

Commentary

Let's Have Informed Consent While Awaiting Research Results

Joy Diane Shaffer, M.D., is a graduate of CalTech and Stanford Medical School, and Diplomate of the American Board of Internal Medicine. Dr. Shaffer, who has a private practice in San Jose, has been active in California's sexual minority communities since 1978.

Dr. Sandberg has written wisely and well, and I find very little with which to take issue. I agree that the presence of substantial surgical and psychological morbidity (unhealthy outcomes such as pain, depression or suicide, social or sexual dysfunction) in many adults who received genital surgery as intersexed children calls for a prospective cohort study of operative and non-operative management of intersexed children. (In a such a study, researchers would investigate a group of similar intersexed newborns, performing surgery on some, and not on others, and following them throughout their lives.)

Unfortunately, this would have to be non-random by design, as many parents would insist on operative treatment for *their* child ("I ain't gonna raise no freak-show morphodite!") Such parents would be willing to travel to multiple medical centers to obtain operative treatment of their children. This would result in a selection effect where the parents who are the most comfortable with their intersex children would be more likely to consent to participation in the non-operative arm of the study. Definitive outcome results may not be available for 50 years.

In the present day, I think a good first step would be for pediatric surgeons to be required to provide true informed consent to parents of intersexed children. This consent would include the disclaimer is that there is *no evidence whatsoever* that intersexed children benefit from childhood genital surgery. Furthermore, there is *no evidence whatsoever* that deferral or refusal of genital surgery on intersexed children causes more psychological trauma than early surgery. Parents should also be routinely informed that many intersexed adults

who received childhood genital surgery consider themselves to have been *harmed* by the procedure, and are frequently *estranged from their parents* as a result.

Telling these simple truths to parents could result in enough parents declining genital surgery for their children to facilitate obtaining long term follow-up data on non-operative as well as operative management of intersexed children. There is nothing to fear except the discovery of the truth. ■

Counterpoint

Endless Calls for "More Research" as Harmful Interventions Continue

Howard Devore, Ph. D. is a licensed psychologist, certified by the American Board of Sexology as a sex therapist, and is a Life Clinical Fellow of the American Academy of Clinical Sexologists. Dr. Devore has extensive experience working with intersexed children, adults, and their parents. We are proud to have Dr. Devore as a member of ISNA's Board of Directors.

I was saddened and disappointed by Dr. Sandberg's article. During my post-doctoral affiliation in John Money's Psychohormonal Research Unit, and in my years of private psychotherapy practice, I have seen first hand the harm inflicted on intersexed children and their families by current medical practice, and the unreli-

ability of research conducted *in the setting where the harm was done*. Dr. Sandberg's wish to "do better" for his intersexed patients is obstructed by several of his beliefs.

First, he seems to believe that useful information can be obtained only by formal, academic research, and dismisses the adult intersexual voices now made public by ISNA. Certainly ISNA is a self-selected population, but it is also a rare and therefore highly important one. What is said in the atmosphere of a mutual support group is likely to be much more accurate than the testimony of a child in a clinic setting, with parents and staff carefully attending to his or her responses.

Second, he dismisses the surgical harm attested to by adult intersexuals as a product of outmoded surgical technique. Instead of seriously considering the value of ISNA's position, he implies that surgery is probably now much improved, and calls for "more research." This shopworn excuse has been used to justify continuing harmful treatment of intersexed children ever since surgical treatment was introduced, many decades ago. ■

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Counterpoint

Time to Re-examine Old Treatment Paradigms

Anne Fausto-Sterling is Professor of Medical Science at Brown University. Her first book was *Myths of Gender: Biological Theories about Women and Men* (Basic: 1992). Her second, still in the making, is about biology and the social construction of sexuality and will have two chapters on intersexuality.

Kudos to ISNA, *Hermaphrodites with Attitude*, and Dr. David Sandberg for initiating discussion and debate on the question of childhood surgical intervention in intersexed births.

Dr. Sandberg suggests that ISNA have as its goal research into the question of whether patients would be better off postponing potential surgery until they can decide for themselves. Such research should, as well, or even primarily, be a goal for the medical research community.

