

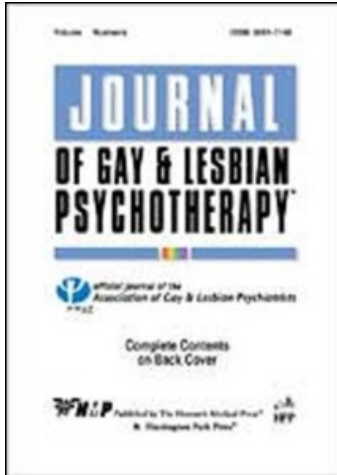
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Intersexuality in the Family: An Unacknowledged Trauma

Arlene Istar Lev, LCSW, CASAC

ABSTRACT. People born with intersex conditions experience trauma and stigma that have not been fully recognized by the medical and therapeutic professions. Current treatment protocols require rapid diagnosis followed by surgical alteration of infants born with ambiguous genitalia which has led to a lack of thorough attention to the psychosocial issues faced by these children and their families. Histories of surgery and silence have left children and families unable to address many of the traumas associated with intersexuality, including stigma, shame, surgical complications, and potential questions about sexual and gender identity. This article outlines recommendations for alternative treatment protocols. In addition to withholding unnecessary surgeries until children born with disorders of sex development are old enough to be involved in decisions regarding their medical treatment, this approach calls for the inclusion of social workers and other mental health experts as part of an interdisciplinary treatment team to serve as advocates, educators, psychotherapists and family systems experts, addressing ongoing issues in the lives of families and children living with intersex conditions. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

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SURGICAL TREATMENT OF INTERSEX CONDITIONS

Intersex refers to congenital anomalies of the reproductive system, which can involve atypical development of the genital and reproductive systems, sometimes resulting in genital ambiguity. Intersexuality has been recognized cross-culturally throughout history and was the focus of much medical attention within Euro-American cultures in the past 300 years (Dreger, 1998; Reis, 2005). Using the broadest definition, those born with medically diagnosed intersex conditions represent almost 1.7% of the population (Fausto-Sterling, 2000), and the number of people whose lives are strongly affected by an intersex condition is about 0.1% (Blackless et al., 2000). According to Consortium on the Management of Disorders of Sex Development (2006b), *Handbook for Parents*, this means approximately one child in 1500 is born with an intersex condition.

In recent years, the standard protocols for the medical treatment of people born with disorders of sex development have become the focal point of intense professional debate, engaging physicians, nurses, bioethicists, and political activists. There has been, however, silence within the social work, counseling, and family therapy communities regarding the therapeutic needs of people with intersex conditions and their families and there have been few clinical resources or informed advocates.

The standard medical protocols for children born with intersex conditions recommend surgical alteration of a newborn child's genitalia with the intent of fostering the best adjustment within the assigned sex. These protocols are based on a theory of gender development advanced by John Money and colleagues in the 1950s and 1960s, a theory that assumed human infants are psychosexually neutral at birth (Money, 1961; Money & Ehrhardt, 1972; Money, Hampson & Hampson, 1955a, 1955b; 1957; Money & Tucker, 1975; c.f. Diamond, 1996). Money believed that a child's gender identity could develop as either male or female regardless of the biological sex, as long as gender rearing was in the same direction as the sex assignment. Money and Ehrhardt (1972) argued "if the parents are consistently unequivocal in their rearing of their

child as a girl, then the chances are high that the child will differentiate a girl's gender identity" (p. 16).

Medical protocols have been guided by attempts to determine the "optimal" gender assignment for those born with intersex conditions with the hope of assisting in the development of a stable gender identity (Money, Hampson, & Hampson, 1955a). This was determined by a complex series of decisions involving projections regarding the child's future reproductive and sexual functioning, and overall cosmetic appearance within the assigned sex (Mayer-Bahlburg, 1998, 1999). It was believed that healthy psychosexual development depended upon the *appearance* of the genitalia and that the creation of a morphologically correct body would foster the internal experience within the same gender. When physicians assign a sex to the child, they "endorse the view that the perception of the child's genitals is more influential than anything else in terms of gender identity formation" (Crouch, 1999, p. 31).

From this perspective, the birth of a child with ambiguous genitalia is seen as a "medical and psychosocial emergency" (Parker, 1998, p. 15) and gender assignments are often made within days of the child's birth; it is recommended that surgical alteration quickly follow to establish and stabilize the gender assignment as early as possible. Surgical "correction" of ambiguous genitalia based on the sex assignment assessed by pediatric endocrinologists and urologists is currently the routine and recommended treatment protocol and this treatment strategy has been endorsed by the American Academy of Pediatrics (AAP) and prominent physicians for the past 30 years (AAP, 1996a, 1996b; AAP, 2000; Donahoe & Schnitzer, 1996; Federman & Donahoe, 1995; Grumbrach & Conte, 1998; Lerman, McAleer & Kaplan, 2000; Migeon, Berkovitz & Brown, 1994; Witchel & Lee, 1996).

Children with ambiguous genitalia are most commonly assigned as females (Schober, 1999a; Wilson & Reiner, 1999), primarily because surgical skill for reconstructive genital surgery is considered more successful in the creation of female genitalia. It is, however, also possible that the criterion for functioning female anatomy is held to a lower standard than males, and that women's reproductive potential and appearance takes precedence over their sexual pleasure. For example, for females whose intersex conditions permit a capacity to bear children, the most salient criterion regarding sexual assignment is the preservation of reproductive functioning (Dreger, 1998) or what the AAP (2000) refers to as "fertility potential." As Donahoe, Powell and colleagues (1991, quoted in Fausto-Sterling, 2000, p. 57) said, "Genetic females should always be raised as females, preserving reproductive potential,

regardless of how severely the patients are virilized. In the genetic male, however, the gender of assignment is based on the infant's anatomy, predominately the size of the phallus."

