But I mean I just, I knew there was pain but I just didn’t— I mean there’s-- The psychology of it is, well, this is what somebody like you deserves. Or in order to be normal, this is just one more thing you have to do. But I think it was not just the surgeries. But it was I think the whole aura of society, which is unless you are a married woman with children, you’re not normal, you’re not acceptable, you’re not-- You know. Uhm. So my idea of sexuality is tied to what somebody was telling me it’s okay to be. And the surgeries, what I say to people that can’t understand it—and especially men, because they get this—I say, okay, we’re going to take your penis, we’re going to submerge it underneath your skin, and then we’re going to tie it down. And how would that feel? What it feels like is that there’s always a great deal of straining and pressure. But there is, I mean, there’s a lot of pleasure.

She further explains the pain she experiences, and how she has managed it:

My clitoris, because of that pulling... My vagina because it’s small, and it doesn’t lubricate. Unless there’s a lot of time, it just hurts. And I’ve really gotten-- One of the things I’ve done in the past two years is take back my body, and be the only one to decide what goes anywhere. And that’s been really, wonderful. And it kind of dawned on me one day, it was like a year before I realized that I just decided not to
put anything inside it. You know, not a finger, not anything. And I was really fine with that.

She also has managed to figure out how to live with her ongoing medical treatment:

I was really bad about taking my medicines when I was in college and when I was in my early twenties. Or seeing a doctor, an endocrinologist. I’d go to an endocrinologist when I knew my medicine was ending, and I really needed to have it some of the time. I just was not good… I wanted control. In that really stupid way. And I think that’s what we do, we pick really stupid places to have control. Like, I want to be in control of how much alcohol I take, or how many cigarettes I smoke. We take really negative control of our bodies. But it was just kind of this-- You know, maybe a part of it was if somebody really explained what this did. I mean really, what does it do?… Well, I mean, so disconnected was I from, uhm, my body, I don’t know the times that I was having troubles that I would connect it to the fact that I was not taking medicine. I don’t remember particularly anything happening. Although I would-- there were definite times I would get like sick with the flu or a virus when I would realize, I really need to make sure I’m taking my medicine. But not until really, really later—like in my thirties—did I realize that the way I was feeling could be from the fact that I wasn’t taking my medicine anymore.

Linda describes her first experience with a therapist:

I can remember seeing a therapist when I had my operation at eight. They started to have me--that fall, I can remember--they sent--had me go to a woman. A kind woman by the name of ______. Who was up at ______ Hospital. I think they found her because they were dealing with kids that had trauma. And I remember her being really kind and doing some kind of play games with kind of wooden families, and maybe some dolls. But I don’t remember it going on for very long. And I don’t remember talking about what was going on. I think that all of us, the kids in particular, have real rough trouble talking about the things that are bothering them. If they say it out loud it makes it real, if they don’t say it out loud they can just pretend it’s not in there…You know, but I don’t know that I ever really felt that it helped me. I don’t know that she ever said, Gee, how does it feel to--? I don’t remember the connection between like what was going on here and this effort to really address maybe what I was feeling.

When she was 28, her husband committed suicide and she entered therapy on her own:

But I didn’t talk with her at all about me. It was kind of processing the grief and being the survivor. And that’s what I went to her for, but there was some really important questions in addition that were floating. Like, why did you pick such a
damaged person and when did you know this about this person? …And we went, from him, and him and me, to my husband—my second husband, who I was also having terrible trouble with. And kind of went all the way down the line, and really started to talk to her about me in probably…the year 2000. And by then we had just been working on my relationship with husband and they way things were played out. Then, I went in and said, I think I’m really done now and I think I’ve gotten all I’ve gotten here. And she said, I don’t think so. It was really at that place that I knew we had to start on me. And it’s been a lot of hard work. But I’m very lucky. You know, I see all these postings on the message boards. And I meet people that are really damaged. And I know that you cannot, like, make sense of this unless you’re really working diligently. And you can go back and then go forward. You know my most difficult time was when she said, you know you have to go back and get young Linda. And I didn’t understand, there was such an absolute disconnect between whoever that growing up child was and myself. And I wanted and worked very hard to keep that disconnect. And, ah. But it’s been a lot of hard work.

She began to grapple with her long held sense that “things were not quite right”:

Here I had this particularly—you know from the outside, this ideal life. You know, the husband, the kids, the house… All these, like, you know, dreams. And this life. I’ve always been very productive. And that’s how I kind of dealt with this, I just became so productive I didn’t have time to think. And I just knew that I was still struggling somehow. Even all of these goodies. You know, things people would die for… two healthy kids. And I just was… And I was always escalating If I have the surgery, I’ll be okay. If I date this boy, if I marry, if I have kids, if I live this way… If I did all these right things, and it still… It didn’t feel quite right.

It was while in therapy that Linda first tried to find out her full medical history:

…[when I was] 41, 42. I first tried to get it from my mother. I hit this really difficult wall I think when I was 37 or 38. And I didn’t know why, but it was like I needed to know what happened, I needed to know about the surgeries. Because by then I realized I was different and... I just knew I had surgeries. I knew about the one when I was eight. I was looking for some holes to be filled in. And, uhm…It was probably about the time I realized I was running out of other people to talk about. And not only that, but that certainly my involvement with these people, and the way I took relationships, and had relationships, and talked and processed things—that all of that had to do with how I felt about myself and what I felt I deserved. But I do think it was part of the process, part of the therapy. It was kind of this bizarre quest of like, Tell me who I am? Or tell me who I was? Or how I got here? And I was just really depressed. And I went to my mom and I’m like, You gotta fill in some blanks. And she just - She just didn’t know very much. And you know my father was the same way. He said, “They told us what we needed to do and we did it. You don’t try this with just medicine. And we’re, “okay.”” My mother expressed this, you know - She said that she always knew that I had terrible issues with my body. And, uhm… You know, that I used to have really long hair and I
used to have like really bad posture. And just be very closed in. She just thought, she said, “I just, I guess I hoped it didn’t matter anymore now that you’re married and you have kids. You seemed to be like, life was okay.”

Her pediatrician responded similarly, with “‘You know’, and he always used to call it ‘this business’—the business about… ‘Why are you concerned about this business about how your body looked? It’s all done, it’s all fine…’ It was that simple, You’re married, you have children… You know, like, everything’s fine!” She did finally get a full copy of her records.

*Family response to Linda’s condition.*

Linda describes her family’s experience at her birth:

What I know now is that because they couldn’t identify my sex, they kept my mother sedated for days, until they could tell her. I still don’t know what they told her. But they - my medical records say, I think, on the second or third day that they identified I was female, but noted that I was a pseudo-hermaphrodite. A fake something. Which was something my parents never knew was on my chart—never—until I got the charts and transcribed them. And—I had two grandfathers—my mother’s father was hooked up with _____ Hospital. But was kind of a whiz around doctors. And his take on this—and this is from other people—was, she’ll be fine, whatever care she needs, she’s a beautiful child... We’ll just do it; we’ll take care of her. My father’s father came to the hospital and told him they should let me die. And he was a doctor. That I was never going to grow up to be able to marry and to have children. And basically, who would want a girl that looked like that? And that would be the kindest thing to do. So my father had a lot to take care of. Which is no wonder a month later he said to somebody else, “You’re in charge…”…You know, “Whatever you can do is good.”… They were involved but they were told what to do. The doctors said, this what we need to do. This is what we do with children. And I have-- There’s a letter from my father--when I was about two weeks old, maybe three weeks, and I have a copy of--it was to the doctor at ______. Saying, Thank you for taking care of our daughter, and we trust you completely. And basically, whatever you tell us to do, we’ll do. So. Which is what they did.

She explains the kind of communication that happened in her family around her illness:

Other than the things that they felt comfortable talking about, the fact I wasn’t growing, or that I was overweight, or I was… I don’t think they talked at all about how my body being different. I don’t know what they told them when they went to
the hospital, but—or when I went to the hospital. But I know my mother didn’t talk with anybody about it. She still is friends with the woman who was her dearest friend back then. And she said she had no idea. She didn’t tell anybody… I think that she probably talked to him, but I don’t think that he - Their pattern was that. My family was not a family that talked about what was going on. They talked about anything else. And anger was the same way, you never really knew why the anger was there, or whether it was… It usually was not directed at the proper source.

Linda reports that the level of secrecy and suppression in her family was such that her siblings found out the nature of her condition “Only when I told them when were all in our 40s. But they knew nothing about the surgeries per se or what the surgeries really were or what is up with Linda”. Her role as the youngest and the sick child left her deeply misunderstood by her siblings:

I have a sister that is four years older and a brother that is two years older, but you know, in looking back, first of all my sister knows is that she is really happy for two years and then one came along and then another came along, and the last one that came along needed a lot of attention. So, from her perspective of growing up that is really the way that she viewed me and felt about me. I know she felt really bad about feeling that way about that child. Then, my brother being the only boy, being the middle child, being a son of a really repressed, very conservative and conforming father, a lot of the rather negative attention really fell to my brother. And because I was the smallest, the weakest, had problems, they really kind of did not expect too much from me. So, I just think everybody thought I had it really easy.

She felt loved by her family, but she describes her painful internalization of their expectations:

They were very caring. I was the only sick kid in the family. But very caring because I was compliant. And I was a really loving kid, I just was, I mean, I just was probably easy to be around … Because I lived my life from that place. It was about what other people expected and wanted for me, you know, in a really genuine way. And the desire that they should create a little girl that grows up into, you know, a good girl and a good woman. Which really only meant one thing, which was marrying and having kids. And I just did what I was told. And that’s really sad. I mean, I was born in this place where being different, in ways of sexuality, was-- I mean, there were no words for it, there was no discussion about it. It just this really shameful feeling. And did I make the connection that because my body was different my sexuality was different or my fantasy life was different? No. But I just think it made me feel worse about my body. And, you know, my mind is bad too.
And there is just nothing that was kind of acceptable that way. So I just was really this very molded, compliant kid.

**The effect of Linda’s experience on her relationships.**

Linda had long felt ashamed of her body and it began to show in the way she carried herself. Her posture was hunched and she “went to school in dyed big flower shirts and jeans and stuff that was too big, and had long hair and wear padded bras and whatever I could do.” But even more difficult and confusing than her shame about her body were her secret feelings about her gender and sexual identity:

I know that I had this feeling when I was young, six or seven, that I was a boy. They just had told me that I was not a boy, and I kind of remember going through that phase. I am really a boy… I wrote a poem about kind of always thinking I was a little boy and knowing it, and waiting on the exam table for somebody to tell me that, until I stopped waiting. But I just kind of always have been like that. My body was boyish, my thoughts were boyish. I knew that little girls should not like, go that way. When it all comes down, never mind my body image, but my attraction was so unsuitable. And I just knew that it was not something that I can even ask about. I just had to like hide and push it away. And that was really what happened when I was about 38. I just was realizing this draw to women was not going away. It was not diminishing, no matter what I had around me, that perfect life, I was a pretty strong woman. I mean I did a lot of pushing and I just, you know. You know the story of Sisyphus? That was my boulder and I just was getting weakened by it, and I did not know how to get it away anymore.

As she has learned more about her condition she realized that her same-sex attraction made sense on a physical level:

You know there has been an incredible dawn in my consciousness in the past five years. Topics of gender, sexuality were really not places that I could go before… I had not made the connection that my body might be tell-tale of my mind’s thoughts… But just understanding it, I mean I got a whole lot of male hormones for somebody that has got ovaries… My epiphany was wonderful and terrible at the same time when I realized that girls with congenital adrenal hyperplasia, it is their brains too. When I speak to doctors what I say is “if you want these surgeries to be really successful, you need to be doing lobotomies at the same time.” … I mean I do believe that my body and my mind were created very similar like and then that attraction that I had for women is just part of what I am. And that is something I did not understand, you know, when I was a kid…But that struggle to get to that point
was a terrible struggle and one that I did not want. I did not want that absolute connection because I fought that connection for so long.

Linda has slowly come to terms with her sexual identity, but notes that her body doesn’t always cooperate:

I am definitely orgasmic, and have great clitoral orgasms. Also have vaginal orgasms. And, you know, I had them with lovers. So I am really lucky in that way. The physiology is there. It is just the psychology that, you know, has to go along with it.

Linda describes the effect her medical experience has had on her abilities and self-esteem:

You know, the medical experience is not just about the body, it creates this psychological person. And I just felt that I always had to make up from this place of deficit. And you know, kind of be all, be the best friend, the best wife, the best mother, and the best lover, and you know, the best volunteer, and the best driver, and the best gardener. I mean I just had to like excel everywhere else. You know, I am trying to prove that I was okay, and when I say for a long time that I aspired to be normal. It is just a terrible thing like for a kid to want to do. But I believe that is the way that I handled it, just by overachieving everywhere. At a great price, you know, I mean all that busyness was a great price to, you know, myself…How do you gain self-esteem when the self that you were was so unacceptable? And you know yourself as a soul, but also like this shell too, but I mean, they are so closely intertwined. There was always something to be shameful for. And something to hide and, you know, all of those things just weigh on your ability to live a balanced life.

Although she continues to get her medical care, she is no longer as “compliant” a patient; she expects her doctors to be willing to learn, and learn from her:

I am very suspicious of doctors, of surgeons. I think that the way that we put medical care in place in the society has really been along god-like change and we have just, you know, handed it over to people who we thought were experts, to people that are still learning. And also go from their own paradigms of what is right and okay and acceptable, and what they would like. You know, I do not know that there is any surgeon who is out there doing these surgeries that isn’t thinking “would I want to be with this woman like this?” And it is the same thing with kids that are, you know, boys who are born with micropenis. “How would I feel if my penis were only this size?” They just do not know how, in some cases, to [remove] their own biases…In the past, I have tried to look for doctors that have experience with women that have adrenal hyperplasia, but there are not a lot. I mean it is not the kind of
condition that you base your practice on. But the most recent endocrinologist, who I picked was a woman who is in New York, did not have any patients with adrenal hyperplasia, but was willing to learn and understand. ...I mean it is such an odd thing for me to feel that these surgeons could actually do a good thing.

She is also frustrated by the lack of expertise about the intersex experience in the psychological community:

You know, therapy is about going and telling the truth and being able to dig, you know, you have to want to do the digging. But the person that I have been working with now for 12 years really, I mean, she knew nothing about this. What she knew was what she knows about all patients that have been through trauma, been through childhood trauma, and connecting the dots, and you know, doing their own research, and you know, and then catching up with it. But this psychological community, I mean, they are just beginning on this. You know and people are looking for like experts and people within their sex conditions.

She recommends the following to people in the psychiatric community who are working with the intersexed:

And what I say to every psychologist that say I have got a patient and I do not know what to do, and I say you treat them from the mode of care that you would any other patient where you know there is trauma and prolonged childhood trauma, and shame, secrecy, and isolation, which are things that are common threads through so much of those childhood traumas.

Linda has a tremendous amount of empathy for her family and the choices they have made in her care:

You know, I did not have as hard a time forgiving my parents as some other people do, because I do give them that place where they were coming from, which was not a lot of information, which was somebody said to them, “we can heal your child.” And they said, “Where do I sign?” And as a parent, I mean, I would understand that motivation. I know that some people have much difficulty. I mean there is the religious aspect of being thrown in there about punitive damages to cells and just being parents not being able to deal with a kid that is different, and if they do not like the devil that is at work, or they did not repent hard. I mean I see some really twisted people that are brought up in these really religious homes. I never felt that from my family. I really felt love and cared for. Growing up, I kind of understand why my sister always felt that I was taking too much time and understanding, how that has affected her and our relationship. And my brother and I really had a sibling rivalry; we were really fighting and nobody would separate us. It was bad. But I think that I feel compassion for my mom in particular. You know, to have the
responsibility of having a sick kid, especially in those years when you did not know except what was told you. You know, it must have been a really difficult thing. And then to not feel you could talk about it. It must just have been horrendous.