Now that ISNA members are questioning what had never before been questioned, it seems to me that medical researchers and practitioners in the field need to re-examine their assumptions and paradigms. Answers to how best to design research studies, and which sort are actually practical, ought to result from active discussion between medical practitioners and ISNA members.

One thing which emerges clearly from my own survey of the medical literature is that short term studies are relevant only to the question of the immediate physical success of a procedure (i.e., were there infections, fistulas, scarring, a need for a second operation, etc.)

Those studies which assess the long-term effects of surgery refer almost uniquely to vaginoplasty. Here some fairly large investigations suggest that success is quite limited, if one means by success, achieving regular, heterosexual sex involving vaginal penetration.

Even with vaginoplasty, however, the possibilities of other forms of sexual

expression (e.g. oral sex—either hetero- or homosexual) have never been studied. A good long-term study must break with the heterosexual, penetration paradigm of “normal” sexuality and look instead at a variety of sexual practices, both heterosexual and homosexual.

I think it might be useful, as Dr. Sandberg suggests, for ISNA to begin to develop training programs for counseling and “management” of intersexuality. What seems clear from the clinical literature, interviews with surgeons (conducted by students of mine), and the anecdotal evidence from newsletters such as ISNA’s *Hermaphrodites with Attitude*, and A^LI^AS, the newsletter of the British AIS Support Network, is that proper counseling for child and family virtually never occurs.

There is a great deal of lip service in the medical literature saying how important counseling is, but in truth our medical system is not set up to deliver counseling in any consistent, long-term fashion.

ISNA could help here by offering guidelines, but again there is a big burden on case management teams to give counseling the highest priority, while making early surgery (when not needed for physical health reasons) a rare event.

The argument is always that the surgery makes the parents more comfortable. But counseling can do that too, and it is not irreversible in quite the same way as surgery. The question is: Do we use surgery to make parents more comfortable in the short run in the (often mistaken) belief that this will improve the psychological outcome for the intersexed child? Even though it may mean severe impairment of sexual function in adulthood?

I look forward to further debates and discussions. I am excited that some members of the medical community have begun to respond seriously to ISNA. I hope that the conversations will spread until there is a nationwide re-evaluation of treatment practices for intersexuals. ■

Possible Meanings of Genital Variability

1. Your genitals signify neither of the two gender categories. We need to know what gender you are, therefore we must do further testing.
2. We know your gender. Your genitals signify the wrong gender. We must operate to make them conform to the right gender.
3. We know your gender. Your genitals, although not within the normal range for your gender now, will be in the future. We expect they will clarify on their own.
4. Your genitals are providing a clue that there is an underlying medical problem that needs to be addressed. We prescribe a non-surgical treatment.
5. Your genitals are inferior (less functional, ugly). We pity you and suggest cosmetic/corrective surgery.
6. Your genitals are superior (more versatile, attractive). We envy yours and want ones like them.
7. Your genitals are just another body part that varies from person to person, like noses and ears, and it doesn’t matter what they look like as long as they function well. We don’t think very much about your genitals, or our own.
8. Your genitals signify something about your parents. They have misbehaved or are genetically unsuitable. They are embarrassed by you and your genitals.

From “Meanings of Genital Variability,” presented by Suzanne Kessler at the 1995 Annual Convention of the Society for the Scientific Study of Sexuality.

Commentary

Medical Science—or Swinging Pendulum of Fashion?

Sherwin B. Nuland, a clinical professor of surgery at the Yale School of Medicine, is the author of "How We Die: Reflections on Life's Final Chapter."

Better watch out or the pendulum of medical dogma will bash your head in. It swings back and forth far more often than people realize, and with far more velocity.

The recent report that testosterone's role in male aggression may be quite the opposite of what has long been thought is only the most recent example of physicians' tendency to flip-flop dramatically, and with great confidence.

Thirty years ago, patients with diverticulitis, an inflammation of small outpouchings of the colon, were routinely treated with a diet low in roughage.

There was no uncertainty about this course of action because decades of experience *and clinical studies* had verified its value. And yet, only a few years later medical opinion reversed: Decreased roughage was found to be not a panacea but a cause of the disease.

This new medical discovery was announced with the same assuredness and supported by just as much evidence as had been used for precisely the opposite viewpoint.

Such pendulum swings suggest that medical science is much more of an art than anyone wants to admit. And one can pull many more examples from the history of medicine.