Vaginoplasty, for example, is commonly performed while the child is an infant, because it is believed to improve functional outcome in an adult (Houk & Levitsky, 2004). However, women who have experienced vaginoplasty as infants and express satisfaction with the outcome, still suggest that these surgeries be postponed until adolescence or adulthood (Creighton, 2001; Wisniewski et al., 2000). Decisions about altering the infant's genitals rarely take into consideration issues of future sexual arousal or sexual functioning, as the more pressing concern is that the child appears "normal." Kessler (1998) refers to this as trading "function" for "appearance." It is assumed, and indeed takes on the quality of a cultural imperative, that women will want a vagina that is adequate for penile intercourse. Liao (2003) has suggested that for some intersex women the ability to engage in sexual intercourse (at least for heterosexual women) validates and reinforces the sense that they are "normal" women. Additionally, enlarged clitorises are "recessed," making them look more normal but impacting their erotic sensation (Creighton & Liao, 2004).

Males with small penis, even those with no discernible medical problems, are often surgically altered and assigned as female, sometimes following attempts to enlarge the penis through hormonal injections (Guthrie, Smith, & Graham, 1973), or more recently by innovative surgical techniques (Kwon, Yoo, & Atala, 2002). The decision to raise the boys as females is based on estimates of the eventual size of the adult penis, whether the boy would be able to urinate while standing and whether or not his penis could successfully be able to penetrate a woman. However, the medical assumption that living as a man with a small penis would result in psychological harm may be based more on cultural practice and "fashion rules" (Creighton & Liao, 2004), rather than evidence-based medicine (Hawbecker, 1999; Liao, 2003). Intersex genital surgeries are based on the idea that if the genitals have been physically normalized then psychological and sexual development will follow a typical path, an assumption that is far from proven (Creighton & Liao, 2004; Morland, 2005).

CONTROVERSIES SURROUNDING INTERSEX SURGERY

The current medical protocols have recently become the focus of great controversy and criticism by medical professionals (Creighton, 2001; Creighton, 2004; Daaboul & Frader, 2001; Diamond, 1996;

Diamond & Sigmundson, 1997a; Diamond & Sigmundson, 1997b; Kipnis & Diamond, 1998; Howe, 1999; Lewis, 2000; Melton, 2001; Reiner, 1997; Reiner, 1999; Scannell, 2001; Schober, 1999a; Schober, 1999b; Wilson & Reiner, 1999; van Seters & Slob, 1988; Zucker, 1996), bioethicists, social scientists, and legal advocates (Beh & Diamond, 2000; Ford, 2001; Kessler, 1998; Dreger, 1998), and individuals with intersex conditions who have undergone these medical procedures (Alexander, 1999; Caldera, 1999; Cameron, 1999; Coventry, 1999; Crouch, 1999; Devore, 1999; Groveman, 1999; Holmes, 1997/8; McClintock, 1997; Triea, 1999; Walcutt, 1995/6; Yronwode, 1999). Outspoken political advocacy groups including the Intersex Society of North America (ISNA) and the United Kingdom Intersex Association (UKIA), believe that no surgical alteration of newborn intersex children for cosmetic purposes alone should be done until the child is old enough to determine his or her own gender identity.

Some physicians are beginning to concur with this growing protest. In recent years, there have been many publications, including ones in prominent medical journals, suggesting that surgery and hormonal treatments should be performed only with the informed consent of the intersex person (Consortium on the Management of Disorders of Sex Development, 2006a; Kipnis & Diamond, 1998; Howe, 1999; Schober, 1999a; Schober, 1999b; Wilson & Reiner, 1999). Even those who adhere to the current medical protocols—and who express skepticism regarding the concerns raised by intersex activists—have acknowledged the concerns and responded to the challenge with a receptivity to review their medical treatments. For instance, Heino Meyer-Bahlburg, a member of the intersex treatment team from Columbia University's Presbyterian Hospital in New York City, has shown a willingness to examine current protocols (1999) and to advocate for “less surgery for ‘minor’ cases of genital abnormalities” (Laurent, 1995/6, p. 13), and Daaboul and Frader (2001) recommend a “middle way,” that honors parents preferences for or against surgery and advocates shared decision-making.

Activists argue that there are numerous reasons to revise the current protocols including the fact that reconstructive surgeries for infant genitalia have a high rate of complication, and there are very little data on the indications, long-term risks, or efficacy of these surgeries. Surgical complications can include: reduced post-surgical sensation, potential need for repeated surgeries and life-long hormonal treatments, and in some cases compromised sexual functioning and damaged fertility (Alizai et al., 1999; Barrett & Gonzales, 1980; Baskin et al., 1999; Chase, 1999a; Chase, 1999b; Creighton, 2004; Creighton, Minto, & Steele,

2001; Crouch, Minto, Liao, & Woodhouse, 2004; Dittmann, 1998; Kessler, 1998; Newman, Randolph, & Parson, 1992; Kipnis & Diamond, 1998; Schober, 1999a, Schober, 1999b; Wilson & Reiner, 1999). Although these surgeries have been performed for almost half a century, some consider them to be still experimental. There are claims that surgical techniques have improved functionality (Houk & Levitsky, 2004; Schnitzer & Donahoe, 2001); there is, however, to date, no conclusive evidence (Crouch, Minto, Liao, & Woodhouse, 2004; Creighton & Liao, 2004).

In all fairness, it must be noted that early assessment of children with ambiguous genitalia is necessary in order to detect the most common cause of ambiguous genitalia—congenital adrenal hyperplasia—which can be a life-threatening condition if not treated quickly following birth with the administration of glucocorticoid and mineralocorticoid (Houk & Levitsky, 2004). Additionally, some medical interventions purposely forestall surgeries, for example, giving testosterone injections with the hope it will enlarge the micophallus (Guthrie, Smith, & Graham, 1973). However, it is standard protocol to surgically reconstruct atypical genitalia, based on an assumption that this will assist in gender stability within the parameters of the assigned sex.