As a result of her experience growing up as a sick child, Linda describes her struggle to find reciprocity in her friendships and romantic relationships:

I have always been a great friend and for really long years of my life, I hooked up with friends that depleted more than they gave, but that is what I expected and I picked. So, I just picked friends where I particularly had more to give and will take less. I have always been uncomfortable taking or asking or needing. I mean, those are just things that I just do not think I have the liberty to do… I really did always find people that were somehow more damaged than I was. People that I felt I could make better or make them happy, you know. I got exactly, I mean, it was like I did not want ask for too much and gave a lot. Even when I did not know what I was doing, I knew that I gave a lot of myself and my time and my attention, and I kind of vicariously loved in those relationships, because what I was doing and not what I was receiving, and I did that always.

When asked if she thought her condition should have been handled differently, Linda was clear about she would like to see for other children with intersexed conditions:

You know, I do think that surgeries need to wait. But the discussions with the kids, I know that there were times that I got information at age-appropriate basis that calmed me, when the fact that nobody was giving me answers, made me really anxious. And then even years later when I read my medical records and I could see, I was like, “that was what that was about.” And I think, my kids are not stupid. They do understand a lot more than we give them credit for. So being involved with it, I know how I became a teenager and I was more involved with the decisions and the care, even though I did not feel great, I was feeling better than I did.

And what she would have wished for herself:

I think that I would always need to take care of my body in some way because of the salt wasting. But I think that if they have left my clitoris unhitched and because of my orientation, I just think that is the way that I would have been drawn. But really what they did is they created a person with a psychology that was about childhood trauma and medicalization. And that the normal thing that they tried to replace for me when I got to that point, as an adult, that all the things that were done to create my body, created a really bad psychology. So, you know what would I have been like without all that medicalization? You know, from not having all that kind of intervention and concern and being told that my body was like unruly, you know, what would Linda’s life have been like? Very different. For sure, very different.
Linda’s experience of the interview.

Linda describes her experience of the interview:

Obviously it is cathartic to talk about it… I always think that maybe I will get through this one without tears or without, you know, having that welling of emotion, but you do not, you know. And I think it is why people do not agree with the interview is because you know it is a sad place and a difficult place to go back to and no matter how much you have accomplished and even how much life you have lived. To think that you are still so connected to this distant past is it is a little jarring. It is why you know it matters…And you know, the thing that will happen from here is, as I go away from this interview, I realized that I recover much more quickly. That it does not take my soul anymore. It does not throw my guts on the table and then push them back in, and let’s go back out on the street. It just does not harm me as much as it did at the beginning. I think since I opened my mouth the first time, you know, really this is not just about me and my story. You know, this has much larger potential for change, which is why I do it.

She elaborates further on how giving interviews is in some ways, empowering:

I think, talking about exposure. You know, and being exposed and being examined and being micromanaged. You know, the difference is now I voluntarily expose myself so that I have the power and I, I understand how that power played into all of these, and being powerless and going through life kind of powerless. Thinking that somebody else was in control - but nobody was in control.

In spite of the tremendous progress she has made in making sense of her experience, integrating her conflicting feelings and building some mastery over her trauma, Linda admits she continues to struggle with the aftermath of the medical attempt to normalize her body:

But, you know, I think about how really hard it must have been to be that kid. And now it feels like I am manufactured and now I have to live my life in this manufactured body. And that is something that I cannot change and I do panic. I kind of get angry with that one. But also because of the psychology it created. You know, I have lived a fairly fucked-up life, more fucked up than some people, I do not know. But it was definitely created in this quest to avoid all of that.
Kara

Kara is a white woman in her mid 30’s who was raised as a girl. She was born with Penile Agenesis, which is the absence of a penis in an otherwise biologically normal male. She was, at the time of the interview, nearly finished with an associate’s degree, and had been working in the service sector for the past 14 years. Although she was raised in a conservative western religion, she considers herself as “secular,” holding to her own personal religious beliefs.

*Kara’s condition and her experience of her body.*

Kara’s childhood was in many ways organized around two conditions: the Penile Agenesis or “birth defect,” as she, her family, and her doctors referred to it, and her Attention Deficit Hyperactivity Disorder or as she describes it, “the hyperkinetic syndrome, which also was accompanied with a learning disability such as dyslexia, and dis-coordination.”

She states that she always had the sense that there was something different about her body because she was frequently told so by her doctors: “I used to have visits every six months to Dr. _____ and his associates, who would explain to me that there was a genetic birth defect that happened when I was younger and that these are the measures that they are taking to try and correct it, so that I can have as normalized a life as possible.”

To that end, she underwent surgery as an infant, she was given hormones at age 8, and at age 9 she underwent a series of major surgeries to reconstruct her urethra. Doctors explained the hormones: “I was told that there are some girls who developed breasts
normally and there are some girls that need to take female estrogen, which is a hormone that my body lacks due to the birth defect that I had when I was a child.”

Again at 16, they explained to her why she would need a vaginoplasty: “I was told that I was going to have to have a vagina surgically created in order to have intercourse when I pursue a relationship with a man; that there are some girls who have periods, some girls who don’t, that there are birth defects and when you have a birth defect, as the type of birth defect that I have, it’s necessary to recreate the vagina through a surgical means and that I’m not the only woman that has gone through this procedure.”

Beyond her doctors, however, Kara had no one she could confide in about what was happening to her body, “Both my mother and father virtually discussed nothing about this situation.”

But she asserts that she took the impeding news of another surgery in stride:

Well, to be honest, I really didn’t care. It was simply something like being told, you know, you have a blister and you need to have this procedure to have it removed. I was really preoccupied in my own life, which was coin collecting, karate, I had various hobbies at that time, and so there wasn’t any preoccupation with the anticipation of this particular type of surgery until I got a boyfriend, and then I realized that there was an inadequacy in my body and now that my memory is coming back also, when I was about maybe 11 or 12, I would compare genitals with friends. It sounds strange but looking back, I don’t honestly believe that it’s that strange for teenagers and even for children to look at each other and make comparisons of how they look. I did become aware then that I didn’t actually have the vaginal lips that most regular girls do. But since it wasn’t a painful matter, it really didn’t concern me all that much, until I had a boyfriend.

She seems to have taken a rather clinical, observational view of her body, even at the age of 8. And, in spite of her awareness of an “inadequacy,” she felt that her doctors were able to provide her with a “close enough experience to an average woman”:

At the time, I wanted to fit in and look like other girls, especially in gym. So I was eager to start the hormone therapy because, my voice was a little deeper. I didn’t complain about it, but in my medical records, my mother is very adamant about my
squirish looks, meaning that in her opinion, not that her opinion ever mattered to me, but in her opinion, she thought I was very boyish-looking and so she also was having anxiety about how the particular hormones were gonna affect me. But once I went on hormones, I was very satisfied with the result. Even as a child… To me, you know, I wanted to look like a woman. Looking back retrospectively, I was raised as a girl. I never knew anything else. So as I developed the right curves in the right place, and as I slimmed, my legs slendered out, and my breasts began to grow. I was very satisfied, especially, going to gym when I could clearly see other girls going through this particular experience and I didn’t wanna miss it. I wanted to experience what they experienced.

Kara describes her ongoing interest in other girls’ bodies and an early attunement to the way her own body did not quite look the same, as well as her confidence that the doctors could shape whatever she found “inadequate” into something that approximated a normal female body:

What to me, the doctors, I mean, it was a good experience because I had, what I call little tweaky issues. I didn’t grow pubic hair until I was in my late 20’s…I had these little wisps and I would go and I complained, this is terrible, I see girls they got this, they have a lot of pubic hair, why don’t I have it? The doctor says, “If you like, okay.” We’re gonna prescribe you this medication to see if it helps. You know, I remember one complaint I had about having painful knees and about having painful elbows and the doctor’s like, well, okay, this particular type of estrogen is causing swelling of the you know, of the ankles so were gonna try a different medication. Another time, I went in because I realized that as women develop their breasts, the nipples got larger and as an effect of being a genetic male, I had very tiny nipples. I remember my mother very blatantly saying, “Who cares what size your nipples are? What normal child complains and moans about the size of their nipples?” And my attitude is, I’m going to the doctor - if I wanna talk to the doctor about the size of my nipples, that’s my business and I’m gonna talk to that damn doctor about my nipples.

She also explains that because of her ADHD she was experiencing severe emotional and social problems in school, making concerns about her body not nearly as important as they might have been, “that particular condition gave me more social problems, far more than having, you know, genitals that were a little different.” She again describes her satisfaction with her medical treatment and with her emerging body:

You see, the difficulties that I had weren’t with my body, and a lot of this had to do with that I went through the hands of Dr. _____, and Dr. _____, at the time, was the
highest acclaimed plastic surgeon in the world, and he specialized in urological disorders, everything from Cloatia [sic], to even though it wasn’t called Intersex at this time, but to birth anomalies of the genitalia. So I was surgically created, close enough to an average woman and because I’ve, like all kids, I had the opportunity to, steal pornographic magazines and compare myself to the pictures or just for my own curiosity’s sake. I realized that women were different, from body to body to body; and so I didn’t see my differences as anything different than any other woman.

*Kara’s medical and psychological treatment.*

Although she didn’t know this until she was an adult, Kara underwent her first surgery soon after birth:

What was done was they removed the gonads. They took the remaining skin that I had and they refashioned a clitoris, and then they instructed my parents that they were unable to create a vaginal entrance but it would be better to wait until I was older so that I felt that I had a part in this decision as opposed to just create something and they were also, they’ve had experiences in the past, of it is better to wait until the child is older and has a part in the decision than to make all of the choices for the child at birth. So, that’s what they decided to do, to reconstruct more feminine-looking genitalia and then at the appropriate age, which was what they felt was when I got my first boyfriend, provided that I was going to have a boyfriend, because they were uncertain about what my sexual orientation was going to be, and they felt that, the least amount of surgery, or should I say, a surgical intervention should only be what is necessary at the time.

She explained the medical need for the surgery as:

Well, at the time, the physical danger had to do with probably two issues. Number one was that when you have bisected testicles, there’s the issue of temperature. This particular part of the body is not able to be kept at the right temperature that a normal biological male is kept at when the gonads are in one sac. This can cause infections very early on, causing possibly gonadal cancer early on even as early as puberty. Number two, there were issues of the urethral muscles that are actually used to be able to control, you know, going to the bathroom. So, they were able to determine that these were also underdeveloped and so that reconstruction of this particular area so that I wouldn’t be in diapers for the rest of my life meant a major reconstruction of removing the entire area to reconstruct that particular area and in addition to that, in penile agenesis, the penis is actually internal but it’s highly underdeveloped and what happens is that the urethral tract goes through this particular underdeveloped organ and as early as two years old, I began having terrible bladder and urethral infections, which at nine years old required a major operation of going in through my abdomen, reconstructing the urethral pathway, removing the seminal vesicles, and removing what they call the artificial vagina, which actually was the underdeveloped phallus.
So she returned to the operating room again at age 9:

I was urinating blood and I was in excruciating pain; and it was explained that if you don’t have this operation, your pain will never be cured, which was the truth. That wasn’t a lie or deception or anything like that. So, at nine years old, I was in the hospital for four weeks, while they, you know, by having an incision going across here and they went in, also to make sure that the bladder had formed normally and to do, you know, I also had a problem with leakage. I used to have to wear tampons because every time I go to the bathroom, I’d continue the leak for, for the night, and so this was necessary and Dr. _____ was considered to be the genius at the time of urethral reconstruction and he was able to reconstruct normal urethra muscles so that I could go to the bathroom like everyone else without having to wear a tampon - not a tampon, a pad. So, that was at nine.

She would later return in the next year for a surgery to correct the angle of her urination stream because it would it would run straight down her leg, as well as four exploratory surgeries, “with a thick scope and they put that up the urethral entrance to try and look inside to see what needs to be done.”

Kara felt a particular gratefulness to Dr. _____ because he included her in the process:

In fact, Dr. _____ was quite amazing because he explained to me exactly. He had a big chalkboard I remember this and he would draw what he believed I had inside and what had to be removed. In one particular incident, you know, he had all of his colleagues leave the room so it was just me and him and the nurses, and he actually had a second TV monitor set up for me so that I could watch on the TV what he was doing and what the inside of my bladder looked like and this to me, this was probably extremely reassuring thinking back, because I was a part of it. I knew what the doctor was doing. You know, it was even interesting to watch this type of technology at that age. So, you know, I felt included. I didn’t feel like I was excluded from what was going on to my body. It was no doubt that it was painful and it was traumatic, but I was informed, even at nine.

At 17, Kara began a relationship with her first boyfriend, and was scheduled for a vaginoplasty. She woke up to two unpleasant surprises, the reality of dilation and two large purple scars where the doctors had removed skin from her buttocks to fashion her new vagina. She handled these problems in quite different ways:
I stopped dilating because I was a kid. I didn’t like it, it didn’t seem natural having to put something, a part of my body that wasn’t there earlier, but didn’t feel comfortable sleeping with, and there was the smell. I’d pull it out and it would have a bad odor you know, and then there were the infections you know, there was an issue of areas where this surgery had been done, where these pockets of infection would occur, and of course, I wasn’t gonna use a dilator with the infection up there, it hurt. So, then once the infection would clear up the vagina would shrink down again and I got to a point where now, I can’t get a dilator up, so I have to go back to the doctor.

But the scars on her buttocks were a different story; she pursued repeated surgeries until she was happy with the results:

The type of scar tissue that was really bad was what I had on my buttocks from that surgery, but I complained, I went back and said what are these big purple things, and they’re like, okay, bring her in and they removed the skin off the buttocks again. Okay? Once again, a couple of months later, the skin would grow back and you’d see the little bumps, the red bumps scarring, and they’d go out, when it comes to scar tissue, the way that they resolve it, is they remove the skin off that area and allow it to grow back again and so after about maybe three times finally, the skin grew back, grew back smooth without any lumps or without any scar tissue and not only that but I have got sensation on my buttocks and, I’ve communicated with other people who have gone through similar operations that if there is ugly scarring, the scarring can be removed. It’s just you have to be willing to proceed with this, where some people its kind like a choice, you know. If you have, let’s say, hideous scarring and you’re not willing to go in and have that scarring removed, then whose fault is it? Or that maybe fault is the wrong word. We are all, I am, at least, you know, the captain of my soul… if you’re unhappy with the scarring that’s there, you know, to me it’s no different than being unhappy with crooked teeth. You have to be willing to go back, make a complaint, and put the braces back on or go to a different doctor who, maybe is a little more skilled with his knife and get the scar tissue removed.

In her late 20’s Kara decided she did want her vagina enlarged. She returned to a trusted surgeon, who offered soft dilators rather than the older glass version, and prescribed an estrogen cream. She reports that by wearing them 24 hours a day she has “been able to work my self back up to a normal size”.

She also continues with hormone replacement therapy, albeit on her own schedule:
The type of testosterone that affects how you look, more body chemistry, you know, sexual urges, and the estrogen - when they mix, it has an acidic effect and it gives me terrible body odor under the armpits and I mean, literally I have to carry soap and wash cloths and deodorant with me. If I go off the estrogen, the effect goes away. The moment that I’m back on it, and the estrogen levels reach to a certain peak - so, what I do is like one week on, one week off, two weeks on, two weeks off.

Kara describes the problem of going to the doctor as not located in the exams or medical experience, but in the tension between her and her mother:

[I’d go] at least twice a year, sometimes more. Let’s start off by saying that usually me and my mother always fought by the time I was going to the doctors. “You’re going to the doctors because you’re a retard. You’re going to the doctors because there’s something wrong with you.” This was the type of relationship that I had and when I got to the doctors it was like you know, he had all these book shelves. All these, what I thought as a kid, amazing books and so I would wanna pick this book out and pick that book out and I actually found the doctors fascinating people. It was more like I didn’t really believe that there was anything wrong with me more than I believed there was something [wrong] with my mother. So when I went to the doctors, it was more like, I would complain about my mother to the doctors and then my mother would turn around and complained to the doctors about me, that there’s something wrong with me.