The lead article in the June issue of the *New England Journal of Medicine* describes the increased risk for breast cancer in postmenopausal women who are given hormone replacement therapy. This is well within the memory of the teaching that hormone treatment does not affect the likelihood of cancer at all.

The data that supported the old opinion seemed just as unequivocal as today's contradicting data.

Leeches, a staple of the therapeutic arsenal for more than 2,000 years, began to disappear from American pharmacy shelves after the mid-19th century French physician Pierre Louis used statistical methods to show that there is no benefit to removing blood from a patient's body.

Now the little worms are back in style, albeit locally, to decrease congestion during certain kinds of reconstructive surgery.

The advent of antiseptics and modern obstetrics near the turn of the 20th century demanded perineal shaving, absolute sterility and a surgical aura for childbirth, until it was shown that such precautions were unnecessary. Today's hospitals strive to create the same atmosphere that was present during home delivery a century ago.

And what about breast cancer? Until late in the 19th century, attempts to cure it were almost always futile. Most physicians, in fact, had never seen a patient survive more than a few years after an operation.

And so a mood of what historians call "therapeutic nihilism" prevailed; many afflicted women thought it useless or even harmful to seek medical help, and their physicians agreed.

And then, along came Dr. William Halsted in the mid-1880s to point out that the real problem was surgical timidity. If operations were extensive enough, he argued, many women would be saved.

Halsted's introduction of the radical mastectomy resulted in a cure rate so impressive that it became the gold standard against which all other forms of treatment were measured.

For decades, very few doctors questioned the wisdom of mastectomies,
continued next page



regardless of stage of the cancer or individual variation in the malignancy.

But radical mastectomy became a victim of its own success. Recognizing that cures were possible, patients began to seek help earlier in the course of disease.

For these women, less radical operations were eventually shown to be just as effective.

The drastic shifts in breast cancer treatment, from nihilism to radicalism and then back toward minimalism are due to several factors: new knowledge, earlier diagnosis and a changed cultural perspective on what patients find acceptable.

All of these are easily explainable to the general public. What is more difficult for most people, though, to accept is that medical care is often based on much less solid scientific evidence than has been assumed.

Unlike other areas in which fads come and go, medical styles are meant to be supported by irrefutable evidence. That assumption is so far off the mark that "medical science" is practically an oxymoron.

Dr. David Eddy of the Jackson Hole Group has estimated that no more than 15 percent of medical interventions are supported by reliable scientific evidence.

When the new testosterone findings were reported in the *New York Times* in June, Dr. William J. Bremner of the University of Washington was quoted on the vagaries of hormone research.

"It's more of an art form than a science form," he said. His comment is applicable to virtually all medical practice.

Clinical theory and decision-making are a mix of science, experience, contemporary culture, authoritarianism, personal bias and even emotion. Each time a factor changes, the stage is set for one pendulum or another to begin its journey to the other side.

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Counterpoint

Is it Ethical to Perform Essentially Cosmetic Surgery on Infants—Who Cannot Consent?

Morgan Holmes wrote her Master's thesis, "Intersexuality Beyond Pathology and Erasure," at Toronto's York University. She is currently pursuing a doctoral degree in interdisciplinary studies, combining medical anthropology, bioethics, and political science. See the Winter 94 issue for an account of Morgan's normalizing but destructive clitoral "recession."

Dr. Sandberg seems to worry that even if ISNA members are representative, and many patients do feel harmed by the treatment, surgery might nonetheless be necessary to solve parents' discomfort about their genitally atypical children.

"If the parents see their child as a freak, the prognosis is poor. Some parents...would not accept the child whose genital appearance was not normalized." Thus Dr. Sandberg justifies the surgical removal of erotogenic tissue from children, and evades the issue of what the medical establishment and the parents really fear: a child who cannot be stamped as "straight."

After all, it seems obvious that in other cases which are of a primarily cosmetic nature, parents must learn to accept their atypical children. Yes, cleft palettes must be fixed so that a child can eat, but we have entered an age when parents no longer pin back their children's large ears; and a child who demands a nose job is usually told, "Wait until you have finished growing dear, and then see how you feel about your nose."