Chase¹ (1999b) offers three salient arguments against newborn genital surgery for non-life-threatening conditions. These include (1) damage to potential sexual function, (2) establishing that the baby is “not acceptable as he or she was born” (p. 453), and (3) the fact that some people are assigned incorrectly.

Sex assignment is not a foolproof process and numerous “failures” have been reported in the literature (Meyer-Bahlburg et al., 1996; Meyer-Bahlburg, 1999; Reiner, 1996; Phornphutkul, Fausto-Sterling, & Gruppuso, 2000; Wilson & Reiner, 1999). Preves (2003) noted that 24% of those she interviewed in her seminal contemporary research on intersex identity had reversed their gender assignment. Ironically, the index case that set the stage for John Money’s theory of infant psychosexual neutrality ultimately proved the difficulty of gender assignment based on anatomically correct genitalia, but only after a public expose and sensationalistic media attention (Colapinto, 2000; Diamond & Sigmundson, 1997a; Money, 1987; Money, Devore, & Norman, 1986). Thus, it is argued, that withholding surgery on newborns until later in life could not only decrease the rate of future sexual gender *reassignments*, but that those who were unsuccessfully assigned would not have to deal with the physical sequelae of earlier surgical procedures (Houk & Levitsky, 2004).

With these aspects mind, Kipnis and Diamond (1998, pp. 186-188) offer three recommendations regarding the treatment of those born with disorders of sex development:

1. That there be a general moratorium on such surgery when it is done without the consent of the patient . . . ;
2. That this moratorium not be lifted unless and until the medical profession completes comprehensive lookback studies and finds that the outcomes of past interventions have been positive . . . ;
3. [and] That efforts be made to undo the effects of past physician deception (pp. 186-188).

“Physician deception” refers to the current practice of withholding information from individuals born with disorders of sex development. Secrecy is often maintained from childhood into adulthood, and the true nature of their medical condition is hidden even from those living with intersex conditions (Chase, 1998; Preves, 2003). This practice is based on the same assumption which leads to surgical assignment of babies born with ambiguous genitalia: to eliminate the social problems thought to emanate from medical conditions or physical ambiguities by fixing and disappearing any anatomical or physiological difference. Therefore, if the fact and history of the intersex condition is successfully treated, it is “erased,” as if it never existed (Chase, 1999a). According to Morland (2005) “intersex medicine aims to make unfamiliar genitals instantly familiar, recognizable, not worthy of a second glance” (p. 336). What is ambiguous or unusual is made regular and therefore any potential problem associated with the condition or its surgical history is resolved and effectively eliminated, not requiring further discussion or disclosure.

Consequently the “condition is often shrouded in silence and lies” (Dreger, 1998, p. 190); parents are counseled to maintain secrecy, and are often poorly informed about their child’s medical condition, and therefore children with disorders of sex development are not only misinformed about their bodies, but do not have their parents advocacy when they seek knowledge and information (Liao & Boyle, 2004).

Please note: these medical policies were not developed out of malice, or a desire to cause harm. On the contrary, they were motivated by compassion for the families of children with intersex conditions as it was believed these protocols would eliminate psychosocial trauma (Howe, 1999; Wilson & Reiner, 1999). Nevertheless, the surgical treatments and the secrecy surrounding them may have actually amplified

difficulties they intended to solve. In some cases, rather than eliminating trauma, they may have unintentional, created it (Foley, Sallie, & Morley, 1992; Dreger, 1999; Kessler, 1998). As a result, the emerging questions surrounding the surgical treatments of intersexuality have generated a growing bioethical debate.

PSYCHOLOGICAL ISSUES AFFECTING THE FAMILIES OF THOSE WITH INTERSEX CONDITIONS

The numerous therapeutic issues facing people with intersex conditions, their parents, family members, and their partners have received little or no attention in the therapeutic literature. Meyer-Bahlburg (1994) outlines some of the prospective problems in gender development for those born with intersex conditions including: "body image problems associated with ambiguous genitalia or with the beginning development of gender-contrary secondary sex characteristics in puberty; questions about sexual orientation; [and] gender insecurity or doubts about correct gender assignment" (p. 22). In addition, surgery itself can create physical health problems, impaired infertility, physical scarring, cosmetic challenges, and decreased sexual response. Sequelae to surgery can invite other psychosocial difficulties including shame, sexual dysfunction, gender dysphoria, and the feeling of betrayal, and devaluation (Alderson, Madill, & Balen, 2004; Creighton & Liao, 2004; Chase, 1999a; Melles, 2000; Preves, 1999; Preves, 2003; Schober, 1999a).

Due to the silence surrounding intersexuality, children may be angry with their parents for withholding information; parents may be angry with physicians for not offering them alternatives; and parents also may feel guilty for unwittingly hurting their child or angry at the child for the burdens imposed by having a disorder involving sex development. Certain vaginoplasty surgeries require repeated dilation of the vaginal opening which is a painful procedure, commonly performed by the parent, presumably the mother. It is reasonable to imagine that both parent and child are affected to some extent by the need to repeat these dilations on a daily basis, further raising questions about the traumatic impact to the child's sexual development (Foley, Sallie, & Morley, 1992; Money & Lamacz, 1987). People with intersex conditions are mostly a hidden population, and receive "little psychological support" for either themselves or their families (Dreger, 1998, p. 190). Consequently, issues of trauma inherent for the families of children born with intersex conditions often go untreated.

Trauma related symptomatology can include insomnia, isolation, depression, high anxiety, dissociation, suicidal ideation, flashbacks, sexual dysfunction, sexual numbing, substance abuse, mood instability, self-mutilation, weight loss or gain, and work or school difficulties (APA, 2000). Herman (1992) has suggested that trauma survivors experience a “dialectic of trauma”—labile moods that alternate from expressively frozen to intensely dramatic emotionality, as the client relives their trauma and dissociates from it. “People who have survived atrocities often tell their stories in a highly emotional, contradictory, and fragmented manner which undermines their credibility . . . the story of the traumatic event surfaces not as a verbal narrative but as a symptom” (Herman, 1992, p. 1).