When asked if the constant genital exams troubled her, she responded “Nope. Done. Thank you.” And again, when the issue of medical photography came up, it was cause for more tension with her mother, “I do remember there was a couple of incidences …where I would get a different doctor than I would normally have, and they would come in with their photographers and my mother would be like “Out! You are not photographing my child.” That’s really the only recollection I have of… [It was] Just another crazy mother thing – I didn’t care, you wanna photograph my [crotch], go ahead. I don’t care!”

Kara has long felt helped by psychological services. She was started with two separate psychiatrists at the age of 8 or 9. The first focused on her gender identity, “well, because my mother thought I was a boy. I didn’t, but my mother did. So, you know,
they would send me to this therapist where they would ask me questions, show me pictures, you know, “Do you know who you are? Do you know what you are?” The second focused on her sexual identity, “Questions about sex. “What do you wanna know about sex Kara? Any questions.”

Additionally, she was seen in counseling at school:

But note though, there was another one for the ADHD, but that one I got through the school and that had a lot to do with, I don’t have a peer group. You know, I was called in school, a boy, probably because nowadays, people understand that there is just a large variety of behavior. So, you know, I was considered queer in school. The girl that didn’t act like a girl. So, you know I used to get beat up. You know, dragged through mud puddles. You know, kicked, punched, books, bags stolen, and when I was really young, I literally went into like a cocoon for a while, complete social withdrawal. This had a lot to do with, as much to do with school as it had to do with my mother’s almost oblivion to my feelings about who I was. So my attitude in school was terrible. I’d come home. Home was terrible. So I’d walk in, I’d have a big bucket full of dinosaurs, I used to love dinosaurs as a kid, or I have my coin collections, or I like to read, so, I had my books, and I’d come in and I’d shut the door and I wouldn’t want to have dinner with my family, I wouldn’t want to go to school, developed a habit of ripping my hair out, and it was the doctor that once again came to my rescue.

She explains how it felt helpful:

Well, I mean, it kinda took the focus off that not all of my problems were about me because children tend to be egocentric. In all senses children tend to be egocentric and especially in the sense that if I had these problems, they were my fault. So, the therapy kind of called that out, that you know, a child isn’t necessarily good or bad. You know a child is a child. You know, you have certain behaviors that if you want to change you work on changing them. You know, if you have certain behaviors that are good you work on promoting those behaviors, but that doesn’t mean that you are a bad person. So, they worked on my, what’s the right word for it? They worked on developing my self-esteem.

She reports that the doctors didn’t focus on reinforcing stereotypic female behaviors, and in fact, intervened on her behalf when her mother seemed excessively concerned about her boyishness:

When I read in the medical records, especially from the different therapists, they’d say, you know Kara identifies female, she identifies female. You know, the same
thing when my mother would complain about my boyishness. The doctors would reassure her that there is a large spectrum of behavior exhibited by males and females and as both feminine and masculine, and in their solemn opinion, identifies as female and exhibits normal behavior for most children.

Efforts to engage her parents in family therapy were met with “they don’t need therapy, they’re adults, they didn’t do it, you know, they were egocentric, it wasn’t their fault, it was my fault.”

Kara denies that her medical treatment had any effect on her sexual functioning. She had her first masturbatory experience at age 7 but couldn’t replicate it again for another 10 years. She did not become orgasmic until her 30’s, but she thinks that was due to her shame about her attraction to women rather than any loss of sensitivity in her genitalia:

You know, if you feel ashamed because you’re having certain thoughts about sex, it’s gonna be difficult for you to just go with it, where if you don’t feel ashamed about something else, about sex, you’ll go with it, even if it’s not really pushing the right buttons. It’s kind of a shame complex. I was rather not comfortable, at least initially, with my fantasies about women.

Kara finally found out the entire truth of her medical condition almost by accident while in a general check up with her primary physician:

I was the only intersexed patient he had, and he made it a point to get, go to _____ Hospital and say he wanted the whole kit and caboodle of all my records, and he kept them you know in a big, gigantic folder, and this is just a portion of the big, gigantic folder. And, one day he had to answer a call and I was like (whistling and singing), I saw these pictures and I was like - whoah! Did I just…?!? you know the doctor came back in and I was like, I saw those pictures in my medical records! He was like “Oh!” it was almost as if he was waiting for me to open the package up. He goes, “well Kara, you know it’s, I know it’s a hard thing. You know, anyone in your situation would be shocked to see those but you know, that is how you were born”. You know, and immediately I requested, I want my medical record’s copy.

She describes the emotional impact of finding out that she was born male:

I got my records and I mean, I couldn’t even wait to get home. You know! Pulled in to like a Walgreen’s parking lot and then yeah, when I saw that I was born a genetic male, I bawled my eyes out! Because I had, suppressed emotions about what
had happen to me and to actually read again; ‘cause you remember I’d lost my mother? I had you know, a distant relationship with my father. So to start reading again about my mother and her reactions and reading about my father’s and how the doctors were aware of his non-reaction to this whole situation, you know, and just, I mean for a moment I saw this, this, I felt like there was this boy inside of me. Now mind you, this is just a subjective, but I felt like there was this boy inside of me that everybody had stuffed into the closet, locked the door, and now, I was seeing me. For the first time, almost, you know, like opening, like when they discover that girl who had been chained to a toilet her whole life. I’m sure you’ve heard that particular story about the parents. They fed her bread and water, and she never had socialized. Just seeing this child that was me that I had been denied from, you know, it was like learning that there was this whole other side to who I was, and it had been locked away from me! The person who was this person locked away, and I felt such self-pity that I couldn’t stop crying. Both because of the memories that were re-invoked about my mother, but also to about myself! Poor me! Look what I’ve been through. I had no idea what I was really struggling with. You know, I went through a transition from a male to a female, and it was a rocky, bumpy, painful road! One which you know, with a blindfold on me even and, I felt a little angry that why didn’t anyone tell me this? It might have made it easier! It might have not…

Family response to Kara’s condition.

Kara vividly describes what she has learned about her own birth experience:

Initially, when I was born, I found this out from my aunt. At birth, the doctors literally began arguing. I mean the birthing doctors about; “it’s a male, it’s a female, it’s a male, it’s a female.” With my mother in the room. On the table! And immediately another doctor came up and put a gas mask over her and knocked her out.

When her shaken parents were finally allowed to see their 2 months premature child they were shown that Kara had no phallus at all. “So, they told my parents that they have experienced other males without phalluses. They have been raised as females and the females were happy with their choice. So, based on more of what they’ve experienced in the past, that this is probably the most appropriate choice for this child.”

Her mother’s father made the important decision about what was to be done to Kara:

Actually it was my grandfather who was really the head of the household because my mother was a child. She was in her 20’s. She got pregnant out of wedlock, you
know, my grandfather made my mother and father get married. He couldn’t fathom how my mother, who was a high-anxiety woman to begin with, was gonna be able to raise a boy who had this really severe anomaly - for they didn’t call it anomaly, they call it a defect. So, he agreed that the best course for both the baby and my mother was to listen to what the doctors’ advice was and follow through.

Kara’s parents were in a forced relationship, a fact that became even more inescapable once Kara herself was born with so many medical concerns:

When I was born with the medical issues, I was told by my aunt that, my grandparents insisted because my father had a job that had medical insurance and so on, and so forth, that she had to stay with my father because of the severity of my medical issues. She would not have been able to cover the extraordinary medical bills that were required unless she was married with someone that has a stable job and had Blue Cross, Blue Shield, which at that time covered everything unconditionally. So, you know, my mother was boxed into a corner in this relationship with my father.

And Kara was told that she was to blame for her mother’s unhappy situation:

My mother was an alcoholic, a social alcoholic you know, not a falling down drunker, a social alcoholic, and, when she would come home, she would have drinks and she would claim that I essentially ruined her life. She wouldn’t tell me why, you know, I didn’t know.

Kara reports that after her sex change in infancy, her parents rarely spoke of her “birth defect” but would argue about her behavior and poor attention. Kara’s father worked 12 to 16 hours a day on average, and it was left to her mother, a highly strung, unhappy woman, to raise Kara and manage her medical interventions. Kara describes how difficult it was for her mother to muster any empathy for what Kara was going through:

You know my mother would have manic feelings of depression over what was happening to her child, but that’s her. There’s a difference between sympathy and empathy towards what’s going on to someone and being personally depressed. She’s depressed because this is her child, that this is happening, too; not depressed because "Oh, the poor baby."
Throughout her childhood and adolescence, Kara experienced her doctors as more caring, supportive and helpful to her than her parents:

These doctors were very caring, very thoughtful of my feelings, far more than my parents were. To be totally honest, it was my parents that were inconsiderate and had lack of understanding of what I was going through while on the other hand, it was the doctors who I felt really had the sympathy that I could not find at home.

Kara believes that it was her mother and not the doctors who made the decision to withhold the information of her original gender:

My mother did not want me to know and insisted that if I learned that I was a genetic male that she would not consent to any more surgery for me and a lot of these had to do with her complex about she didn’t wanna have to answer. Well, I mean I’m guessing now my mother’s deceased so I can’t, it’s hard for me to jump in her shoes and really say what she was thinking, but if I might guess that my mother didn’t wanna have to answer for the choices that were made for me. My mother did not want me approaching her and saying “What did you do to me?” you know, so her way of dealing with this is this child will never know and because I was her child, and they had, the doctors needed her consent to have these operations, they had to play by her rules.

In addition to the limited understanding from her parents, and the painful secret that they kept from her, Kara felt her ADHD was also terribly handled, particularly by her mother:

I was on the highest dose of Ritalin that had ever been administered to a child at that point. So, basically I spent fifteen years of my life heavily drugged. A part of that had to do with my mother. I’m sure you know how ADHD children are? You know, my mother would go psychopath, she had no problems hitting her kids, she was very physically abusive, like that, and so the doctor’s way of coping with this is medicate the child and that was the common protocol. I mean I can’t turn around and fault my doctors for that particular decision because nowadays I would like to think that parents are more open-minded to other types of solutions, but at this time my mother was so self-absorbed in her own personal life, that she wasn’t going to take the time to try and deal with this problem on a therapy level, meaning that she gets therapy to deal with it, you know.

While Kara’s behavior and learning disability were frequently discussed in the home, the “sex stuff” rarely was spoken of. Her father worked, and her mother took her
to the appointments. She wishes that her father had been more involved, because when he was, he was able to show some understanding, if not about her concerns exactly, at least that she was entitled to her concerns:

He probably had more empathy for me than my mother did about the situation. He clearly felt that, why are we taking her to the doctors in the first place if she’s not, if this isn’t her…I remember the issue with the pubic hair and one of the very few times that my father actually accompanied me to a doctor’s visit, my mother was mortified that I was complaining about pubic hair, but not my father. I remember my father mocking my mother. So what if Kara wants more pubic hair, if the doctors can do something for her, leave her alone! So with the very little support I got from my father, he was a little more level-headed if and when he actually accompanied, which may be out of the, I don’t know. I’m guessing out of the 20 or 30 visits that I had over my lifetime, my father accompanied me in, like four of them.

Her mother seem to have the attitude that doctors should not be questioned or complained to, and was clearly uncomfortable about so much focus on her daughter’s sexual functioning:

[She was] kinda like, you embarrass me if you have questions. She took it on herself. Like, I remember this one particular time when the doctors were asking about how the vagina was working. You know, and I said, I remember it, I said, “Well, I really don’t think my first boyfriend was a good example. He was well hung.” And of course my mother felt, I mean, we got out of that office and she was like, “Ew, imbecile! You, you… well hung! What kind of language is that to be used in front of a doctor?” And my response was, “I answered his question!” “Well hung!” You know, she was just embarrassed, I don’t know. She was embarrassed.

Kara clearly understood that she was to keep her condition quiet, and she felt that she wanted to keep it secret. To that end she “insisted that my doctors give me excuses out of gym and that’s how I dealt with it. No gym for me period.” Because she pretty effectively kept her concerns about her body at a distance in her day-to-day life, she denied having questions about her body except when it came time for an appointment:

I didn’t have any questions about my body. I mean, I didn’t think anything was that dramatically wrong with it. I have breasts. I need to take pills for them. Okay! I, I had to have vaginal surgery. Okay! Let’s get this over with. You know, it was
more than when, as I would anticipate going to the doctors. You know, I would think up. Well, you know, I’ve got complaints about my nipples or I’ve got some complaints about my pubic hair or…

She states that she simply never had questions for her parents. It seemed that she rarely felt taken care of by her parents, and as she grew older this was made more stark by the demands her parents made of her to watch out for them:

I had a special role in my family because they were alcoholics. In fact, not that this is even at all related to intersex but, my father would repeatedly pass out behind the wheel of the car and he’d drive off the road into a ditch, and my mother would get on the pay phone, call me, and you know, she’s drunk herself and say, “Kara, get in the car and drive to this location, we’re in a ditch, and we need you to drive us home.” So, I kinda played the role of almost taking care of my parents when they would get hammered.

The effect of Kara’s experience on her relationships.

Kara denies any serious effect on her experience of her body but explains that she still has some self-consciousness about her genitals:

I try not to put any, too much emphasis on, my body being different because I’m intersexed. If there was an area that I was a little self-conscious over, a little, it was probably to do with the fact that I don’t have a normal labia and, you know, there is a little issue because I like to give and receive oral sex. There was a little issue about, well you know, I might not be a bad idea to tell my partner that, my genitals are a little more different than, let’s say, someone else. So, it’s an issue of where at some point I can’t just let my partner stumble upon it and go, “Whoa!” You know, there needs to be a discussion about it.

She notes that she thinks of gender as the way she is experienced by others rather than how she experiences herself, but she acknowledges that there can sometimes be a discrepancy between the two:

…as far as how I want people to address me? Well, look at me, I look like a woman. Make it easy on other people. Address me as a girl. As far as my emotions, most of the time I feel like a woman, but I mean if I’m happen to noticing a real pretty girl that’s really exciting to me, you know, I might feel like a male at that particular moment looking at her, you know, my sex drive is probably the only thing that I really consider that’s male like, so yeah! You now, maybe when I’m having sex I
might imagine I’m a male, penetrating a girl or doing other things but you know what? That’s in here. That’s not outside and that is to me what gender is.

Her experience of her sexual identity has radically changed since finding out that she was born a genetic male:

Well, ever since learning that I was intersexed and that I was born a genetic male, it’s given me a much broader understanding of my sexual interests. You know, no wonder why I’m attracted to women, for God’s sakes I was born a genetic male with almost normal gonads. You know, give me break! Or give myself a break! You know, yes, there are moments when I have sex, and I feel feminine and female. Yes, there are moments when I have sex and I feel masculine. I’m aware that my sexual response is not traditionally like a male or a female but then again I wasn’t born like a male or a female. So, I should expect that my sexual response system, you now, how I respond sexually to other people might be a little different than the normal. Before I knew that I was intersexed, I was so confused about why or how I operated sexually, and maybe that’s 50% of the population anyway. Maybe not everyone understands their sexuality but I certainly didn’t, growing up, understand how it worked. Once I learned the truth about my past then it was very easy to understand.

But she confides that she still is confused about which sex she is more drawn to:

Its probably my most ambiguous feelings that I have is with whether I really want men sexually or I really want women sexually. I tend to find that it’s easier to have sex with men where sex with woman is fine when it’s a fantasy type of, but woman I far more trickier when it comes to really getting down to the mechanics of sex. You know, yeah I got this ambiguous feelings and maybe in the future there will be a resolution to that maybe there won’t, you know, but in the meantime, I’ve discovered it’s actually more important to have a good relationship with someone than it is to be in a relationship where the sex is great, but everything else is trash, and I’ve been in that situation.