My question is this: If it's my nose, *why aren't they my genitals?* Intersexuality is essentially a cosmetic difference. Why, then, are minors denied the right to consent or refuse treatment? Why aren't the parents told to allow the child to grow up, to "wait and see?" Why is all the potential for choice erased in infancy?

If parents were actually informed about what these cosmetic procedures entail, would they be less inclined to grant per-

mission? Why is it that in this era of informed consent, no one protests when medical textbooks advise physicians to dissemble to parents about intersex diagnoses and "corrective" surgical procedures?

This question requires us to take a closer look at the meaning of "informed" consent. Currently intersex specialists simply assert that the child is ill, that surgery can cure the child, that the child's mental health will be at great risk without surgery, and that surgery presents no risk of harm. Parents assent, and the child is scheduled for the same genital surgery which many adult patients characterize as sexual mutilation.

Does the intersex specialist lie to the parents? From my point of view, yes. But from the physician's and parents' point of view, no. They actually believe—a convenient belief—that it is the health of the child that they are protecting. And as to the damage? Recently, I attempted to dissuade an acquaintance from permitting a clitoroplasty to be performed on her months-old infant. She responded, "Well, the clitoris isn't important to many women, so why should it matter? They'll just fix her little problem and be done with it." I wish I had proxy over her clit.

What I wish for most is that all cases of a primarily cosmetic nature be left alone until the minor has reached an age at which s/he can articulate his or her desires. I am not saying that surgery should never happen, but the prognosis at a purely physical level is much better if the body has already finished growing. And I would be inclined to argue that, illusory or not, the ability to choose for oneself favorably affects the results. ■

Counterpoint

Physicians: Intersexual Adults Have Much to Teach You

Laura L. Post, M.D., is board-certified in Psychiatry/Neurology, in Sexology, and as a Forensic Examiner. During her medical education at State University of New York at Buffalo, she spent one senior elective rotation in Pediatric Endocrinology working with pediatricians and other staff at Buffalo Children's Hospital.

I read Dr. Sandberg's article with interest, because during my medical education, in 1987, I worked a Pediatric Endocrinology rotation at the institution with which he is now affiliated.

Though I disagree with Dr. Sandberg's seeming laissez-faire attitude regarding treatment policy for intersexed children, I choose to describe my own experience, from another point of view, rather than discuss his argument point by point.

As a medical student, I assisted in consultations with intersexed neonates, toddlers, infants, and peri-adolescents and their families. Though the physical appearances of my patients were initially shocking to me—not having been taught anywhere in medical school about the realities of hermaphroditic presentations—it was more shocking how poor were the resources from which we drew in making decisions about surgery and psychotherapy for our patients.

If we had access to ISNA's literature, some of the decisions we made would have felt morally more appropriate, and might have been better for the patients and their families.

If we had been able to speak with people who had made their own decisions about intersex situations, if our patients and their families had been able to speak with adults who had lived through intersex childhoods and adolescences, then there would have been more information at the disposal of the team who had to make crucial medical decisions, with their broad psychosocial ramifications.

I agree with Dr. Sandberg that outcome research is needed for the different solu-

tions possible for intersex situations, but I believe that the knowledge and experience proffered by intersex adults and formerly intersex adults* is valuable. I also believe that more public speaking and writing about intersex will, gradually but

*According to Dr. Post, professionals at Buffalo Children's Hospital use the term "formerly intersex adults" to refer to adults who have had a "decisive medical intervention." Many ISNA members doubt that such a creature exists, except in the minds of pediatric endocrinologists and genital surgeons!

Counterpoint

Lucky to Have Escaped Genital Surgery

Eli Nevada, a legal female, has recently completed an undergraduate degree in Biology and plans to attend medical school in the Fall of 1997, with the intention to specialize in Endocrinology.

As an intersexual who has been fortunate enough to escape surgery, I must voice my opposition to Dr. Sandberg's views. I cannot see how my life would have been improved in the least by genital surgery.

And why should they be changed? Is genital surgery performed merely so that intersexed children will "fit in" with what is considered normal in this society? And how could what is essentially damaging cosmetic surgery on a child who is too young to give consent be considered therapeutic or even ethical? Why should anyone besides me have such final and irreversible say over my body? I enjoy my genitals just the way they are, and so does my bisexual lesbian partner.