This traumatic symptomatology is evident in the stories of those who have been subjected to intersex surgeries during infancy and childhood.² Discomfort with sexual and gender issues on the part of a parent, repeated visits to doctors, hormonal treatments, and the general silencing of questions regarding medical history, physiology, sexual functioning, gender or sexual identity exploration may never coalesce into one coherent matrix, but may be seen as isolated and disconnected symptoms.

There are three areas where psychosocial support has been absent, or in some cases, misdirected. These include (1) parents of newborn babies with disorders of sex development; (2) children and adolescents with intersex conditions; and (3) adults who are beginning to recognize that they were born with intersex conditions and were surgically altered as children.

PARENTS OF NEWBORN BABIES WITH DISORDERS OF SEX DEVELOPMENT

For most parents, the birth of a child born with atypical sex anatomy or an intersex medical condition is a frightening event, and one for which they are ill prepared. Books for new parents that routinely address common medical conditions and pre- and post-natal complications, do not discuss disorders of sex development or intersex conditions. Sometimes health care professionals who specialize in obstetrics and genetic testing often do not have the knowledge to counsel parents when chromosomal anomalies are discovered during prenatal testing that reveal potential disorders of sex development. There are often no protocols for informing parents, and in some situations the professionals themselves were

misinformed about the impact of these conditions and therefore have offered misinformation to parents (Abramsky et al., 2000).

When a child is born with a visible intersex condition, medical experts usually remove the child from the mother for examination and sex assignment determination. Mothers are sometimes questioned regarding their prenatal behavior as medical experts try to figure out if the condition is congenital or due to chemical exposure, substance abuse, or physician prescribed medication. Although these medical questions may be necessary for evaluative purposes, they sometimes leave mothers feeling responsible and blamed for their child's condition. Parents are told that physicians need time to determine the accurate sex of the child. They are not told that the child's condition is outside of common sex categorization or that the physician is making an educated guess regarding sex assignment based on an unproven theory of gender identity and psychosocial adjustment.

The American Academy of Pediatrics (2000) now recommends that parents avoid naming the child or registering the birth until the sex is determined and that this should be accomplished quickly, within 2-3 days. The assignment of sex is usually followed by recommendations for genital surgery and parents are told that these surgeries are medically necessary. Parents have historically been left out of the full decision-making process, since it was believed that a successful outcome depended upon the parents' complete and total conviction that the gender of rearing was the child's proper sex identity: "the establishment of a child's psychosexual orientation begins not so much with the child as with his parents" (Hampson & Hampson, 1961, as quoted in Fausto-Sterling, 2000).

Following these protocols, there has generally been very little support, education, counseling, or therapy offered the parents, and parents are poorly educated regarding what it might mean to parent a child with an intersex condition, medically and psychologically. Certainly, whatever "pre-operative counseling" is provided is rarely sufficient to address the multiple issues that the family will surely face.

Parents have not always been able to refuse surgical treatments for their children without reprisal. Some professionals have suggested that for a parent to refuse genital surgery is akin to child abuse and have recommended using the legal system to force parents to surgically alter their children (Rossiter, 1998). At other times, children have been surgically altered despite their parents' explicit desire to resist the surgeries, raising ethical and legal problems (Lehrman, 1999).

Clinical guidelines are currently being developed that outline physician responsibility including parental involvement, careful attention to language, and respectful, gentle treatment of the infant (Consortium on the Management of Disorders of Sex Differentiation, 2006a). A family coping with the birth of an intersex child is facing complex issues, including: understanding the nature of the condition and the child's medical needs; making informed decisions regarding the surgical alteration of their child's genitalia; advocating for their needs with physicians, medical institutions, and health care insurers; explaining the nature of the child's condition to family, friends, and babysitters; physical and emotional care of the child's "different-looking" genitalia; understanding human sexual function as well as normative sexual diversity; grief, loss, and confusion over the birth of an "imperfect" child, and the need for emotional release and psychosocial support. The following clinical guidelines address each of the above areas; these protocols build on the work of Chase (1999b), Kipnis and Diamond (1998) and the Consortium on the Management of Disorders of Sex Differentiation (2006a).

- Protocols should be developed within gynecological and obstetric offices and departments to provide or refer clients for genetic and pre-natal testing for sex chromosomal related anomalies. Staff must be trained and competent about the existence of intersex conditions and able to convey potential outcomes in a non-judgmental manner.
- When a child is born with ambiguous genitalia, she or he should be examined to determine if there are any medical conditions needing immediate attention. The medical team should attend to any medical emergencies and delay any non life-threatening medical interventions.
- The child's birth should be celebrated as one would celebrate any other birth. The medical staff should emphasize positives and refer to the baby as a "whole" child, not just a set of genitals. Parents should be reminded that sexual ambiguity is a minor anomaly compared with many other congenital conditions. The child should not be needlessly isolated in the neonatal intensive care unit for the convenience of medical access to the child, or to spare the family from having visitors see their newborn child.
- The child's condition should be evaluated by a team of experts which should include medical specialists such as pediatric endocrinologists, urologists, and geneticists, as well as qualified mental health professionals who are trained in understanding both

family dynamics and issues related to sex and gender development. This could include a family therapist, social worker, or a child psychologist.