Kara has worked hard to maintain a positive view of herself and her abilities through an extraordinarily difficult up-bringing. Here she describes her feelings and thought process as she confronts the more painful aspects of her life:

I kinda turn negatives into positives. Everyone in this world wants to be like everyone else and wants to be an individual...So, I look at myself and say, “You wanna be an individual? (laughs) You’re one in 30 million births. That’s an individual!” You know, I am very creative because I possibly have aspects of my neurology that are both male and female, you know, because of the way that I was born, that gives me this creativity that is unlike a lot of people. So I feel like, “Kara, you are one in a million.” Oh! Excuse me one in 30 million! You’re an individual
but I pretty much even unclothed, fit in normally with other girls. Nobody, unless I
tell you knows, that I’m intersexed. It’s completely up to my discretion to tell
anyone about my personal situation. So, if anything my self-esteem has (whistles)
gone up since I’ve, I mean, initially it kind of took a dip, you know, “Am I male?
Am I female? Oh God, what am I?” Yeah, I went through that stage but then, you
know, it’s like, “All right get over yourself that happened 20 years ago. Life goes
on. The world is not stopping to rotate while you have your own little personal crisis
about whether you’re a male or a female! Get over it!” And I did and I went on and
now, you know, my self-esteem is like, “Wow! Not only are you one in 30 million
but you survived something that, you know, might have caused a lot of people to
either commit suicide or just jump into that bath of what I call the “eternal victim.”
And I am clearly not that!

Kara is unique in that, of the women interviewed in this study, she had a mostly
positive experience of the medical profession:

Well, I praise my doctors and for the most part I thought they were wonderful, I
mean, there was one that I wasn’t particularly that fond of but for the most part I
think they really did exactly what they were supposed to do and that is to take this
very unique child and put her some place where she belonged and give her the right
type of surgery at that time that she needed it. I think the right choices were made
along the way. But on the other hand, I know that there are doctors that are bastards.
I know there are bad doctors out there and so, if a couple of intersex people have
unfortunately run into these types of doctors that have made their lives very difficult,
yeah! I feel remorseful for them. I know there are bad doctors out there but it
doesn’t mean I’m gonna turn around and think that the medical community overall is
bad.

She has previously said she found the therapy she received over the years to be
helpful. She seems to have experienced psychiatry in much the same way she has
experienced the medical profession – she has made use of a service offered - rather than
build a relationship with a professional clinician that might be potentially healing in and
of itself:

I see a therapist once a month… Every once in a while, you know, therapists are like
rugs you gonna take them out, flip them out and, change them and get something
fresh and, you know, I’ve been with this one girl now for about two years and she’s
a flake. She’s completely out there in left field as far as who she is, but yet, you
know, she’s there exactly for what I need her to be.
Not surprisingly, Kara continues to feel tremendous anger and conflict about her family:

I don’t like my family. I’ve got a lot. Okay I’ve got a lot of resentment with my mom, even though I missed her to death and wish she had never died and still have crying fits every once in a while cause you know I lost my mother. I can never get that back. I’m angry at her, I mean deep-seated, I’m angry that she was so cold considering what traumatic experience I’m going through. I’m really disappointed with my father for … some parents take care of their kids … You know, they make sure that their children get the best, and get all of the advantages that they need. They don’t compete with their children meaning that “Well, I don’t want my kids being any better than I am.” You know, my father was all of those things … I really don’t think he wants me to succeed any further than he has…I got issues when it comes to my family. I just, you know, I don’t really feel that they were model parents in any way shape or form.

She feels quite positively about the friends she has made over the years:

Well, I have a small group of friends, but they are very good friends. I’m very picky and choosy about my friends. I need to be with people who don’t focus too much on my, you know, on the problems of life and people who remind me that, you know, we’re here in this world to have fun too. I don’t know if that’s necessarily an intersex issue, but more as it is, or maybe it is because you know, a lot of… I have had opportunities to meet other intersex people, and they tend to have grave difficulties with a lot of their interpersonal relationships, and so I try and not follow that mold.

But it was not always such an easy thing to make friends. She describes her tentative first steps at building friendships:

Oh my God! I mean, I can remember like back when I had my first part-time job just literately. I mean hyper focusing on. Step one talk to this person. You know, step two invite them over the house or invite them to clothes shop, you know and I remember feeling like I have climbed Mt. Everest when that average person just said “oh yeah! I wanna shop for curtains, We’d like to come along. And I mean, I remember running home like “I made a friend” you know, it just, I mean I remember the milestones as I’d learned how to make connections with people, and even now it’s still kind of a delicate balancing act of… I am a very complex person, and people who come off as too complex can scare other people until, you know, you gradually… so I’ve learned that when I making friends to, you know, started as superficial level, you know work your way in term, you know, more personal levels, and then when you feel comfortable, get in to the more complex level about friendship, and it’s worked for me.
Romantic relationships have been more complicated. She never had a lack of sexual interest but she didn’t often make an emotional connection with potential romantic partners:

Well, it’s kind of interesting in the fact that I never had a problem getting sex, and I think that that is just a genetic lucky draw that I ended up being an attractive girl, and not just an attractive girl, but an attractive girl who has a very powerful, almost radiating sexuality and that may have something to do with, you know, cause men tend to be you know, very powerful or some men can be very powerful sexually, you know the old myth that goes - the first thing he does when he sits down with the girl, the first question that comes to a man’s mind is will I have sex with this girl? You know a lot of people pick up on my sexual energy. So you know the first, usually the first step, or one of the biggest steps in our romance is working up to details of sex. At least I think so and that has never been problem with me. You know if anything that the problems that I’ve had in relationships have been more with the mind, the thing making the connection, making the emotional connection, and of course, deciding when I should or when I shouldn’t tell a person because I mean as long as I’m not engaging in oral sex, meaning that I’m… someone performing it on me, I can pretty much slide right under the roof and no one would suspect that there is anything wrong with me.

Since finding out the details of her birth and condition at the age of 31, Kara has exclusively been with women. She explains that part of the reason is that she has yet to find a man who is intellectually stimulating to her, but also that she would find it harder to explain herself to a man:

I’ve really yet to meet a man that I consider you know, really intelligent enough to hold my interests. I found it kinda difficult to try and explain, not explain the way that I can explain it to you, but you have that fear that you know, that men are homophobic, and that you know, they’re not gonna know the distinction between a transsexual, you know, a man that changed himself into a woman and a person born with a really serious genetic birth defect, and this is what had to be done. I kicked my boyfriend to the curb so quick, and this is after nine years being with this man and having of very, very intertwined relationship with him, and then yeah! I kinda went to this entire rediscovering of who I was … but it’s easier to talk to women about who I am, what I am, what happened to me, and you know I feel ultimately “oh” I don’t know! I feel comfortable around women … now I feel I finally found someone who is a good intellectual match and so that’s why me and Elizabeth seem to pair up very well, and she had the same problem too with other partners. You know, being a lesbian that she is, as she would get together with other girls, even
girls that went to college, and she didn’t find anything upstairs that really interested her.

Kara describes how she wishes her condition had been handled differently:

I wish that I’ve been told that, you know, when I was beginning to develop my sense of sexuality, that I was a male and that this particular thing had to happen, I mean, god sakes they had my birth pictures. They could have shown them to me. I would’ve said “Well, I guess I understand why you did, what you did,” and then I probably would’ve started my sexual relationships or my relationships with women sooner. Had I known earlier, had I known younger about my medical condition, you know, I would’ve had a lot more time to sexually explore the different aspects about myself and then maybe the role would’ve of taken me back to men anyway. I still don’t know in the long run if the road won’t take me back to a man.

*Kara’s experience of the interview.*

Kara describes the effect of talking at length about her history:

Well, talking about my past is, it really doesn’t, it just doesn’t faze me anymore. It’s not like I get all emotional about it. If any thing, you know, more powerful emotions are provoked when we start talking about my mother or my father and my relationships with them.
Julie is a white woman in her early 50’s who was raised as a boy. She was born with XY/XO Turner’s Syndrome or genetic mosaicism, a form of mixed gonadal dysgenesis. She was never told the exact chromosomal makeup of her gonads at birth, but she knows she had either two ovotestis or two dysgenetic testes. This rare form of the syndrome results in usually a milder form of Turner’s, including increased stature and more sexual development than one usually sees in people with the XO version of the syndrome. Her condition was not diagnosed clearly when she was a child, and she did not undergo the current medical protocol to normalize her genitalia. She is unusual in this cohort for being the only woman to chose her “reconstruction” surgery as an adult, when she decided to begin living as a woman. Julie has done some graduate level study, and currently works in the technology sector. She is active in her Christian Church.

Julie’s condition and her experience of her body.

Julie’s condition was never explained to her as a child, and it is likely that neither her parents nor her doctors ever had a clear idea of what her condition actually was. As she explains:

Well, you have to remember that I was born in 195_ and it wasn’t until, I think, 1960 that Turner did this original study. So, they just didn’t know and there were clearly issues with having open inguinal canals and, they were worried about gonads shouldn’t be up there, they should be down there and can we make them move down there, but I don’t think they ever connected the dots on it all. I don’t think they thought of it as an overall diagnosis. I don’t think they ever knew that…

The only things discussed with her at medical appointments were her dental problems:

They always said things like, you got your Mom’s small jaw and your Dad’s large teeth ‘cause my teeth wouldn’t come out on their own and they were way
overcrowded, so they have to pull a bunch of the adult ones and it’s because of the Turner’s, but it was always just, you have to go to see the orthodontist and I started going to the dentist when I was probably 3, because they had to try and they knew there is gonna be a problem…There was never any words said about gonads or genitals except they, I mean they did a lot of things and they examined a lot of things but a lot of that was just never explained and when I finally had everything explained to me, I went and talk to my dad about it, my mom was dead at that point, he’s like, “Oh! That explains a lot of things,” so I’m not sure he was in the loop.

Julie’s condition meant that she had very small, delicate stature and a very high-pitched voice. She always felt that she was different from other kids, but until she hit puberty it didn’t bother her terribly:

I had intrauterine growth retardation as well as being small, so when I was born half the mass of my body was head, ‘cause my head was big and the rest of my body was small and so they were concerned about that. Okay, so I didn’t have any hair till I was two. I had, my left eye would wander off to the right when I was tired. They were thinking that they might have to have surgery for that. I was, even when I graduated from college, I only weighed 115. I weigh like 150 now. So, it’s just I don’t have very good spatial memory so I couldn’t learn to dance or to do basketball lay-up, that sort of complex geometry and my brain just doesn’t get. Well when you’re small and behind your class physically and terribly uncoordinated there I think is concern about me so…I knew when I was young that there was a lot of concern…Well, I mean my peers were all typically three years ahead of me in growth and development. I started out with a voice that was a lot higher-pitched than even girl children usually begin with. That changed sort of gradually over the years and I was so small and they were concerned about that. They’re concerned about some other issues with the heart and so I just knew that I was different. It wasn’t necessarily that different, just different.

But even though she began to grow at puberty, her body never virilized like the other boys. She describes her growing alarm and the way she defended against the thought that she was not in a “normal” body:

A lot of it I think was from within me because I was realizing that the gap, since I wasn’t developing, the gap between me and my classmates continued to grow and so I just withdrew inside and didn’t wanna go to the doctors. I didn’t want anything, and my parents sort of went into a mode where, “Okay, nothing’s wrong.”

Unlike the other women interviewed for this paper, Julie stopped all treatment when she began to grow in stature at puberty. But her body didn’t produce hormones and
she never developed the secondary sexual characteristics that should emerge at that time.

She describes her experience of her body being “in between” and her growing sense that she didn’t fit in any particular gender:

I had the sense that there was something unusual, but there was a process of discovery at multiple points along the way. For instance, my parents encouraged me at whatever I thought that I’d like to do and one of the things was singing in the choir and I could sing. I could hit the C above high C and sustain it and sing very well and but you know when I hit 11, 12, 13, people are like you shouldn’t be singing like that anymore and you know...as you age and people are maturing around you sexually and you’re not, the differences can become more of an issue. In high school, nobody bothered me. In college, my maiden name was _____, and what the boys in college called me was “clit,” which is clitoris, right? And part of that was small size, part of it’s lack of development. Part of it was still being soprano probably, but I had never, up until that point really... I had just always assumed that my parents wanted me to be a boy and they, although they had never pressed the issue early, I just sort of went along with it assuming that was part of the deal. I didn’t know that there was a choice in the matter and at least not until I graduated from college at 21 and since my parents had been...that had been just their goal for my life that I could shove aside anything else until I graduated and then when I graduated, game over. That was it.

She describes her confusion about her gender:

I was probably 11 or 12 before, no probably 12 before it dawned on me that I wasn’t gonna get periods. Because half of the time when there was just a lot of ambiguity and I was the smallest child in the class with the exception of _____ in fourth, fifth, and sixth grades and my friends were girls until seventh grade and I don’t think that it was something that I thought about. My parents were acting as though it was gonna be my choice anyway and the activities that I ended up doing weren’t necessarily because I wanted to be a girl, but just because when you’re that much smaller than the boys that you play with, and you get hurt all the time, and they’re not that interested in having you do it. I’m sorry it’s not that good explanation but it was just kind of an idea in the back of my mind. I knew I was different. I knew I wasn’t like the boys and I knew I wasn’t like the girls and I knew my place was boy but there was always this assumption that, when puberty comes along they’ll all understand that I’m just normal.

But even though she finally “got big,” her gender didn’t fit any better. She didn’t have a clear sense of what gender she was, and once she got to college she stopped trying to be a male:
And so I let my hair grow and just basically stopped playing and the perception then was, half of the people thought I was gay and but as I said that, there was a realization to people that I physically wasn’t there either. And then the school talked to me about, “You’re registered as a boy and you really need to start looking that and act like it.” The school decided that “for you to stay here, we want you to undergo counseling and as you start the counseling we want you to undergo testing so which for them the MMPI and the MMPI I think showed that I was stressed out basically … but their attitude was you need to at least look the part.

So she made an attempt to “be” a boy, but the experience was clearly distressing to her:

So I cut my hair real short and I thought, well I’ve never really, really tried being a boy and just being instead of pretending to be, and so I tried and it did work. It just took me back to the point of where I was being so reckless with my life that my life was gonna come to an end whether through…once, I bought a motorcycle, started being pretty reckless with it and it wasn’t that I wanted to get killed, it’s just that, I don’t think I cared at that age, and managed in the middle of all that to graduate from college all the way, and then I decided rather than continue the cycle to where I was dead, go to the doctors or get someone to talk about it to the psychiatrist, psychologist and…

She describes the dawning of the idea of obtaining a sex change:

Its just, plus by the time I was 21, I was so tired of being in between that, I mean, when I was in high school my prayer was “God, please make me a girl, let me be able to have children, but if not then make me a boy,” just one way or the other…and so I jumped into the whole, okay let’s change legal status and in order to that you need one of your parents to sign an affidavit saying a mistake was made and a doctor, and the only way the doctors will do it is to normalize you, meaning have enough surgery that you look at least within bell curves so…

She attempted to go through the accepted, legitimate channels but was stalled by the protocol that transgendered people must go through in order to obtain reassignment surgery. She explains the crucial moment, when she decided to transition to a female gender with hormones, and later surgery:

And I knew that I had to deal with who I was. So I went to the doctors and there was a psychologist or psychiatrist, I forgot which, that referred for _____Hospital, so I did spoke with her to get a referral to _____Hospital ‘cause I knew that they knew about this stuff and her reaction was, without a physical exam, to say that I had to try being a male homosexual, try being sexually active before I could talk to _____
Hospital, and I had never been sexually active. I had no desire to be, so I left and found an endocrinologist, and his main concern was my size and my weight. He said I needed to gain at least 20 pounds and he wanted me to put me on testosterone-anabolic steroids and high-calorie diet and after explaining five minutes of explanation, verifying what I thought that would do to my body, and I know it wouldn’t make certain aspects of my body would be that much more masculine. I just thought, - I’ve lost my small size. I’ve lost the ability whether, it’s mentally or physically, to sing, and I don’t think I can handle losing the rest of it and it’s like, well you have to take hormones. Physically, your health requires you to take hormones. And it just seemed like wrong you know? I’m not sure I wanna be a woman but, I could probably survive being a girl. And so he’s like well, we’ll give you estrogens, and okay so that’s all the choice comes down to, I mean why didn’t you tell me this like before I started growing and before all this other stuff. So they put me on hormones and I got pubic hair and started getting breast development. So I took the backdoor approach to it all. After a year-and-a-half on hormones, when I decided that it was time to change my legal status, I quit work and got on an airplane and went to _____, and basically I got a more feminine haircut in the last week, and got on the plane, went to the doctor in _____ and was scheduled for surgery a week later.