Sandberg says that parents may not accept a child whose genital appearance was not "normal," and that ISNA is unrealistic to expect otherwise.

It was not long ago that babies with any kind of birth defect were considered to be touched by the devil and were subject to infanticide. Today we consider this to be a barbaric practice driven by ignorance and superstition.

inevitably, erode the sex-phobic, difference-intolerant climate that is the heritage of Western civilization.

ISNA and *Hermaphrodites with Attitude* are an important impetus to that forward evolution. Thank you for this opportunity; keep up the good work. I look forward to reading and learning more about intersex and to future dialog about these issues. ■

As long as there is no pain and the person is able to void urine without any problems, there is nothing pathological about intersex genitals. I wonder what he says to the parents of children born with *real* medical problems. If a child is born with flippers instead of hands we do not counsel the amputation of the offending appendages.

By Dr. Sandberg's logic, if a parent cannot accept a child who is different in a very minor and personal way, then it would be impossible for a parent to accept a disabled child, since their children would be visibly and constantly very different from their peers in every aspect of daily life. Should these children be euthanized to save their parents from social embarrassment?

Acceptance begins when the medical staff does not treat a child like a freak or a disease to be cured. Parents can be counseled regarding the medical options their children can choose when they reach the age of consent. This way the child's body can finish growing without the hindrance of scar tissue, and the child can explore who s/he is and how s/he functions sexually. Then they can have the option to change things, if they wish, with their full understanding and consent. This is not a "dogma" for or against any treatment plan. This is the rational, ethical approach to this situation. Anything else would be barbaric. ■

Counterpoint

Clinicians: Look to Intersexual Adults for Guidance

David is a health care professional, an adult intersexual, and a frequent and thoughtful contributor to HWA.

First, I would like to thank Dr. Sandberg for initiating this dialog with ISNA. I am heartened by his acknowledgment that families need counseling at all stages in their intersexed child's development, and that the child needs age-appropriate information with the goal of full disclosure.

That said, I am deeply troubled by much of what Dr. Sandberg has written. First, I get the strong impression from his writing that he thinks of surgery as a neutral experience.

My experience as a health care professional in a teaching hospital for the last 17 years, and my personal experience of surgery for intersexuality, have taught me that surgery is always a traumatic event. Surgeons, however, paint a picture of nearly any proposed surgery as routine, low risk, highly successful, and only mildly uncomfortable. This picture is accurate—if we consider only the surgeon's involvement. I don't believe that they give serious consideration to the emotional impact on patients of what they do.

Dr. Sandberg also seems to believe that there are many adults who feel that they were more helped than harmed by treatment for intersexuality. I say, where are they? Why is it impossible to get their stories? Why is the subject of intersex still taboo? Why don't they share their experiences with us, tell us how they escaped becoming as badly damaged and isolated as the rest of us?

I desperately want to hear such stories. I feel ashamed that I have healed so poorly when "all those others" have done so well. Why is it that I cannot find information on these well-adjusted adults?

In the absence of believable reports of positive outcomes, I am compelled to trust my own experience and the stories

I believe our stories are accurate and representative, not exceptional.

of the *only other* intersexed adults I have ever been able to locate. Our stories all have remarkably similar themes. How on earth did we all come up with such similar stories, living in absolute isolation? I believe it is because our stories are accurate and representative, not exceptional.

Dr. Sandberg says that it is crucial that parents accept their intersexed child, not view the child as a freak. But how is it possible for parents to accept the child just as s/he is, when the entire medical system is geared toward changing the child to look like everyone else? I do not believe that gender is only skin-deep, that it can be "normalized" by surgery.

Are you naive enough, Dr. Sandberg, to believe that parents who would reject their own child can be coaxed into genuine acceptance by cosmetic surgery?

The program for treating intersexed children is actually geared toward the parents, not the child. When the child grows to adulthood, and is no longer the parents' child and charge, s/he is invariably "lost to follow-up." The problem disappears—for family and medical professionals—but we are left alone in our agony, isolated from peers and any emotional support, left to contemplate, alone, "what is wrong with me."