- The family should be an integral part of the entire treatment team process, receiving adequate attention, education, and time to understand complex medical issues.
- Based on the information available, and the best “educated guess” of the medical staff, and the agreement of the family, the child should be assigned a sex, with the understanding that genital anatomy and biological underpinnings are “signals,” not determiners of gender identity. All sex assignments should be assumed preliminary.
- The family should be sent home to bond with their newborn.
- Surgical alteration of the child’s genitalia should be avoided, except when there is definite medical need, and cosmetic surgeries should be avoided until the child is of age to consent and is capable of a realistic understanding of the possible risks and benefits of the surgery. The person with the intersex condition must have autonomy and desire to undergo any surgery. Parents must be allowed to refuse surgical treatments for their infant children, without fear of reprisal.
- When surgeries are performed, the family and child should be informed about potential problems with sexual sensation, less than perfect cosmetics, and the need for further or on-going treatments. It should be made clear to the family that surgery does not “cure” the intersex condition, although it can make the child appear more like others. Surgery may not alleviate any of the other psychosocial issues related to having an intersex condition.
- Through the process of therapeutic follow-up, families should be informed of the many choices available for treatment, including cosmetic surgeries. Parents should be encouraged to seek out additional information, speak with family and friends, and seek counseling before making any surgical decisions.
- Therapeutic support should continue to be available to the family, including offering medical information, education about sex and gender development, and assistance in making informed medical decisions. Linkages with other families and adults with intersex conditions should be encouraged.

Parents must be supported in expressing a full range of emotions regarding their child’s condition. Coping with the birth of an intersex child can be an emotionally devastating experience for some parents,

particularly in a culture that is silent on this topic and where sex, sexuality, and genitalia are not common topics of discussion. Parents are forced to think prematurely about their child as potentially sexual beings at a time when few parents are thinking of the later developmental stages of their child's life (Sutton & Whittaker, 1998). The family is entitled to have time to understand what they are facing, information to make educated decisions, and resources to develop a support network that can nurture them through the range of emotions they will experience.

THE ISSUES FACING CHILDREN AND ADOLESCENTS

The primary treatment strategy for the rearing of children with intersex conditions has been to "fix the problem" at birth and maintain gender congruent parenting. The hope is to eliminate later gender-related developmental difficulties, and to keep the history of the condition a carefully guarded secret. Consequently children with disorders of sex development often have little information regarding their medical conditions or surgical histories, although what they do not know looms large in their fears and imaginations. To be fair, most children and adolescents have little information regarding their bodies, their reproductive capabilities, and most of all their sexuality. However, for children who have been surgically altered or who have "different looking" genitals, who have experienced repeated scrutiny of their sexual organs by teams of doctors and who may need further corrective or cosmetic surgeries, this silence can have an untoward psychological impact.

Preves (1999) found that, "being encouraged to keep silent about their differences and surgical alterations only served to enforce feelings of isolation, stigma, and shame—the very feelings that such procedures are attempting to alleviate" (1999, pp. 55-56). Many intersex adults are now reflecting on their experiences and expressing anger at physicians for their surgical treatment as infants (Dittmann, 1998). One woman wrote to her medical doctor saying,

In my teens, when I first realized exactly what had been done to me, my reaction was that I must have been truly repulsive to my parents and doctors if the result of the surgery performed on me could be considered an improvement. The assurances of my therapist that my doctors considered my surgery to be a success only strengthened that conviction. (Joan W., 2001)

Children and adolescents are often examined by medical specialists who are checking on previous surgeries, or making plans for further surgeries, with little regard to how those who inhabit intersex bodies may feel (Creighton, Alderson, Brown, & Minto, 2002; Dreger, 2000). Body parts of intersex people are publicly examined in medical hospitals and photographed with eyes properly blocked out, furthering the sense of objectification and alienation; the process of being photographed is often experienced as invasive and abusive (Creighton, Alderson, Brown, & Minto, 2002; Money & Lamacz, 1987). Cheryl Chase says, "Surgeons are not trained to deal with patients who are upset. They are trained to 'fix' things. When people like me grow up and say, 'this hurt me,' they don't want to hear it, because they would have to see how they had hurt their patients, and they would have to admit their impotence in addressing this by surgery" (Yronwode, 1999, p. 21).

Parents have, of course, been counseled to maintain this secrecy regarding the child's condition and never reveal any ambivalence regarding their child's sex or gender ambiguities, or—they were warned—that they would severely harm their children's psychosexual health. The information offered to children is usually veiled, may contain outright misrepresentations, and parents have consequently appeared withdrawn, withholding of sexual information, cold, and resistant. Children whose questions produced feelings of discomfort or anxiety in parents (and doctors) have too often found that their questions were ignored or deflected, and they experienced unintended humiliation as a result (Liao & Boyle, 2004).

This secrecy and silence has a traumatic effect on children whose memories of their bodies and surgeries have been denied, whose questions about why they have had surgery or why doctors are examining their genitals is avoided, and who have often sometimes been the recipients of outright lies (Liao, 2003; Walcutt, 1995/6). Feelings of betrayal and humiliation often lead to highly negative feelings not only about their trusted relationship with their parents, but also towards helping professions, so that intersex adults may avoid medical care and resist seeking counseling. There is no evidence that secrecy regarding intersexuality is helpful to children or adults. However, research of adult men with micropenises showed that parents who fostered open communication and support within a framework of normalcy "produced more confident and well-adjusted boys" (Reilly & Woodhouse, 1989, p. 571). It was, however, not secrecy, but its opposite—open communication—that allowed for superior adjustment.

Families built on secrecy and shame are not healthy places to live in, even if the intentions are protective. Children and adolescents often act out hidden issues, even if they are unsure what the actual issues are. Adolescence can be “a powerful season in family relationships” and a “revelation of a long-standing secret *whose essence belongs to a child* will have reverberations across all family relationships” (Imber-Black, 1998, p. 259, emphasis added). Intersexuality is clearly a secret whose essence belongs to the child. Keeping secrets will not avert the problem, but make it go underground, straining familial relationships, as well as the very gender and sexuality related concerns that the secrecy was supposed to ameliorate (Lerner, 1994; Liao, 2003). Children who have intersex conditions, but do not have ambiguous genitalia, are often not recognized until puberty. If a child finds out later in life the truth about his or her body, medical conditions, or surgical histories he or she could feel so betrayed that it could cause a permanent rift in the parent-child relationship.