*Julie’s medical and psychological treatment.*

It’s not clear to Julie what her treatment was, exactly as a child, but she did undergo frequent exams and medical photography, as well as multiple painful dental procedures. She describes what it was like to go to the doctor and explains how she tuned out her physical self over these repeated painful and intrusive experiences:

My mom was a nurse so typically, she wouldn’t allow anything without her standing in the room. Generally with her, there was only one doctor there. My dad generally handled the orthodontic side of things and when you get stuff stuck in your mouth to make solid forms out of, or when they’re yanking teeth out every so often, you’ve just learn it to not be there. Most of the pictures and stuff like that, where, when I was old enough, that I just disassociate and get done with it.

But once she decided to take hormones and undergo surgery as a young adult, she had a whole new relationship with the medical profession. She was now going to require medical follow-up for the rest of her life. Here, Julie describes her first surgery:

I had a modified McIndoe procedure. McIndoe is where they take either a skin graft or scrotal tissue or some other suitable tissue and build a vaginal lining with it, after making a cavity. My genitals were small but masculine. Being that the surgeon was
someone who would do surgery on anyone basically, without questions, and his
office was in a hotel room, the methodologies aren’t always the same as you might
get elsewhere. But at that time, San Francisco wasn’t allowing that type of surgery
on adults, they still do it on kids and Hopkins wasn’t doing it on adults. So the
choices were limited. But the issue then became, if you use available tissue, the
vaginal cavity is only gonna be as big as what you, the available tissue was. Also, if
you use a skin graft, skin graft is not gonna wanna stretch, it’s gonna wanna contract
and so, we have to keep a foramen in place all the time. And you have to vigorously
dilate daily. There were three stages. The first stage, they cut some of the blood
vessels so that it will strengthen other blood vessels. A week later, they do the main
surgery and then a month after that, they’ll do the cosmetic parts; the exterior
cosmetically. It included reducing the size of the phallus to where it was within 3%
normal Gaussian clitoral size, maintaining the nerves, and that was back in the early
70s, so I don’t know why they still can’t figure it out now on the babies.

It was in following up on the dilation that Julie made the first steps in finding out
the real nature of her condition:

After surgery, there’s lots of things they will tell you about surgery like you’re
gonna have to dilate and it’s not gonna be pleasant, and even having sex may not be
pleasant, and the feelings aren’t gonna be as good, nerve endings weren’t gonna be
as good, but it came. There was a program now, so there are benefits of being with
the program, but when I went to my gynecologist and I knew I needed a set of
dilators and he pulls out these dilators and I look at him and I go “nuh-uh, nuh-uh.
Guys aren’t like that big, they’re not”. And he said “Yeah they are,” but, I wasn’t
like anyone here...you know, even the smallest one there, and so I started looking
and talked him into the genetic workup, but you know the genetic stuff came back
Turner’s and I looked up all this stuff and it started falling in place.

An initial roadblock in confirming the Turner’s syndrome, thrown up by another
doctor, led her to discovering the world of on-line intersex support networks:

The first time I went to see a geneticist was after they did the genetic workup and the
first thing that he said when I walked into his office was I don’t need to examine
you, you’re not Turner’s, you’re AIS. Well I went home crying, and then I looked
up the AIS support group, and it turned out that a week later they were having a
meeting, in England of all places. So I booked a flight, went and met them, and I
met 50 ladies who are XY and they said, “You’re not AIS because first place, just
look at the women who are AIS, look at women who are partial AIS,” and I just sort
of got stopped, abstracted back from it. You find that there’s something in common,
just facial features or something very, very subtle. “and you don’t have that, but
there’s a lady over here that’s got 5-alpha-reductase and there’s all these other
related conditions, and clearly you’re welcome here because you fit, but you need to look more into Turner’s and see.”

Her excitement at meeting other intersexed people was mixed with the painful realization that she was going to have to face the reality of her own condition:

And so, the thing was that it was so great there because, after just doing all these stuff with these women, you realize you’re just ordinary people, and so it’s like, well they’re okay so maybe I’m okay. But then you know what, you go home and you start thinking - I know they’re okay, but they’ve got an intersex condition, and that means that there are really people who have these conditions, and therefore my condition is real and I don’t wanna know about it.

She explains further what realizing she had an intersex condition meant she had to give up:

Have you ever read Orson Scott Card’s books, science fiction; it talks about degrees of alien - that there can be something so alien that there’s no way to even sense it. There can be just minor differences between you and the norm but as you progress along that scale, there are points at which you become a threat and points which you pass beyond being a threat. When I was singing in the choir, there was a certain acceptance to my being so much smaller than everyone else and singing like wind chimes and spending most of the rest of my time reading even at four years old…It’s like finding out that you’re not an elf but that you’re a deformed human and there is a difference in alien there in that being an elf would be more alien but…It’s a more pleasant alien to me.

In spite of her fears, she continued to pursue an exact diagnosis. Upon her return to the US she had her genetic workup done again, and when it confirmed Turner’s she found a geneticist who specialized in the syndrome:

And so, they went through all of the testing again and came up with these identical results and then I contacted a Dr. Rosenfeld, I think was his name who’s an expert on mosaic forms of Turner’s and he said, well yeah that’s what you got. The childhood stuff that’s in, the teeth, the heart stuff is all stereotypical of that form and so that helped things until, you start finding out things like, well the reason that you didn’t develop was this is your gonads are a mix of ovarian tissue and testicular tissue, neither of which was functional, and then, it takes you about a day and a half and then it goes, and then you realize what word you call that. And then you’re like, can I just go back to being what I was like when I was six years old, because I don’t wanna deal with this. Hermaphrodite, you know. And because you normally think
of, I mean even the statue photos, just like breasts with a penis, and that’s not what the condition is that I’ve seen.

Meanwhile, Julie was struggling with her new, re-constructed body:

The dilation issue was, over a five-year period, was basically a losing proposition. I ended up with a vaginal cavity that, not only was about the size of my small finger, but was scar tissue so hard that there is no way to stretch back out. So, I went, maybe 15 years, before I got the nerve that I can go do surgery again. And part of it was, I just figured, look, I’m not gonna have sexual relations till I get married, so there’s no point. And so I waited until I was thinking about marriage. Then I had a sigmoid transection vaginoplasty which takes part of the sigmoid colon and transposes it to where it accesses a vaginal cavity and it’s basically, they take a section of your colon, open it out, flop everything out, do what they gotta do, and flop it all back in, so it’s major surgery. And of course, insurance isn’t gonna cover it. So, I speculated in the stock market over six months and made the 30 grand. Anyway, so two good things about that: One is that the colon lubricates itself, and two it doesn’t shrink. The problem then is you have to stretch out the vaginal opening. But I can get by with, on the outside, dilating once a month, which is wonderful. It has sensation. I’m not sure whether it’s good or bad sensation. It feels just like it would feel if somebody stuck something up your butt, you know which is where your sigmoid was. There’s certainly other places that have enough sensation. You know after breast reconstruction, I don’t have much feeling in my breast area either.

She describes her mixed feelings about having done the surgeries:

You know, the surgery has normalized things and hormones have normalized things, so yeah you’re on drugs for the rest of your life but you’re not different from everybody anymore, and of course then, you still have to go back to the doctors and the doctors think you’re different.

And how finding out her condition has affected her experience of dealing with doctors:

It felt like I had a name to put on it, which was good. It meant that all these years of my questioning the doctors and trying to get them to do stuff and having them not tell me what stuff meant that I could no longer allow anyone else to make medical decisions for me just period. I recently…My gynecologist had a private chat with my primary care physician and she decided that they weren’t gonna do something in my treatment and so I’m not going back. I’m gonna go to somebody else and it’s not a matter whether or not they let me do it, it’s a matter whether or not, they make the decision on my behalf. I’ve been in rooms where, there’s more than one doctor and it’s yes they asked you but they asked you while the guys are walking in or, you know I’ve stood against the wall and had pictures taken and then you know what
I’ve been in rooms with one way glass windows and stuff. It’s not that it was traumatic but this whole body autonomy thing gets to me and I think it gets to me partly because there are things that, had I known they could have done treatment to prevent changes - and I’m not nearly as active as some of the people I’m sure you’ll talk with.

*Family response to Julie’s condition.*

Julie describes her family as loving and close-knit:

It was always very low key, at least when I was young. They were fairly protective of me physically, although my parents were the type who believed that everyone should be independent or at least capable of being completely independent. So, if there were dishes to be done or yard to be mowed or tools to be handed to my father, it could be any of the kids that have to do it. As far as the physical stuff, I don’t remember being treated any differently from my brothers and sister as far as medical stuff. You know, there were enough concerns about my development and whether or not was I gonna grow, but my brother and sister went through medical stuff too and it wasn’t like they wanted to say I was any different. We were all encouraged to do the things that we liked and that they thought we would be good at, and we’re all strongly encouraged to read and to do well in school. You know, you come home, everybody eats at the dinner table, and homework is done before you watch TV and really fairly typical, I think, of American life back then. I don’t remember there ever being anything said in terms of being odd that I was in the choir but there were some, I think, defensive maneuvers like [around] getting my hair cut.

But even though she felt she could “be herself” in many ways growing up, there were certain unstated rules that she knew were in place around her gender expression:

I mean, my family was a very close family. I knew that we could always talk through things with our parents, but this was one area where I just was always afraid to talk to them. They seem to be in, sometimes I wonder whether they were in extreme denial about it or complete acceptance at that point because, I could have Raggedy Ann as my favorite thing to carry around, and wouldn’t bother anybody, but wanting to have ballet lessons was something that I was afraid to ask. Or wanting to get my ears pierced, I was just afraid to ask…Well, but I mean like, they were really pretty lenient, because I was allowed to do things like learn to sew and cook and sew clothes for Barbie and stuff like that, and it didn’t seem to faze them. It’s just the line was that, I think there was a line where it’s like you can have all these things and the medical stuff maybe that will go away someday, and maybe all the rest of these gender things are just a phase, but they drew a line at a point where it became reality, I think, for them, which was letting my hair grow or sharing clothes with my sister. And my sister is three years younger and I were about the same size most of the time, so we shared clothes.
When she was a teenager, Julie’s parents began to state the unstated rules a little more clearly:

The two limits that my parents placed, well one, I couldn’t appear in public as a girl and the other was I had to have my haircut short because with my hair longer they thought I looked like a girl. And I, when I was a young teenager, my dad started in on keep your hand still when you talk and don’t talk with an inflection.

When, as an adult, Julie followed through with the “legal status change,” her parents had very different responses, which to some degree replicated the pattern that had long been established in the family; her mother was more able to tolerate Julie’s more unusual gender expressions than her father:

When I finally went for the surgery, my mom expressed a sense of relief. She said that she had always thought that they were gonna lose me, that I would die and that after the surgery, she didn’t feel that way anymore. She felt like I was gonna make it. My dad was like, “oh wow, that explains everything,” like it’s not his fault anymore, and I’m like, a karyotype explains everything. Okay. If that’s all it takes for you, that’s great, because we have been estranged for a long time. When I decided to change my legal status, he didn’t take it very well. He is okay with that now, I think.

Julie’s mother passed away more than 10 years ago, and she was estranged from her father for many years after she transitioned to living as a woman. She missed the opportunity to ask her mother many questions about what their experience was like when she was born. Her efforts to find her medical record were frustrating:

I tried to get my medical records from when I was very, very young, and all I could get was information about how much they fed me and they were worried my weight, and worried about critical development I think more than anything. So, I don’t think they connected the small dots to it and I don’t think they connected the hard stuff. And then I think it was enough of the stress that when I started growing normally, it was like “okay nothing’s wrong,” you know. “It’s done, over with.” And I wouldn’t say that my parents did anything wrong. I mean, for instance when I went to the endocrinologist in the early 70s, they didn’t do karyotypes, you know.

In spite of the love and support she obviously felt from her family,
Their attitude was there’s nothing that we’re gonna tell you you can’t do physically. But I think they so actively encouraged the things that I expressed interest in and did well. And I think even to a certain extent, I think Dad just overlooked whatever cultural connotations there might be of a little boy trying to solve, but I can’t think of any time where the issue of either genitals or gonads entered in the family discussions about stuff like that or about what, arguments and stuff, just not on the radar screen. I would not have talked with my parents about that. As much as I love them and as much as they loved me, I wouldn’t have. I would have probably needed to know that they would accept my answer before I would have given an answer. Otherwise, I would’ve given the answer that I thought they wanted.

Julie does remember one possible time an explicit question about her gender may have come up, but the fear she describes in her response points to the unspoken expectations her family had for her:

By the time I was a teenager, we didn’t talk about it a lot. It was like you just understood that there was an issue, but nobody wanted to deal with it and - I think memory is notoriously faulty, but I think mom asked me when I was in grade school about changing over to living as a girl and I think I told her no. I think I was way too afraid to even think about it at that point. I was wondering what she saw that I wasn’t hiding that brought it on.

Julie explains the way that even she never quite “put her finger on” the ways in which she was different when she was a child:

I think I already had a feeling at that age that there was little bit of cognitive dissonance or dysphoria - some sort of that my body wasn’t doing anything, that I had expected things to happen earlier, and there was a dawning realization that I probably wasn’t gonna turn into a normal person, at least not any time soon. And yet, at the same time I would have been hard-pressed to point any one thing on my body and say “this is weird” because I wasn’t that much aware of it.

Even so, by the time she hit puberty, she knew she wanted to keep her body well covered up:

After I reached maybe, let’s say, the 11, 12, 13 age period. You wouldn’t catch me with shorts on or without a top of some sort, just wouldn’t happen. I’m not sure I’d thought about it consciously, but I just didn’t want to.

Elsewhere in the interview, Julie alludes to herself as “angry,” “anti-social” and “feral” at different times in her life. But even as a young child she was clearly
communicating something about her experience through her behavior. She describes her role in her family as:

I was the brat. Well, since we went to visit some friends of theirs, they had two daughters and this is when I was in second or third grade. We’d go visit them once every month or so, and the parents were friends and so the kids would play together. And one of the girls had a hand-held mirror and I wanted to play with it and she wanted to play with it and since she would not let me to play with it, I smashed it. And then immediately felt remorse to the point of tears, like I’m sorry, but I was always doing that sort of thing and picking on my younger brother.

The effect of Julie’s experience on her relationships.

Julie describes the effect of her experience on her feelings about her body:

I think that prior to that 11, 12, 13 age period, I was happy with my size, expecting that I would, someday grow to be big, but I was carefree in terms of body other than, having teeth pulled and all that other stuff. The medical issues didn’t matter to me. After that period through high school and into college, I grew to hate the differences. I joked with my husband about, because he wants to know how do you think people are gonna be in heaven, and I said ‘I’m gonna be six years old, I’m gonna be back where I’m small and my voice is high and undeveloped,’ and he’s like, “Why do you wanna do that?” Well ’cause it’s just where I’m most at home with what my body is, that’s all.

Her relationship with her gender is even more complicated; in some ways she chose being a woman because it was less objectionable than being a man, both because being a woman was closer to the image she liked of herself at age six and because she simply passed better as a woman:

I had decided to change my legal status. To do that you have to, I thought I had to have surgery. And at some point before going out there, it occurred to me that it would make sense to get a more feminine haircut… To call in, just forget about it and change your legal status for a day and just, go out and see what happens. And so, you know, go buy clothes, go have dinner at the mall, go do all that stuff, and the first thing I noticed was that nobody paid any attention to me at all anymore. You know, it wasn’t cracks or stares or anything, it was just like, well. And then I started going, “what is the deal here,” because I didn’t consider myself swishy. I didn’t think that I was particularly feminine or gay or anything else, but it just seemed like a natural thing to be doing in terms of how people are treating me that I thought, well okay, this is gonna work, I can fit in, I don’t need to go around wearing dresses, blue jeans are fine with me.
She describes the effect the changing her gender had on her life:

Changing my legal status helped enormously. Obviously, the psychological problems and bitterness and antisocial behavior didn’t disappear in a day, but the root cause, the thing that was driving me, went away. After surgery in _____, there was a time of recuperation and just going out and doing things like going ice skating and flirting with boys and just having a life that, just doing things that - there was something in me before the change in legal status, but I would not have tried that sort of thing, just wouldn’t have done it.