"One might wish the world to be different, but that's the way it is," says Dr. Sandberg. I was born intersexed, and my parents were horrified and ashamed. I was "treated" and lied to, and I was made to feel like a freak and a monster *anyway*. And *that's* the way it is, Dr. Sandberg.

I find myself living in a world full of social prejudices of many types, and that is also the way it is. And I find myself in a world of honest and caring and accept-

ing people who respect me for who I am, and for my integrity as an intersexed person, and that's just as real as the prejudice I encounter daily. (In the teaching hospital where I work, I see so much cruelty toward difference that I am afraid to be "out" as an intersexual there.)

Dr. Sandberg says that for the time being, the only thing a clinician can do is to listen carefully to the thoughts and feelings of each family who comes for help. I disagree. There is more you can do. You must listen carefully to the thoughts and feelings of intersexed children in your charge before you allow them to be surgically changed forever. Are your patients too young to articulate their hopes and fears? Then you must listen to those of us who are what s/he will one day become: an intersexed adult (though perhaps presenting, even identifying largely as male or female), interventions notwithstanding.

Surgery is not at the top of my personal list of grievances; that place is reserved for the cruelty of silence and the restriction of choice. I want to see parents and clinicians have as much information as possible, especially the stories and feelings of intersexed adults, as they make decisions about the care of intersexed infants and children.

It is the feelings and needs of the patient which must be given the greatest consideration, for it is s/he who will have to live with the results of these decisions long after parents and doctors are dead.

In closing, I do hope that Dr. Sandberg will maintain contact with ISNA and be an advocate for those of us who, until now, have had no voice. ■

Guest Commentary

A Call for Clinical Research

Dr. David Sandberg, a psychologist at Buffalo Children's Hospital's Psychoendocrinology program, shares his responses to ISNA's literature. This special issue contains a variety of responses to Dr. Sandberg from ISNA members and friends.

David Sandberg is a psychologist in the Psychoendocrinology Program at Buffalo Children's Hospital, where he works closely with endocrinologists who are occasionally faced with clinical management decisions regarding intersexed children. We asked Dr. Sandberg to comment on ISNA's educational literature.

Surgery—helpful or harmful?

The ISNA pamphlet *Recommendations for Treatment: Intersex infants and children* advocates “avoidance of harmful or unnecessary surgery.” Of course, no one can argue with that. But how does one know, in advance, whether the surgery will be harmful? As to the question of it being “unnecessary,” that is an empirical question; will the individual do better with or without surgery?

To determine if genital surgery is helpful or harmful for infants born with genital defects, one would want to study the behavioral, emotional, and sexual functioning of individuals who had received early surgery, and compare that cohort with a group of children with comparable defects who had not been operated on. In the absence of such data the debate proceeds without objective information.

Urologists will undoubtedly make the claim that their patients are better off with surgery; ISNA members challenge that claim. Urologists will in turn respond by saying that the members of ISNA who report more harm than benefit from surgery are unrepresentative of the patient population as a whole. The only way to enlighten such discussions is to conduct research. There is currently very little research that is helpful in this context. Shouldn't this be a goal for ISNA?

Mental health care surely important

The pamphlet strongly recommends “qualified mental health care” for intersex patients and their families. Once again, no one would argue with this.

At the Psychoendocrinology Program at Children's Hospital of Buffalo, I am asked to consult in such cases. I am very well aware how important it is to assemble an appropriate team of professionals to provide optimal clinical management of these highly complex cases.

Long-term follow-up data not available

I am familiar with the model deriving from Hopkins and John Money. I don't want to debate the pros and cons of various approaches here. I would suggest, however, that there is very little data to support either Money's or ISNA's approach. We are unfortunately all flying by the seats of our pants, clinically. Our patients deserve better.

But until we have data from long-term follow-up studies, we are forced to rely on clinical anecdotes, whether from our own practice or others. Perhaps ISNA could advocate for the availability of such services, help to formulate training guidelines, support the development of training programs, etc.

Some may be harmed by treatment, but are they a majority?

I don't question that ISNA members and others feel that more harm than good was done to them. But what about all those that don't feel that way? Are they a majority, minority, or is it 50/50? If more are helped than hurt, ISNA might actually do a disservice, by having parents believe that negative outcomes are the rule rather than the exception.

ISNA literature emphasizes the negative impact of early genital surgery. I assume that most of your members received initial surgical procedures when they were quite young.