Children and adolescents who are born with ambiguous genitalia need assistance sorting through their feelings about their bodies, their sexuality, and their identity—as all children and teenagers do. Intersex children would especially need space to mourn and grieve their situation (Grovesman, 1999) in order to develop a sense of comfort in their bodies. This is especially true for adolescents who are beginning to date, exploring their bodies, developing sexual feelings, and reaching out to others to begin intimate relationships. Social and sexual development for intersex people may be delayed (and sometimes severely delayed or not occur at all). Intersex individuals may not begin to address issues of sexuality till they are in their late teens, or in early adulthood, and this developmental lag may isolate them from peers, and create an awkwardness regarding the awakening of sexuality and intimacy issues.

The taboo surrounding honest discussion with children and adolescents about their body can be traumatizing to children and can disrupt their normative emotional and sexual development as well as create and reinforce tension within the family system. In addition, as the child grows he or she may recognize that there is undue attention paid to his or her genitals, and that this attention causes parental stress. The child may also find that his or her questions (about medical status, history, scars, pain) are unwelcome and cause the parents to react with odd emotions.

Intersexuality, by its very nature, raises concerns about gender identification. Surgical sex assignment is performed with the hope of stabilizing gender identity. Although many children are comfortable in the sex they have been assigned (Bradley, Oliver, Chernick, & Zucker, 1998;

Meyer-Bahlburg, 1999), the research on children born with ambiguous genitalia reveals numerous cases where the gender assignment “failed” or where the child later chose a sex *reassignment*, as has been noted, (Dittmann, 1998; Meyer-Bahlburg et al., 1996; Phornphutkul, Fausto-Sterling, & Gruppuso, 2000; Reiner, 1996; Wilson & Reiner, 1999) including examples in John Money’s own research (Money, 1987; Money, Devore, & Norman, 1986). Some children and teenagers verbalize at a young age that they do not feel comfortable in their sex (Cohen-Kettenis & Pfäefflin, 2003) although they may not be aware of their history or medical condition. When the family is embedded in maintaining secrecy, the child who is experiencing gender dysphoria will likely be further shamed and silenced. If surgeries were postponed until the child was old enough to consent, and the nature of the medical conditions were allowable topics of conversation within the family, then the child who was wrongly assigned could more easily readjust and “change sex,” without the literal and psychological scars of sex reassignment. Although considering the possibility of sex reassignment may be overwhelming to a parent, the alternative is to ignore the possibility and make adjustment even more difficult (Lev, 2004).

Many narratives now reveal that some intersex children struggle with some gender related issues, whether the struggles are rooted in biology, or in socialization, or simply in coping with a sexually dimorphic cultural environment. Instability in gender identity is extremely uncomfortable for many people, especially parents, in part because issues of sexual orientation are thought to flow directly from assumptions about one’s gendered body. It is not only difficult to know “for sure” someone’s sex if they are technically a mix of both sexes, it is also difficult to determine the nature, direction, or meaning of sexual orientation. Is the child who was born with both male and female gonads, who is surgically assigned as a female, and who grows up to be a lesbian, really in an opposite sex relationship, or is she acting on a “heterosexual” desire as someone with an internal core male biology or identity? Parents often worry that intersex children will be “gay.” The current treatment protocols are determined precisely to control the direction of sexual desire in heterosexual direction (Holmes, 1995). Medical anxiety about homosexuality and intersex conditions is evidenced, for instance, in this quote: “Tell parents emphatically that their child will not grow up with abnormal sexual desires, for the layman gets hermaphroditism and homosexuality hopelessly confused” (Hill, 1977, p. 813). Surgeries and consistent gender rearing are meant to eliminate these concerns, but in reality they only reinforce stereotypes and make

the normative developmental processes more complicated for children and youth with disorders of sex development struggling with issues related to gender identity and sexual orientation (Consortium on the Management of Disorders of Sex Development, 2006b).

The following clinical guidelines address each of the above areas.

- Children with intersex conditions, including ambiguous or surgically altered genitalia, have a right to accurate information about their bodies and medical histories, as is appropriate for their age and level of development.
- Latency age children and adolescents should be informed of all medical decisions made about their bodies and empowered to determine the course of their own development. That includes the right to request, to defer, or to reject various sexual surgeries and hormonal treatments.
- Hormonal treatments should not be automatically started at puberty, but the child should be educated about their condition and be encouraged to make informed decisions about their medical treatment.
- Care should be taken in all medical examinations of a child's genitalia that they are not treated as a medical curiosity and the children should never be displayed in a teaching hospital without their explicit permission.
- As the child matures she or he may come to recognize the other sex as a more appropriate assignment, and the family, with psychotherapeutic support and the guidance of the treatment team, should be willing to allow the child his or her own self-definition.
- As the youth matures and develops, he or she should be given progressively more detailed and complex information regarding his or her medical conditions and potential treatments, bodies and developing sexuality, and should have access to informed therapeutic services to discuss sexuality issues that they may not want to discuss with their parents.

Sexual and gender identity development is a challenging process for all children and youth. For intersex people it is a particularly complex process, and one that has been the focus of more hypothesis than actual study. Children and youth need to be given permission to discuss their bodies, their sexuality, the gender identities, and their sexual desires as they develop, within a supportive, educated environment. Being "different" can be difficult for young people, and honest communication and accurate information ensure their healthiest adjustment to adulthood.

ADULTS LIVING WITH INTERSEXUALITY

As the issue of intersexuality becomes part of public discourse, an increasing number of intersex adults are beginning to recognize themselves in stories told on television, magazines and books. Adults who have wondered about their genitalia being “different,” or lived with the secrecy surrounding surgeries as children, are slowly beginning to talk with their physicians, or significant others, or perhaps their therapists, about these fears.

Adult intersex clients may have been carrying in secrecy the knowledge of being intersex, or in some cases they may be the last to know (Liao, 2003). Perhaps they wondered about secrecy in the family, or why their own sexual responses did not seem as full as descriptions they had heard or read about in others. There are those who are infertile and unable to find reasons why they could not conceive; or those whose genitals seemed different looking than others.³ Questioning whether you have been the unknowing recipient of genital surgery in infancy, or coming to discover at thirty or forty years old that you were surgically operated on as an infant can be disorienting, and in some cases traumatic. It is an area of clinical expertise that few clinicians are trained or prepared to address (Lev, 2004; Williams, 2002).