Now, she seems to have come to terms with some of her ambivalence:

I wouldn’t consider myself strongly gendered. It’s one of those things that if you had to do it over again, if the doctor had said “Look, you know this will give you muscles and this and that and the testosterone will make your visual motor and aggression problems go away.” That’s one of the things I wanted to know. And they said “no, it won’t help it at all. It will, you know, broaden your shoulders and give you muscles so you have the strength, but you won’t have the agility”. And I would have, had this been said when I was in third grade. “Look, we need to start giving you hormones and it is gonna make you big and strong” and it had allowed me to play the sports. I think I could have turned out a lot differently. But I’m not unhappy. I’m happily married, but I don’t think I’m strongly… I mean, I’m heterosexual, but I think part of it is learned and part of it is by choice.

She further explains her current experience of her gender:

You know, I’ve tried a lot of things that I thought maybe would make me appear more feminine or something, but I always get back to being basically lazy, I suppose, but my attitude changed to basically “look, you know - it’s okay for a woman to do it because I’m doing it.” That makes it okay. I mean if it’s something that is gender-related and just don’t worry about it and I was always fortunate enough in the type of work I did that there was never any hit on salary for being female. So, I guess I kind of settled into something that was comfortable for me and I think that I’m very honest with myself about the details of my condition before and after surgery, and how much of the gender issues may or may not have been related to nature or nurture, and when it comes down to it doesn’t matter a lot. My theory is that at least in XY/XO, in most cases, neither one plays a very strong role. On the other hand, I suspect that I would never be able to change the basic gender place that I’m at. You know, it’s not that is strongly male or female, it’s just kinda to the feminine side of the middle, but I think that’s not just the only measure. I think there’s another measure that says how strongly you’re attached to that particular place or how strongly you’re attached to the stereotypes or revolted by the stereotypes, either one.
Julie explains how her fears of exposure kept her from being sexually active until she finally got married in her later thirties, “I think there was very little temptation to explore, not that there wasn’t opportunity to do various things in high school or college, which is either way. I just never wanted to try it to get to the point that where things could get out in the open, you know, in that kind of situation.” She describes herself now as, “Obviously, I’m not a very sexual person in terms of activities but it doesn’t bother me a lot. I had none till I got married, and you know it didn’t bother me up through college.” She found, in her husband, someone who is a good match for her sexually:

I think that my sexual practice could be more diverse than it is. I suspect that I react more to touch than to images or to sounds or something like that, or even to reading. So being that, there are a lot of places on my body that don’t have a lot of feeling anymore, it kind of interferes with that, but I’ve also always been the kind of person that was more interested in hugging and being close and talking to each other, and I just happen to have a husband who is - one of the reasons that I think he could be Klinefelter’s is because he’s got the type of personality where he wants to spend every waking minute together that he can, and he’s diabetic, which can interfere with other sexual activity sometimes. I think I would have a problem with homosexuality for me, whether I was male or female.

But the surgeries have had an effect on her sexual functioning:

Well the nerve endings worked better before surgery. They’re not as good but there’s feeling and sensation. And, it’s weird because it comes and goes. Sometimes, there’s so much feeling that you can’t tell whether it’s pain or pleasure. Sometimes it’s like touching my arm, nose or whatever.

Julie’s experience has had a profound effect on the way she feels and thinks about and utilizes the medical community:

I was in some ways much less addicted to physicians before. In that, there are consequences from the surgery that go beyond the surgery in terms of your overall health. And just the UTI. But due to the surgery, you are now accepted as female in the nude, which might not have been before. And that can make differences not having to do with sex, just the casual nudity involved in hot tubs or whatever but more importantly, stirrups, the whole go in to get your speculum and why they do
Pap smears but you know, the whole Pap smear spread your legs vulnerability of the physical, I don’t know whether its just the fact of the genitals being rearranged or the hormones or what. But medically, you’re much more vulnerable to stuff than you were even as a hermaphrodite.

She is clear on what she expects from doctors now:

I treat doctors as though I were the customer and they were giving me a service. I try and be as up as I can on any medical issues whether it’s condition-related or not, and I will certainly take and request their input on it, but I expect to be able to choose whatever options are open and take whatever. So it has to do with control … One of the things I felt as I grew up and even as I got into this whole thing about hormones was that they have been so interested in seeing me grow taller and so interested in seeing me gain weight and so interested in seeing me do all these other things that it was always their agenda and sometimes I didn’t see… they didn’t explain to me why it should be my agenda.

She acknowledged that she still feels a loss of control when she goes to the doctor now:

But there’s no control going through the surgery and changing, even after doing what they all think should be done in terms of normalizing the situation. And then you’re in this situation of where you are in the stirrups and there’s not that much more control than you had and you’re still having to have more surgeries and you get tired of the UTIs…

She is even less forgiving when she considers the psychiatric community:

I naturally went for formal counseling and part of it is what happened with some psychiatrist in _____ that she wanted me to try something first that I didn’t want to try and the other is that there seems to be a whole industry built up on gating access to the surgery even though they so pushed it when the kids are small and then when you get old enough to be able to make the decision yourself, there are all these rules about, well prove to us that you’re righteous enough or whatever the word… So, yeah, I’ve got a chip on my shoulder when it comes to psychology and psychiatry, but I consciously try or pass that through things like this. I also have found that talking with someone with the same thing helps, and the support groups help. And so there’s no particular need felt to go for professional help.

Julie explains the effect her experience has had on her relationship with her family:

My sister and I have probably a closer relationship than we did before. When I first started on hormones, all I could tell my mom was that I was starting on hormones. She being a nurse, thought that I had a probable prostate cancer because that’s what
they give ethinyl estradiol for. Well I didn’t know that, and I come into the bleeding room and my sister says, “Mom is crying. What did you tell her, you know?” So I go and sit on the bed and I go, “Mom, you know, Mom, everything is gonna be all right” and my mom is still, you know, recovering from crying. My sister is on the bed looking at me, and it took her about five seconds to realize what was going on because that’s how well we connected and she went cold and Mom looks up and goes, “what did I miss?” And I said “I’m gonna be a girl.” She was still worried about it then, but after the surgeries were all done, I think we became less emotional with each other but closer. My dad, when I told him I was gonna change my legal status said, “no you’re not.” And I said “I’m sorry, but yes I am” and it was the only time in my life I have ever crossed him and yet it took a long time for both of us to get past that, which we did, and then we were close enough that when I got married, he came and gave me away and the whole bit.

And how her experience kept her from forming close relationships:

For a very long time, I was terrified at getting too close. Just because I thought eventually you’re gonna have to open up and I don’t want to go there. But I finally reached the point of where it started out as a spiritual growth in terms of realizing that I wasn’t doing the things that I ought to be doing as a Christian by being off alone in the world, and not only did God want me to be the same in the outside and inside, he wanted me to be a part of the Christian community and that means form your relationships. So then the question becomes, do you tell people up front or not? Well, I believe you shouldn’t because I believe that fear is with them knowing who you really are because of their conception, mis- or preconceptions. So, it held me back and - growing up in a fantasy world and moving every couple of years. I would add it’s easy for me to just continue to live in that castle in the sky, and that part I knew wasn’t right.

She further describes the way her experience has taught her how to escape whatever painful or frightening reality she might have to face in the moment:

It isn’t right to be living in a castle in the sky. I have a huge teddy bear and doll collection and people that are close friends tease me about never having grown up and there are certain parts of me that probably never will and I like it that way and I don’t intend to change it. I try to be here, as opposed to somewhere else, but I do take advantage of the ability to not be here when it’s gonna be new, like you know when I go to a new doctor or when I’m arguing with the doctor and the whole thing is like flashbacks without any images of just the doctor telling me how it’s gonna be. …And it comes in really handy in things like my husband was teaching me how to play pool and I was trying to break and I lost hold of the stick, and I ended up punching the end of the pool table as far as I could. So, things like that actually, but this finger got like three times its usual size within five minutes, but there was no pain. I could feel that my body or my mind just shuts it out, and that can come in handy at times.
When asked how she wished her condition had been handled differently, Julie first speaks of the advice she offers to parents of children with the same condition now:

I’ve had people ask me how to decide whether they’re right in living as male or female in XY/XO. So what people have to do is try and figure out how to play beyond their doubt and that doesn’t necessarily mean that you can say well, here’s a yardstick for your genitals or if you had a penis that is this long or if you’ve got one ovary and one testes, but the ovary doesn’t work and the testes might. You know, it’s like I told the XY/XO parents. They say, well, if we’re not gonna have the surgery they have to be male or female. I say that’s true and what I recommend you do is choose rather arbitrarily male or female and be consistent about it, but ask them and keep on asking them when they’re old enough to be consistent, and when they trust you to be understanding, and they’ll tell you what they wanna do, and let them change a couple of times if they want to. Just don’t let them have surgery until they’re settled down into it. But I would recommend against the surgery until you are going to be needing to use the equipment and desperately wanting it different.

She further details what she would have wished for herself:

But had I to do over again, [surgery] is a place that I try not to spend too much time at. You know, it would have been nice to start hormones, whatever hormones, at 11 or 12 or 13 or 16 just to grow a beard or Basso profundo or breast growth, you know, something. There is nothing that my parents could have done to make it completely normal because its not. And I’m not one of those that wants intersex to become mainstream either, where you get an ‘I’ on your driver’s license so you can be discriminated against in public instead, in absentia. But I don’t know, I had good times in college and high school. I probably would not have done the implants. I probably would have been more patient with the hormones. I probably would’ve started them at 18, as soon as I left home, if I could talk anybody into it, or if I knew that you could get them from Canada like I know now. But I think had my parents … there are a couple of doctors who are experts on XY/XO who think all should be raised as female because of the potentially short stature, but I think had my parents done childhood surgery and raised me as a girl, I think I would have been mad about it because there was … most of the XY/XO adults that I know, and I know six or eight, are not very strongly gendered either way. I know three or four who were originally raised male and are living as women. I know one who’s had surgery as an infant and is happily married as male now. And the rest … some of them had surgery and don’t care, and some of them are like, well, whatever.

Julie’s experience of the interview.

Julie describes her physiological reaction to the interview:
It’s been good, although I still have a tendency, the longer that I talk about these things, I tend to get more and more, not necessarily agitated, but it’s like my whole body wants to start quivering. I suspect it’s just because I’m going through some of the same thoughts that I did when I experienced some unpleasant things…

And the emotions and images that came up for her:

When you asked me some of these questions about my childhood, and how people treated me and the questions about treatment of my body and the various doctors that I’ve been to, tend to bring out physical, visceral reactions that may be associated with memories that are, it can’t be memories because they never happened. Things like a little girl running down the hallway trying to get away from the doctors. Well obviously, there is some part on my brain that’s thinking that was me, but I know for a fact that at least the way the dream happens, it could not have happened. You know, it’s more likely a composite of my fears.

She ends, though, with an explanation of why she feels the need to continue being involved in research like this:

But I think it’s productive in the long run for me to this sort of thing and I think it’s productive for others… I wanna make it better for everybody and that drives me to self examination all the time because I don’t like rules, and I don’t like to enforce them on others.
CHAPTER IV

Discussion

It has been a thrilling and often dizzying period of time to be trying to contribute to the field and to the lives of people struggling with DSD. What has been particularly striking to me has been how difficult it was to find people willing to talk to me. As someone who was relatively welcomed by a small group of respected researchers and patient advocates, I still waited months and finally years to secure the three interviews I eventually conducted. While I was a presence on support websites I received far more contacts from other researchers asking for assistance in getting their own subjects and from crank e-mailers than from people with DSD. These e-mailers seemed to think I might somehow have privileged access to a pool of subjects willing to show themselves. By way of this unusual intermediary position, I got a chance to experience first-hand the prurient gaze of both the public and the medical community upon the bodies of people with DSD, and with it a level of disgust and feeling of exploitation that must be too familiar to people who have been treated under the protocol.

Again, I had read and heard of the reluctance these individuals may have toward participating in studies - “lost to follow-up” is a phrase found over and over again in
decades of articles. But it was not until I sat in the same room with my participants and witnessed their discomfort and pain at retelling their experiences that I began to have a felt understanding for how impossible it may feel for others to come forward and willingly offer up their stories to a stranger trying to make sense of them, all for the sake of a science that had so utterly traumatized them.

As a clinical psychologist, I tend to see the crisis, the pain, or the struggle for an individual first and foremost, and I have without a doubt read these narratives through the lens of trauma. But I would never want to underestimate these remarkable women’s strengths, achievements and resiliency. They may not agree with some of my conclusions about their experiences, but they would certainly agree that they have survived extraordinarily difficult life events.

For the unquestionable impression of this study is that all of the women who agreed to speak with me have suffered remarkable traumatic injury through the way their physical conditions were handled medically, psychiatrically, and in their families. Not only do they describe their fear and pain and efforts to psychologically escape from their experience, in person they each showed varying signs of psychological sequelae to trauma. Rather than the intended result of creating a ‘normal’ body, the treatment seems to have, in Linda’s words, “created a person with a psychology that was about childhood trauma.”

**Thematic Convergences and Divergences**

**An Evolving Protocol**

This paper offers the experience of three very different women with radically different conditions. In the parlance of Anne Fausto-Sterling, here is the experience of a
merm (Kara), a ferm (Linda), and a true hermaphrodite (Julie). It is also a picture of essentially three different eras of treatment: Julie was treated before her own condition had even been identified, and would have been better served, certainly through her excruciating adolescence, if she had been offered some kind of treatment at all; Linda was treated during the heyday of the medical protocol and, frankly, was lucky to have emerged with any of her clitoris left at all; and Kara seems to have had comparatively enlightened care, including delay of vaginoplasty and a doctor who included her in her treatment, describing (to a degree) her condition and explaining the technical details of the surgeries. This speaks to the evolving nature of our understanding of these conditions and a rapidly shifting reality in what actually constituted reasonable, competent care.

These data show that the actual care and treatment that was offered to these women is not entirely in accord with the literature’s “protocol.” That is, the “protocol” was not as rigid as has been suggested nor the treatment from doctors always as thoughtless and inhumane as is sometimes asserted. What the treatments do have in common is that essential parts of their medical histories were kept from each of these women, either through willful obfuscation or, in Julie’s case, ignorance and incompetence.

Additionally, Julie’s experience hints painfully at the problems of not having any clear treatment paradigm. Without a diagnosis she was left in a body painfully situated between male and female during an era with no tolerance for gender ambiguity. As she prayed during high school, “God, please make me a girl, let me be able to have children, but if not then make me a boy.” Clearly for this woman, in that era, some medical intervention, if only hormone replacement therapy, would have been welcomed.
All three women describe their own developmental arc of dawning awareness and a shifting experience of their bodies over time, with their anxieties becoming particularly acute through the process of puberty. One could note that this is not so different from normal development – adolescence is a time of intense focus on one’s emerging, changing body; however, these women note disproportionate preoccupation with and fears about their differences.

Each of these women describes her intensified hopes and fears that her body would conform to ‘normal’ expectations. Kara speaks of comparing genitals with friends at age 11 or 12; she describes her satisfaction with her emerging hips and breasts once she started hormone therapy, and her ongoing requests to her doctors to fix her “little tweaky issues” to more closely approximate an average woman. Kara’s willingness to fashion her own body to approximate a normal female shape seems to have provided her with ensuing control and comfort at being able to pass.