The urologists of my acquaintance would probably say that techniques have

*“We are
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changed dramatically over the years, and that although the result of surgeries performed decades ago may have been very poor, that is no longer the case.

Outcome research has been poor—that doesn't prove poor results

You would be right to ask them “Where’s your data to prove that results today are superior to those in the past?” I concede that I have not been impressed with the quality of scientific publications purporting to provide such proof. The fact that they have not proved good results, however, does not prove that the results are poor. Much better outcome research on this topic is needed.

Parents of boys with hypospadias describe few behavioral problems

ISNA’s *Hypospadias Surgery: A guide for parents* states, “Our discussions with men who have had hypospadias surgery lead us to believe that the physical damage and emotional trauma of genital surgery are frequently far worse than the hypospadias itself.”

In “Boys with Hypospadias: A Survey of Behavioral Difficulties” (*Journal of Pediatric Psychology*, Vol. 14, No. 4, 1989), co-authors Meyer-Bahlburg, Aranoff, Sconzo, Hensle, and I assessed the behavioral and emotional functioning of a group of boys ages 6 to 10 who had at least one surgery. The degree of hypospadias covered the full range from a minor deviation at the tip of the penis to severe hypospadias combined with micropenis. In a forthcoming paper in *Psychoneuroendocrinology*, Meyer-Bahlburg, Yager, Hensle, Levitt, Kogan, Reda and I present an even larger sample of 175 boys with pretty much the same result.

That is, at least at this point in their development, these boys appear to be functioning rather well. That does not mean that every one is doing well. As a group, however, their parents describe them much as parents of genitally normal children describe their sons.

Because hypospadias, at least in its milder forms, is a fairly common condition (one in 200-300 boys), it would be easy to conduct a comparison of those

who had been operated upon with those who had not.

Children need parental acceptance

In my clinical experience, a very strong determinant of how well the intersex child will fair in life is the parents’ ability to accept the child and to understand what has happened to them in a way that does not prejudice their rearing of that child. This issue is independent of whether or not the child receives surgery.

With or without surgery, if the parents see their child as a “freak,” the prognosis is poor. Families need to receive counseling at all stages in the child’s development. The child also needs age-appropriate information, with the goal of full disclosure. I cannot imagine anything worse than such an individual learning from a total stranger at some point in adulthood that all they had been told were lies or half-truths.

Repeated genital exams harmful?

I have also found that children with intersex conditions rarely get sufficient explanation of why they receive repeated genital examinations. Could they perceive these experiences as being abusive, as John Money has suggested?

This problem is particularly acute in teaching hospitals, where interns and residents want to see “an interesting case.” Intersexed patients are frequently seen by multiple physicians, even in the same clinic. I’m sure we can do better by these children in this respect. Once again, is this something that ISNA should cover in its treatment guidelines?

Parental acceptance requires surgery?

Getting families to understand and accept what has happened requires much more than simply providing medical information, as you are aware. Some parents, in my experience, would not accept the child whose genital appearance was not normalized through surgery.

One might wish the world to be different, but that’s the way it is. And what about other relatives and friends of the family? What if they can not accept the child’s intersex status? The social prejudice

experienced by intersexuals is readily apparent to readers of *Hermaphrodites with Attitude*.

Can surgery save intersexuals from stigma?

With surgery, could these individuals avoid the stigma of intersexuality and thereby achieve a higher quality of life? Once again, that’s an empirical question. For the time being, the only thing the clinician can do is work with each family who comes for help, and try to listen carefully to their thoughts and feelings. Dogma “for” or “against” any clinical treatment plan will not be helpful. ■

The Sandberg et. al. 1989 study on boys with hypospadias considered 69 boys aged 6-10 years. All boys had already been subjected to between one and six surgical procedures for correction of hypospadias; the mean number of surgeries was 2.3.

The hypospadiac boys were evaluated on the basis of their parents’ answers by mail to a questionnaire. Dr. Sandberg and colleagues found that, on the basis of the parents’ answers, the boys “showed more behavior problems and lower social competency” than the “nonclinical” boys investigated several years earlier by the authors of the questionnaires.

Boys with more extreme genital anomalies were hospitalized for surgery a greater number of times, and were more likely to demonstrate “increased behavior problems and poorer school performance.”