There are many ways in which clinicians can be helpful to adult clients with intersex conditions. First, clients will often need assistance tracking down records of their own genital surgeries or medical conditions. At times, these records may be closed to the patients themselves (Chase, 1998). Clients with intersex conditions will need to learn the medical language necessary to understand their condition and the purpose of the surgeries they underwent, so that they can converse intelligently with physicians. Clinicians may need an advocate within the medical system because some professionals still feel it is appropriate to withhold any information about intersex condition from clients. Those who are realizing that their genitalia are “different” or have been altered by surgical intervention will probably be dealing with issues of grief, loss, and anger. For many people this will involve feelings of anger at their parents, as well as the medical profession.

When intersex people begin dating, partnering or marrying, issues regarding their physical differences may need to be addressed; lovers and spouses will need to learn about their partners' bodies and sexuality. A partner may feel confused and betrayed by this information, and the intersex person may have to cope with fear of disclosure, issues of shame and self-hatred, as well as rage, at their partner's reaction

(Alderson, Madill, & Balen, 2004; Liao & Boyle, 2004). Liao (2003) notes the ambivalence intersex women often express “(w)ishing for, but not looking forward to ‘sex.’” She postulates that “It is as if vaginal intercourse accomplishes something important, but also represents high risk” (p. 233). Recent research (Alderson, Madill, & Balen, 2004) shows that women with AIS (Androgen Insensitivity Syndrome) have a fear of devaluation as women and a sense that their womanhood has been compromised; they also express communication challenges with their parents, partners and even friends.

In another study examining the physical and psychosexual satisfaction of adult women with complete AIS, the women stated overall satisfaction with their physical appearance and medical treatments, and saw themselves as highly feminine (Wisniewski et al., 2000).⁴ However, *64% stated that they did not fully understand their diagnosis as adults and still desired more information about their condition.* If women who express satisfaction and success with their sex assignment and surgical history still desire more information, could it not be even truer for those who experience dissatisfactions and unhappiness? Since this research was conducted specifically in response to critical outcry from surgically altered intersex adults, it raises questions about the ability to determine “satisfaction” if patients are unaware of their own medical condition. Another study (Minto, Liao, Conway, & Creighton, 2003) examining the sexual functioning of women with AIS found that nearly 90% of the women stated that they struggled with sexual difficulties, including communication problems in intimate relationships.

Helping individuals address these experiences is an understudied area of clinical concern. The following guidelines may be useful:

- Adults who are intersex should be allowed access to their medical records and advocates should assist them in this process.
- Intersex people should be offered therapeutic assistance to deal with trauma and stigma, particularly issues related to shame, deception, grief, and loss.
- Intersex individuals should be encouraged to develop empowerment skills to manage the ongoing issues related to their bodies.
- Intersex individuals should be offered accurate information about their physical condition, surgical history, as well as psycho-educational issues regarding trauma, sexuality, biology, and human diversity.

- Issues of sexual and gender identity should be addressed directly when necessary; it should not be assumed that all intersex clients will have issues with their sexual or gender identity.
- Therapy should be available to intersex individuals throughout the lifecycle, as different stages of development may reveal different struggles with body image, feeling “different,” or questions about intimacy and identity, including issues related to sex, gender, or sexual orientation.

THE NEED FOR THERAPEUTIC EXPERTISE

One area where both activists and medical professionals agree is that more psychosocial support is necessary, in the form of counseling or psychotherapy, for parents of children born with a disorder of sex development, and intersex children and adults throughout their lifespan (Minto, Liao, Conway, & Creighton, 2003; Yronwode, 1999). However, few guidelines are currently available to assist the therapist working with intersex children or their families. For instance, a PubMed search on “intersex and psychotherapy” in 2003 produced only two citations—one of which actually discusses transsexuality rather than intersexuality—and neither is a guide for therapists. In contrast, a search for “diabetes and psychotherapy” produces 420 citations.

Morland (2004) asks us to interrogate the role that traditional Freudian psychoanalytic thinking has played in the underlying philosophical perspective that guides the medical management of intersex treatment, by attempting to alleviate the presumed psychosexual problems in girls with enlarged phalluses, and boys with diminutive ones. Williams (2002) examines the few articles on intersexuality available in the psychoanalytic literature, concluding that analysts have been overly focused on discovering the “true sex” of the patient, instead of the shame and stigma of discovering and living in a body that has been surgically altered. An important exception to this is Liao’s (2003) outline of therapeutic techniques based in feminist and psycho-educational perspectives.

Meyer-Bahlburg (1994) writes, “In most cases, the psychosocial issues of intersex patients are managed, *if at all*, by the physicians who provide the medical care” (p. 22, emphasis added). While pediatric endocrinologists and surgeons have received extensive medical training, they have rarely been trained in counseling skills. Parents often turn to these professionals seeking therapeutic assistance (Grovesman, 2001),

but as Schober (1999a) suggests, “the role of counselor should not be left to an endocrinologist, urologist, geneticist, or surgeon, nor a genetic counselor” (p. 47). Curran and Chase (2001) surveyed fifty pediatric endocrine fellowship programs in the United States and Canada and received responses from twenty-seven. Sixteen said they have a mental health worker available but of these only five offered counseling following the initial diagnosis. Eleven said they would offer referrals for adults who are intersex but only four could offer actual names of actual referral sources and many commented that they were unable to find qualified mental health professionals.