Linda had always felt her body was different, and that she was “just not performing as everybody else,” but at puberty her concern about it took on a level of fear as she entered into her first sexual experiences, “those steps of being naked and being touched by somebody else, I think it brings on panic in the pleasure, but when you have a body that you know is different, there’s just a lot of fear in there too.” In spite of her fear, she leapt into sex and relationships, presumably because her fear of actually being different was much greater than her fear of sex. She couldn’t wait to grow up to be a ‘real’ woman, which to her meant sex, a lover, menstruation, breasts, hips, giving birth, motherhood, and marriage.
In spite of the focus on their bodies, and the fear of being found out as something different, both Kara and Linda seem to have been able to pass at first glance as unproblematically female. Julie’s prayer of being any gender at all is particularly painful to hear and imagine, as she did look so different, with no hope of approximating a typical adolescent boy’s body.

Finding Ways to Escape

All three describe the ways they were able to escape their more difficult experiences. While this may have protected them to some degree from the various smaller traumas of painful medical treatments, contentious family lives, or difficult social interactions, the strategies they employed in escaping from their experience appear to have affected them in both their emotional and somatic spheres. All three women seem to have an extraordinary tolerance for pain, and their descriptions of ongoing experiences of tolerating pain in their daily lives have a distinct dissociative quality to them.

Linda describes spending years diving into her relationships, her productivity, her children, and never allowing herself to be alone or quiet. Once in therapy, she speaks of having to go back to find her child self and reconnect to the child that had been in so much emotional and physical pain. This was a process she strongly resisted: she had worked hard to pretend she was in fact living an expected “normal” life, and paying this much attention to her actual experience seems to have been terrifying. Also, for years she experienced penetrative sex as excruciatingly painful, but she pushed through it anyway.

Kara escaped into dinosaurs, stamp collecting and karate from the day-to-day realities of her school and family or perhaps the more difficult sense that there was
something wrong with her. She currently denies having a sense that she was “bad,” but she also alludes to having her self esteem “worked on” and finding relief in the sense that she was not to blame, in spite of being constantly told that she was to blame. Additionally, she seems to have found some kind of mastering experience of undergoing repeated surgeries as a way to approximate femaleness. In spite of the physical pain involved, she values the control it gives her to be able to pass.

Julie describes most vividly her escape into fantasy to erase unpleasant events and experiences - from going to the doctor, having genital exams, having pictures taken and teeth pulled, having doctors’ hands in her mouth and crotch. Especially poignant is her fantasy of returning to being six, with her tiny body, her voice “like wind chimes,” experiencing herself as an elf. Her tendency to escape is now an established part of her personality, and she has mixed feelings about it, stating “I try to be here, as opposed to somewhere else, but I do take advantage of the ability to not be here when it’s gonna be new, like when I go to a new doctor…” or after an injury where “I could feel that my body or my mind just shuts it out, and that can come in handy at times.”

Knowing Vs. Not Knowing

One of the more affectively moving moments in each of the narratives is when each woman describes her experience of discovering her history. Each woman relates the tension between the protective comfort of not knowing or not looking, versus the painful but eventually freeing experience of finding out the truth. This feels quite similar to the experiences of sexual abuse survivors who have repressed unbearable memories of their early experiences. But unlike sexual trauma survivors, who often ‘remember’
experiences and memories that have been kept from their consciousness, these women have in fact been explicitly lied to by the medical community and their own families.

When, as an adult, Kara finds out that she was born a boy, she describes her shock and sense that a whole separate person had been shut off from her awareness. But over time, it fills in some important understanding about her identity and allows her to understand and accept her same-sex attractions. It also seemed the one moment in the interview in which she made her first real contact with some empathy for her own experience.

After many years in therapy discussing other people’s problems, Linda was able to turn her attention to her own experience and history. She vividly describes her sense that she had been running away from her essential experience, terrified of what might surface if she were to stop her movement, look at her own history and connect to the feelings that emerge. She acknowledges that she has to be willing to do the work, to face it head on. She notes the difficulty of that work but also the wholeness she is working toward and occasionally experiencing.

Finally, the tension can be felt in Julie’s description of finally finding out that she has a disorder of sexual development, “It’s like finding out that you’re not an elf, but that you’re a deformed human and there is a difference in alien there in that being an elf would be more alien but…It’s a more pleasant alien to me.”

Body Autonomy

All three women discuss the ways they have attempted to regain control of their bodies after years of surgeries and medical exams and photography.
For years Linda was “really bad” about taking her medicine in a self-defeating effort to get control of her treatment. More recently she came to the decision that she could and would control what went into her vagina, “not a finger, not anything.” She also has come to expect her doctors to do what she asks, and be willing to listen to her experience and expertise. She found herself surprised by finally feeling that doctors “could actually do a good thing.”

Julie has also taken a more consumer-oriented approach to her medical treatment and now expects to be offered options by her doctors that she has final choice over. However, she continues to find herself feeling vulnerable and prone to flashbacks while undergoing exams, and more likely to need invasive medical attention and procedures to manage her surgically altered body.

Kara does not have the same attitude toward the medical profession as the other two women, and in fact seems to have experienced her doctors as some of the more comforting, understanding caretakers in her life. Much to her mother’s dismay, she seems to have intuitively taken a consumer stance with her doctors from an early age: if she wanted larger nipples, more pubic hair, or an improved cosmetic result on her surgeries, she demanded it. She appears to have retained a sense of control by taking some ownership of the remarkable changes the medical industry was exacting on her body. For Kara, the maintenance of control seems to have been worth the pain of repeated surgeries and physical recoveries.

*Spoiled Self, Impaired Relationships*

All three women relate their ongoing struggles to hold on to a positive self-image and to build and maintain positive relationships.
Linda describes herself as always “making up from a place of deficit” by “overachieving” in every role she undertook. She threw herself into relationships but rarely felt that her efforts were reciprocated. She was uncomfortable “taking, needing or asking” from others. She repeatedly founded relationships with “people more damaged than I was.”

Kara “was considered queer in school,” she got beaten up regularly and “went into a cocoon for a while, complete social isolation.” She felt her therapy was helpful because it dismantled her belief that “if I had these problems, they were my fault.” As a young adult she describes her painstaking efforts to teach herself how to make friends and admits she still finds it difficult to connect emotionally with romantic partners.

Julie doesn’t describe it explicitly, but as the individual with the most atypical gender expression throughout her adolescence and young adulthood, she must have had occasion to be terrorized by classmates and passersby. She admits to relying on her strong ability to “live in that castle in the sky” as a way of tuning out, but her rages as a child and her aggression, suicidal feelings and self-destructive behaviors as a teenager and young adult hint at her underlying misery and self-loathing. She seems to have avoided most close relationships for years and stayed clear of sexual relationships until she married in her late thirties.

There is in these women’s narratives an alarming similarity to the patterns of denial and secrecy in families with ongoing sexual abuse, where the victims make sense of their abuse by assuming that they somehow deserve the treatment they receive. Survivors internalize a sense of badness that pervades and spoils their developing identity, and has long-lasting effects on the capacity to connect with others.
Additionally ‘passing’ has been an important effort for all three women at different times in their lives. Goffman (1963) describes stigma as the process by which the reaction of others spoils identity. Individuals who appear different to others face the challenge of deflecting (and not internalizing) the opprobrium of those around them. Individuals who possess a stigmatizing difference but who manage to conceal the difference are additionally challenged by having to manage their fear of being discovered and maintaining the lie they are implicitly telling the world. Inevitably, relationships with others are hampered and defined by the need to preserve the lie, leading to limited emotional, and in some cases physical, intimacy. These three women have at varying times in their lives been both unable to ‘pass’ and more able to ‘pass,” and both positions have clearly taken a toll on their self-esteem, their sense of positive identity, and the quality of their relationships with others.

Both Julie and Kara allude to their continued concerns about passing, and describe their relief at having their bodies be relatively ‘normal’ looking in the nude. Their ‘normal’ bodies allow them some control over having their intersex identity discovered. As Kara notes, “it’s completely up to my discretion to tell anyone about my personal situation.” Julie describes her relief at the change in her legal status, and subsequent improvement in her feelings of aggression and “antisocial” behaviors. The reader gets a palpable sense of how dangerous it can feel to be ‘found out’ at the mere presentation of a driver’s license. Although she has found great support and healing in her connection with the online DSD support community, and in her relationship with her husband, it is unfortunate that she doesn’t feel able to be completely honest about her past and current self with members of her church community. Linda recounts with a strong
sense of regret the exhausting efforts she has gone to “trying to prove that I was okay... that I aspired to be normal.”

**Implications for Sexual Identity**

One of the more surprising findings of these interviews has been how inextricably related growing up with a DSD has been to problems coming to terms with sexual identity. The shame about having same-sex preferences seems to have both fueled and been fueled by the shame about not being “normal” or having a normal body. All of the energy, the surgical interventions and family efforts to create normality seem likely to have compounded the internal distress, the sense that it was really, really wrong to have same-sex attractions. It may be that the fear and shame and struggle to come to terms with same-sex attraction that most LGBT people experience in their development (Colman, 1982) may be particularly acute in those who have been treated in a protocol where the specifics and realities of the workings of their own bodies have not been made clear to them.

Kara and Linda have both found relief at knowing the specifics of their conditions, because to them it makes it more ‘understandable’ that they would have same-sex attraction - that their bodies are in fact in line with their desires. Given the reality that either of them in a current relationship will be seen and treated as a lesbian couple at some point, regardless of whether they identify as such, it is unfortunate that homophobia played such a role in the understanding of their sexual orientation. They seem to have been unable to allow their same-sex desires full reign or integrate their desire into their identity until they realized there was some hormonal or chromosomal
explanation for it. I feel some concern that this represents a degree of self-loathing that remains unexamined.

Although Julie only hints at ever having same-sex attraction when she was living as a man, she certainly never acts on it, and she too describes relief at finally “disappearing” into a female body, where her body now aligns with her desires. Julie’s homophobia is more explicit: she is quite clear that if the technology had been available to her she could have gone either way in choosing her gender, but she could not be homosexual. For Julie, her desires dictated her gender.

What is similar in all three accounts is the absolute dearth of opportunities these women had to verbalize their interests and confusions, or to play with various ways of expressing their sexual selves outside of their gendered selves.

*Family Dynamics*

Just as a severe trauma can affect the level of functioning of an individual, the level of functioning of a family can change as a result of trauma. It is clear that the birth of each of these women was an enormous strain on their families, a strain made more frightening, at least in Kara’s and Linda’s cases, by the fact that both mothers were sedated until the doctors could figure out what to tell them.

However, there are important differences in the baseline level of functioning of each of these families. Kara’s parents were in a forced relationship that was unhappily glued together by her medical needs. Her working-class parents were alcoholics who emotionally and physically abused her. Her mother, in particular, seems to have transmitted her resentment in painfully clear verbal attacks. She seems to have experienced Kara as a personal narcissistic blow – she was ashamed of her language, her
boyishness and her curiosity about her own body. Both Julie and Linda came from comparatively healthy families with the luxury of higher socioeconomic status. They had additional children to focus on and more emotional and financial resources to offer to their sick children. There is no indication that either Julie’s or Linda’s parents resented them, as Kara’s toxic parents evidently did her.

That is not to say there were not more subtle dynamics in place that seem to have been quite similar in all the families. In all three families there is evidence of understandable relief at passing the buck to family members and doctors who were making the difficult decisions, and who appeared to offer some escape, a chance to make the problem disappear to the casual observer. Kara’s parents seem to have been utterly controlled by her maternal grandfather, and Linda’s parents were provided with a chillingly grim prognosis and advice by her grandfather. These were families living in a time of greater acceptance of hierarchy, both within the family and also when dealing with the medical community. Doctors’ orders were to be followed without question, and there was greater confidence in the idea that doctors could provide clear answers. Any family facing an extraordinary stress may, even in our current day, require significant emotional support and educational resources to take the time to consider all the options, and understand the nuances of potential decisions.

The overwhelming similarity in all the families is the corrosive combination of secrecy and denial. All three women describe a family culture of virtually no communication about what was happening to their bodies. None of them felt that they could talk about their condition or their bodies or even about their medical appointments. There seems to have been a similar pattern in all three families of pretending that it all
was not happening, and even that differences did not exist. And of course a shared trust that doctors could make the differences disappear. Kara’s (and her family’s) willingness to allow repeated painful surgeries to make the scars on her buttocks disappear speaks to this faith in medicine to normalize her body. A reader senses the clear panic that Linda’s mother must have felt in listening to her distraught 8-year old ask about her large clitoris, and then shudders at the quickness with which surgery was scheduled to make that difference go away.

Julie describes feeling pleased at her parents’ insistence that all their kids were equal, all required to perform uniformly in chores and daily routines. This may have been one of the few areas in her life where she did feel normal. On the other hand, ignoring her differences may have served to compound the subtle and unsubtle messages she received about needing to fit in, to have a boyish haircut, to behave like a boy.

Linda’s family in some ways more than acknowledged her differences; they treated her as sick, and weak, and special, and her siblings, not having any clear idea of what her medical problems were, resented her for “having it easy.” This is a pattern that is familiar in many families with one seriously ill child, but in a family where there is no clear communication about what that child is actually facing, there is even less chance for empathy to be cultivated in the healthy siblings. It would seem more helpful to children with DSD to be given ongoing acceptance and acknowledgement of their difference while optimizing the number of opportunities to be something in addition to their difference.

What is most clear is that in each of these families a family culture seemed to exist where questions were not allowed because they threatened to completely dismantle
the denial. Questions about gender, sexuality, and preference were the very questions that most needed to be encouraged and the most likely to be potentially threatening and therefore squashed. Of course questions about gender in particular shake our cultural knowledge to its core – encouraging these kinds of questions may have felt like questioning gravity – and so, in addition to the shame they engendered, questions may have been discouraged because there were no answers to even consider other than the threatened understanding of ‘normal.’

These three women each complied with or pushed at the limits of the silence in different ways: Kara, the provocateur, seems to have found a way to needle her mother, to make her squirm in embarrassment by raising the uncomfortable questions in front of her doctors, but she didn’t seem to bring up these same questions with any frequency at home. Linda describes a whole personality based around her efforts to be a “good,” “compliant,” and unproblematic child, and Julie, at a very early age, knew with great precision the limits of her gender expression – Raggedy Ann and singing were ok, but ballet lessons were not.

Even relatively healthy families who also had significant resources faltered in raising a child with these kinds of medical conditions – the secrecy expected and attendant shame made it almost inevitable that these children developed seemingly maladaptive ways of relating to others and themselves. But families dealing with any problems of substance abuse, parental conflict or violence, the stress of poverty, poor education, or mental illness are at particular risk to exacerbate the trauma of ongoing medical treatment for a young child, and thereby contribute to worse psychological outcomes.
Experience of Psychotherapy

The three women in this study describe participating in a wide array of psychotherapy that can at best be described as well-intentioned but now obsolete, and at worst as destructive.

Kara found her therapy in childhood to be helpful in mitigating the more toxic aspects of her family life and disarming the more negative attributions she was making about herself and her relative goodness and badness in the world. The psychological services she received seemed to be well-intentioned and open-minded; the therapists allowed her to ask questions, had a clear focus on building self-esteem, and appeared to be concerned about the toxicity of her mother’s anxiety about her relative masculinity. Someone suggested family therapy but was not effective at selling it to her parents.

The problem is that she seems to have received a number of disjointed therapies: a therapist for gender identity, another therapist for sexual identity, someone else for attention and hyperactivity problems. The occupations and interests that absorbed her as a kid are not the typical interests of a child with ADHD. It is not typical for a child with ADHD to have the sustained attention and physical focus for reading alone in their room or collecting coins. I question the diagnosis and posit that her behavioral problems were more intimately related to her family dynamics, atypical gender expression, negative reaction of her peers, and her ongoing medical treatment than to a neurological impairment. This was not treatment for a whole person; rather, it amounted to specific treatments for particular problems, with little evidence of an overarching consideration about how the individual problems may interact with and exacerbate one another.
It is not clear what is currently being helpful to Kara in her once-a-month treatment. She admits that she finds her therapist “a flake” and feels that therapists “are like rugs” who need to be flipped out and exchanged for something fresh occasionally. There is an unrelated quality to her description that may be understandable for someone who has always been treated as a series of problems rather than as a whole person herself. She seems to see therapy as a service or technology rather than a relationship, which is very much in keeping with her approach to the medical industry as a whole.