ISNA identifies the difficulty with the current medical protocols: “Non-psychiatrically trained physicians should no more practice psychotherapy than psychiatrists or non-medically trained psychotherapists should perform surgery or prescribe hormones” (ISNA, 1994, p. 2). Even physicians supportive of mental health services may privilege the role of physicians. Wilson and Reiner (1999) propose a progressive treatment paradigm that includes the parents as part of the team, in addition to a child psychiatrist, noting their specialized training in working with children with medical problems. They claim child psychologists and social workers usually lack this expertise although social workers are the prime providers of services to families and children (U.S. Department of Labor, 2000/1). Many psychologists, marriage and family therapists, and social workers are trained in medical and psychiatric conditions and work in hospital settings with children facing chronic and acute health problems as well as child development settings.

Some medical experts do see the value of therapeutic intervention and education (Reilly & Woodhouse, 1989; Wilson & Reiner, 1999). Lightfoot-Klein et al. (2000) suggest, “with some specialized training, mental health professions would be well-equipped to address the emotional distress of the parents and the child as he or she grows up (p. 458). Schober makes an important point: “Surgery makes parents and doctors more comfortable, but counseling makes people comfortable too, and [it] is not irreversible” (1998a, p. 547).

Currently few psychotherapists are trained in working with intersex clients or their families, and skill development in this area should become a focus of clinical training programs. Therapeutic treatment paradigms can, indeed must, be developed that will place psychotherapists, family therapists, and medical social workers securely on interdisciplinary treatment teams. Therapeutic evaluation, education, and psychological support should not be an afterthought to medical services, but at the center of clinical and medical decisions regarding the pre-natal, birth, neo-natal, and child-rear-

ing needs of children born with disorders of sex development. It would be helpful if trained mental health professionals were on medical boards where decisions regarding the protocols for intersex children are currently made.

CONCLUSIONS

The birth of an infant born with a disorder of sex development, in most cases, does not need to be treated as a medical and psychosocial emergency. It is important to note that in the majority of cases, surgery is not a medical necessity, but is done for aesthetic reasons (Kessler, 1998), and because it is believed that the more "normal" looking the child's genitals are, the more secure the gender assignment will be. All professionals agree that newborn infants with intersex conditions need to be thoroughly evaluated for life-threatening health problems, and that in some cases surgeries are necessary for medical reasons. Gender assignment is not, however, a medical emergency, nor does it require immediate surgical attention.

Advocates for change in medical protocol are not suggesting that intersex children be reared without a sex assignment. Medical experts, based on accumulated historical evidence and experience, with the educated support of the parents, should assign a sex, and the child should be reared unequivocally within that sex/gender assignment. However, children should not be surgically altered until they are old enough to understand and be involved with medical decisions regarding their bodies. Surgeries, assuming there is no need for medical expediency, could be postponed until puberty when the family is able to make an informed and carefully considered decision about what would best serve their child, with the child's knowledge about his or her own developing sexual and gender identity.

Surgical attempts to "fix" what is not broken and to "correct" what is not damaged by identifying what is intact as "deformed" (Kessler, 1997/8, p. 34) so that infant bodies appear "normal" even if they are no longer functioning is surely a medical protocol begging for revision. The question remains whether genital surgeries actually succeed in either making the child look more "normal" or even feel more "normal." There is no research evidence indicating that parents will accept their children more easily if they are surgically altered. Furthermore, it is also not clear that surgically-altered genitalia actually look "normal." For example, "Parenting a female with clitoral insensitivity and vaginal complications

is seen as preferable to parenting a female with a larger-than-typical clitoris and smaller-than-typical vagina. Parenting a male with a scarred and insensitive penis is seen as preferable to parenting a male with a normally functioning (but small) one” (Kessler, 1998, p. 76). In a similar vein, Dreger wonders, “are the genitals shaped by the scalpel necessarily less traumatic than those shaped by the womb?” (1997, p. 21). Whether or not the child has had surgery, issues regarding the physical look of their genitalia, as well as other psychosocial concerns, need to be addressed by the parents, and cannot be circumvented by medical experts.

As the surgical profession reviews its protocols—methodically, cautiously, and gradually (Creighton & Liao, 2004) and as parents and medical staff become increasingly educated about intersexuality, it is likely that more children will be spared actual surgical alteration at birth. However, they will not be spared the stigma associated with having a disorder of sex development or the psychosocial sequelae of intersexuality with their families or in adult intimate relationships. Discontinuing surgeries will not assuage all the issues of stigma and shame, as well as questions related to sexual and gender identity acquisition faced by those born with intersex conditions. It is time to begin to listen to the narratives of those who are born with disorders of sex development.

Interdisciplinary treatment teams must include social workers and other mental health experts to serve as advocates, educators, psychotherapists and family systems experts, addressing ongoing issues in the lives of families and children living with intersex conditions. Being intersex within a social system that is gender polarized is an ongoing life experience—one that must be integrated and incorporated into the whole of a person’s life.

NOTES

1. Cheryl Chase is the Founder and Executive Director of The Intersex Society of North America (ISNA), a peer support, education, and advocacy group founded in 1994. ISNA has over 1,500 members and is at the forefront of the organizing and advocacy work dedicated to assisting physicians to reexamine their position on genital surgery for infants born with disorders of sex development. ISNA works to reduce the stigma of intersexuality and offer advocacy and support for intersex adults.

2. It is also likely to be found in the stories of those who are intersex but have been spared medical interventions. Those with intersex conditions who have not been subject to repeated medical examination may attribute their psychological distress to their intersex condition itself. Indeed, they may be in denial about their condition, or even reject the term intersex to describe their condition. Consequently, therapists

may not be aware that the client has an intersex condition because the client does not label it that way.

3. As women's health advocates have always noted, women often worry whether their genitals look "normal," and manhood has often been measured by the size of a man's phallus. It is important that the raising of these questions on a social level does not increase the body perfectionism that is already a socially prevalent fixation. Perhaps physicians and mental health experts have been too quick to dismiss clients' concerns over "odd-looking genitalia," or questions about surgeries, and need to pay more attention to the difficulty clients have in even raising these issues.

4. These women were not born with ambiguous genitalia so it is not clear if this research is indicative of how other intersex women might feel.

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