Linda also received therapy as a child and reports that although her play therapy was apparently not harmful at the time, neither did it feel helpful to her. She may have played out her conflicts and struggles to the therapist’s satisfaction, but she did not exit the treatment with even a simple explanation about what was happening to her body. She acknowledges that she was unwilling or unable to put into words what was really bothering her at the time. Whether it was the particular therapist or the limitations of play therapy as it was practiced at the time, no effort was made to discuss what was actually happening to her: “I don’t remember the connection between like what was going on here and this effort to really address maybe what I was feeling.”

Importantly, none of the therapies described by either Kara or Linda appeared to be concerned with disclosure, something that is currently understood to be essential in helping children understand and manage their chronic illnesses, particularly when stigma is attached to a condition. It may have been the intention of these therapists to help them understand their conditions. However, these treatments occurred during the heyday of the Money protocol, where it was still considered dangerous to a child’s emerging gender identity if he or she were to find out that their chromosomal makeup or birth
circumstances did not fit expected parameters. Without disclosure the treatment served to obscure the actual circumstances of their births, genetic makeup, and what had been done to their bodies.

Julie’s experience of therapy shows the worst of what psychiatry and psychological services have offered in the past, particularly around issues of gender and sexual identity. She was met with gatekeepers who were uncurious about the potential genetic or endocrinological underpinnings of her condition. They locked her out of the surgery she was seeking, and further traumatized her by treating her like a freak and scientific curiosity.

A more helpful approach continues to be difficult to find for people interested in gender reassignment in this country. For Julie it might have involved a holistic, integrated curiosity about what was going on in her body and her emotional world. And it might have included a genetic and endocrinological work-up as a preface to offering some effort to assist in helping her to solidify her identity, and in the integration of and recovery from her physical and social traumas.

By being born before her condition had been clearly identified, Julie had managed to avoid the medical trauma that Linda underwent. But the therapy she received and eventual surgery she elected proved to be an enactment of this same trauma. She was ‘examined’ repeatedly, not provided with full disclosure about her condition to be able to give informed consent, and because she was not provided with any reasonable alternative, such as taking hormones or attempting to pass as a female without surgery, she eventually rushed into risky, poorly performed surgery that left her with significant physical scarring and loss of sensation.
The one exception to this regrettable list of past therapy experiences is the course of psychotherapy that Linda has sought out as an adult. She movingly describes the terrifying process of approaching what she had not known about herself, her effort to find out her history from her family, her medical record, to systematically return to her physical and emotional traumas and painfully re-integrate the experience with her long denied and split-off emotion. She is also honest about how hard it has been, how much will it requires to face past pain and trauma, and how much trust she has had to build with her long-standing therapist.

Additionally, a number of process differences emerged during the interviews that may point to different levels of healing and integration in these three women. Linda was the only participant to complete the interview in the expected time frame, 90 minutes. The other two participants took 5 hours (Julie) and nearly 7 hours (Kara) to answer the questions. All of the participants had told their story previously to researchers and others in the DSD community, but it seems possible that Linda’s long experience in therapy may have made it easier for her to organize her experience in words and communicate those experiences succinctly.

In spite of spending much less time describing her experience, Linda was the most affectively engaged throughout the interview. She was alternately angry, thoughtful, and tearful, but could speak through her tears without getting overwhelmed or disorganized. In contrast, Kara often spoke in a pressured, unmodulated voice that was frequently at odds with the content of her speech. She conveyed her anger clearly but was never moved to sadness, and frequently made light of her past difficulties. Julie appeared very quiet and intellectual and showed almost no emotion the entire time, even when
discussing extraordinarily painful experiences, including periods when she was suicidal. It was therefore surprising (but consistent with the presentation of trauma) to hear Julie report in a rather flat voice her experience of the interview. She described a vivid frightening flashback with detached curiosity about whether it had actually happened or not.

Of course, these women come from very different backgrounds and have their own personality styles and separate family cultures around the communication of emotional experiences. But it seems possible that Linda’s therapy has been instrumental in helping her come to terms with the realities of her physical trauma and the emotional trauma of the secrets within her family. She showed the capacity to revisit painful events with the emotion integrated in the experience.

Even though neither Kara nor Julie have had such positive experiences in psychotherapy, they both have experienced significant healing through alternative efforts to make sense of their experiences and integrate those experiences into their adult identity. Their efforts are notably consistent with Sharon Preves’ description of intersexuals’ coming out and identity integration (1999). They have both reconstructed their medical record and as much of their physical past as possible. They have developed some sense of empowerment in terms of their experience of, and use of, medical services, although Julie in particular continues to be subject to occasional flashbacks, overwhelm, and dissociation during medical exams. They have longstanding committed relationships, in which they have been honest with their partners about their conditions and their experiences. They have connected to an online community and have found comfort, pride, and self-esteem in their intersex identities by ending their isolation. Julie
has also built a community within her church and has found great comfort in her faith in God.

Additionally, all three women have found some healing in participating in what Judith Herman calls a “survivor mission” (1997, p. 207). They have felt moved to some kind of social action to give back to other victims, through providing on-line support and advice to others, participating in research, or becoming a ‘patient advocate.’

*Suggestions For Psychological Treatment*

A small but growing body of research is emerging about what may be helpful to people who have undergone some version of the “protocol” and who now are dealing with the physical and psychological sequelae of their treatment. The themes elucidated in this study certainly sharpen the focus on a picture of the kinds of struggles with which people with DSD have to contend. Previous writers and activists have made broad suggestions about how to best help children born with intersex conditions going forward, and how to avoid the nosocomial traumas the medical and psychiatric establishment has perpetrated on these children in the past. The suggestions I offer here are targeted to therapists who are working with patients who have or who suspect they have a DSD.

*Working with Survivors*

Working with survivors might look like treatment described by a variety of esteemed researchers in the field of trauma, even those working in different theoretical orientations (e.g. Foa and Rothbaum, 1998; Herman, 1997; Van der Kolk, 2002, 1996). The following suggestions are more aptly described as goals for treatment rather than any precise prescription so as to be helpful the widest array of clinicians working in varying styles and theoretical orientations.
The first goal of any therapy is to provide a safe relationship, but creating safety is essential in working with people who have been hurt by the very professionals they have previously turned to for healing. Therapists working with an adult client must be constantly vigilant to their own use of power in the relationship and work tirelessly to empower the client to set her own pace, to titrate her own experience, and to be the “author and arbiter of her own recovery” (Herman, 1997, p. 133). Considering the repeated themes of control and body autonomy seen in the narratives offered here and elsewhere in the literature, it is likely that issues of control, dominance, and submission will inevitably emerge in the transference while working with adults with DSD. Efforts on the therapist’s part to maintain an empowering stance and respect the client’s autonomy are vital here.

The next stage is to help the client explicitly name the trauma and to connect memory to the feelings, both physical and emotional, that originally accompanied the trauma. Many adults with DSD conditions have unclear, confused memories, and scars with no explanations. It may be necessary to excavate whatever information can be obtained through medical records and family interviews, and to help the client reconstruct her story and conceptualize the body she once had. Important in this process will be creating the space and safety to allow the client to mourn the loss of that body.

The final stage in recovery is helping the client to learn to engage differently in the world and in his or her important relationships. Many individuals with DSD have lived lives dominated by secrecy and have developed ‘spoiled’ identities (Goffman, 1963) created by stigma and shame. As Judith Herman elegantly writes, “Recovery can take place only within the context of relationships; it cannot occur in isolation. In her
renewed connections with other people, the survivor re-creates the psychological faculties that were damaged or deformed by the traumatic experience” (1997, p. 133). As the client learns to trust, deepen her emotional intimacy, explore her past, and begin to celebrate her differences with the therapist, she should slowly feel increased capacity to engage in these essential experiences with others.

As the survivor is working through her trauma, and repairing her capacities to trust and be honest with others, a concurrent effort should be made to facilitate a coming out process. Throughout an effective therapy the client should be encouraged to connect to support groups of people with similar conditions. Realizing she is not alone, and acknowledging her difference and experience to others is critical to developing pride in an identity that accepts and eventually celebrates her difference.

It should go without saying that therapists working with intersexed adults also need to educate themselves on the medical treatment and psychological sequelae of the protocol, the disclosure process, and the coming out process. Therapists must also at every stage in the treatment explore and constantly challenge their own assumptions and biases about gender and sexual identity.

Working with the Newly Diagnosed and Their Families

The first imperative in working with newly diagnosed infants and their families is clear: any therapist must treat the family rather than the individual. The diagnosis of a DSD is a crisis for the family just as much as for the individual child. The entire family requires information, support, and re-education, if need be, not just about the specific condition, but also about gender identity and sexual identity.
In addition, working effectively with newly diagnosed infants and children and their families may require a more active role in the child’s medical treatment than most therapists are typically comfortable taking. A first step here is to help the family feel more comfortable educating themselves, so that they feel empowered to question or disagree with the doctors if need be, or to agree with the doctors in an informed (rather than blindly obedient) way. It may be necessary to interface with the medical team and help the family determine the least invasive medical interventions that provide the widest options for gender expression for their child.

Effective family therapy will be focused on helping the family grieve the loss of the ‘normal’ child they had hoped for, and learn to appreciate and embrace the differences of the unique child they have. To this end it will be essential to dismantle the discomfort and shame about having a child with a stigmatized condition, and to connect families to other individuals and families dealing with the condition.

As these children grow, an effective therapist will encourage transparency in all the family’s communications with their child. The best hope families have for their child’s developing a positive identity and adjustment is to provide the child with total acceptance for who they are, while at the same time preparing them to effectively handle the very real challenges of having an unusual body in a society that is not always as accepting. As the child matures, the most important goal of therapy is to facilitate this ongoing effort. Additionally it will be important to communicate the sense that the child’s gender and sexual identities may very well be more fluid than is typical, and to help the family tolerate and support that.
Implications For Further Research

I had originally designed this project as a small qualitative study intended to confirm the trauma that previously published narratives have already detailed and to provide more nuanced suggestions about what might be helpful to people with DSD who decide to enter psychotherapy. The difficulties of subject recruitment have left me with what amounts to a series of case studies.

Inevitable and expected complaints about the limitations of this project are the very small sample size, the heterogeneity of the participants’ conditions and medical treatments, the reliance on self-report data, and the lack of any quantifiable data such as a formal diagnostic workup or symptom inventory. I suppose I could make the suggestion to modify this project in the future to repair these failings. However, I have been happily surprised to find that the case study has proven to be the most apt method for inquiring into these women’s experience with what feels like the greatest amount of respect and highest level of attunement to their struggles and achievements.

The length of time it has taken to complete the project, and the sea-change in what constitutes the standard of care for people with DSD in that time, have radically changed my expectations for this project. I have had to significantly downgrade my fantasies of having grand things to conclude while at the same time I have become more impressed than I ever could imagine with the richness of the data that these three generous women have provided to me.

Going forward, I would like to see more case studies of psychotherapy, so that clinicians trying to help people with DSD have a point of reference to guide them in their efforts. I look forward to seeing how the new standards of care influence outcomes in the
next generation of children born with these conditions. I hope that in the future these people will suffer less.
REFERENCES


APPENDIX A

Interview Guide

Demographics

Age, sex, sex of rearing, education, occupation, race/ethnicity, religious background

Questionnaire

What is the nature of your condition?
When did you realize there was something unusual about your body?
How was your condition explained to you?
How did you understand your condition?
Could you talk to anyone about your condition?
What kinds of things did you talk about?
How did you experience your body at that time?
What did you like or dislike about your body?
Did your experience of your body change over time?

How was your condition handled medically?
How was the treatment explained to you?
What was the nature of your surgery(s)?
Was your surgery medically necessary?
Who made the decisions about your surgery(s)?
What was the experience like?
How did your body change?
Did/do you take hormones?
What was the experience like?
How did your body change?
Did you have any other ongoing physical treatment (shunts, catheters, etc.)?
What was it like to go to the doctor?
How often did you go to the doctor?
What were the exams like?
Did you undergo medical photography?
Did you have any psychological treatment at the time?
What was this treatment like?
Did you find it helpful? Why or why not?
What effect(s) did your medical treatment have on your sexual functioning?
Did you continue with medical treatment? If not, what stopped you?
If, as an adolescent or adult, you were interested in finding out about your condition or your surgery(s) how did you get that information?

How did your family respond to your condition?
If you know, how did your parents react to finding out about your condition?
How did they decide what to do medically about your condition?
Were you included in any decision-making?
How/what did your family communicate with one another about your condition?
How were conflicts about your condition or your treatment handled in your family?
How did your family expect you to handle your condition?
    Were you expected to keep your condition secret?
    Did you hide your body in any way?
    Were you allowed to ask questions about your condition?
    Were your questions answered?
Did you, because of your condition, have a special role in your family?

How has your experience affected you and your relationships?
How has your condition and/or the treatment of your condition affected your feelings about your body?
    Your feelings about your gender?
    Your feelings about your sexuality?
    Your sexual functioning?
    Your abilities and self-esteem?
    Your feelings about the medical or psychological community?
    Your feelings about your family?
    Your friendships?
    Your romantic relationships?

Do you think your condition should have been handled differently? In what way(s)?

What has this experience, talking with me today, been like?
    What made you decide to do this interview?
    What were you expecting about this experience?
    Some people have noted that even talking to a “professional” (medical or otherwise) can bring up feelings that are similar to their childhood experiences. Has there been any thing or any question that has evoked something similar for you today?
    Is there some way this process could have been made easier for you?

Is there anything that you would like to say that we have not covered?
    Do you have any questions or concerns?
APPENDIX B

Participant’s Letter of Informed Consent

I, ________________________________, consent to be interviewed in order to contribute to a research project on the experiences of individuals who have had their intersexed condition treated through corrective genital surgery. Approximately eight to twelve people are participating in this study. The purpose of this study is to better understand the ways that intersexual conditions are managed, medically and within an individual’s family, and how these ways affect that individual’s experiences of their body, their sense of self and their important relationships. Potential benefits of this study include the effect that it may have on changing existing medical protocol, as well as increasing knowledge about what will be helpful to people with intersexed conditions within a psychotherapeutic context.

In order to participate in this study, I agree to meet with the interviewer for approximately 90 minutes and answer questions regarding my experience. I understand that the interviewer may contact me with follow-up questions, but if this happens it will be a one time only event, lasting a maximum of 30 minutes. I understand that there is no compensation or payment for participation, nor any costs associated with participation.

I understand that the interviewer will make every effort to preserve the confidentiality of my interview. I give permission for the interview to be audiotaped, and then to be transcribed by the interviewer. I understand that all names and identifying information will be deleted from the hard copy of the interview, and that the tapes and transcribed interviews will be kept, for the duration of the study, in a locked, secure cabinet in the office of the interviewer. At the end of the study, all interviews and audio tapes will be destroyed.

I understand that participation in this research study is voluntary, and that if I wish to withdraw at any time, I may do so without penalty. I also understand that I may chose not to answer any questions that I am asked, and that I may ask that the tape recorder may be stopped at any time. I understand that I will be asked questions about my body, my experiences with surgery and the medical industry, as well as my experiences with my family and other important relationships, and that if this subject matter becomes upsetting, the investigator will assist me in dealing with these feelings and make appropriate professional referrals, if necessary.

I understand that I may contact the interviewer, Kate Chittenden at (914) 882-9389 if I have further questions regarding my participation in this study. If I have questions about my rights as research subject, I may contact the Sponsored Programs Administrator at Rutgers University at (732) 932-0150 ext.2104.

I will receive a copy of this consent form for my files.

I have read and understand the contents of this letter.

________________________________  _______________
Signature of Participant    Date

________________________________  _______________
Signature of Principal Investigator   Date