When ISNA members who had hypospadias surgery as children discuss their experience, frequent themes are shame about their genital appearance (which they attribute to surgery and secrecy, more than to hypospadias), pain, infection, repeated surgeries, and reduced sexual sensitivity. In many cases these problems do not become severe until the onset of puberty, *after* age 10.

As Dr. Sandberg mentioned, the study made no attempt to examine adults, or to compare individuals who had been operated on with those who had not.

Counterpoint

Physically Screwed by Cultural Myth: The Story of a Buffalo Children's Hospital Survivor

Heidi Walcutt tells what it was like to be treated as an intersexed child at Buffalo Children's Hospital, Dr. Sandberg's institution, from 1966 through about 1980, with one or two follow-ups afterward.

Until I learned about ISNA, purely by chance, at a talk this Spring by Dr. Anne Fausto-Sterling, I had never spoken with anyone outside of Buffalo Children's about my intersexuality. I kept things to myself. Questions. Problems. Shame.

I've spent my whole life with my feelings so bottled up, it's really hard to change now. I feel that it was my inability to talk about my problems that was a major cause of the breakup with my lover, a woman I met on the Internet and had a two and a half year long relationship with.

I can't tell you what my diagnosis was—because no one ever told me. But I do know that I was raised as a girl, and first admitted to Buffalo at age 5 in 1966, where surgeons operated on my enlarged clitoris. In my recollection, it was a fully-formed, functioning penis.

I have some clitoral sensation, and occasionally masturbate, but I am not sure whether I am orgasmic or not. I do experience some muscular contractions, though often I don't. I don't believe that the anyone at Buffalo Children's ever spoke to me or asked me about genital sensation, orgasm, or masturbation, but it was a long time ago, and I can't say for sure.

No one explained anything to me before or immediately after the surgery, but at age 10 or 11 they began to bring me to Buffalo Children's for "counseling" sessions, about an hour long once per month. From age 15 to 17, the sessions were only about four times per year.

In these sessions, I would sit with a psychologist for about an hour, and she would talk to me about very general con-

**“How are you doing?” the psychologist asked me.
“Fine,” I told her.
I guess that's what she wrote down.**

cepts of being different. She told me that I was female, but my ovaries and uterus had been “underdeveloped,” and that I would need to take pills prescribed by Buffalo physicians if I wanted to have puberty like other girls.

Around age 14 or 15, they told me that I would need surgery “if you ever want to have normal sex with your husband.” Indeed, they scheduled the surgery, which was meant to increase the depth of my vagina, but it simply never happened.

I learned later that the surgeon had become ill, and the surgery was never rescheduled, or discussed again in any way. In any case I don't suppose that it is very important, since I am entirely lesbian. But if I were interested in sex with men, I might feel differently, since the vagina they created during the first surgery is just a pocket, about half an inch deep, with flaps of skin on either side.

At age 17, they told me to take birth control pills, “to keep the hormones balanced in your system.” They told me that, because of my unnamed “condition,” I was similar to post-menopausal women, and that I might get weak bones if I didn't take the birth control pills.

But the pills put me on an emotional roller coaster, up one day and suicidally depressed the next. The psychologist never discussed this with me, but after a few months I just stopped taking them, and haven't taken them ever since. A little risk of weakened bones just didn't seem worth the pain of being back on that emotional roller coaster.

Dr. Sandberg talks about the importance of long-term follow-up studies. But their idea of follow-up is laughable. They tracked me down once, when I was about 27 and asked me to come in for follow-up. I spent about a half hour talking with a psychologist, that's it! “I'm a new psychologist, just getting started here, trying to find out how our former patients are doing,” she told me.

I was 27 years old, and living with my parents. I had never been sexual with another person, mainly because I was still unable to accept that I was lesbian. I had never had the vaginoplasty, and I had not taken hormones since age 17, in spite of the risk of osteoporosis. I was “coping” with my intersexuality by *not* coping with it, by simply squashing all my feelings.

“How are you doing?” the psychologist asked me. “Fine,” I told her. And I guess that's what she wrote down.

Dr. Sandberg says, “I cannot imagine anything worse than learning from a total stranger that all you had been told were lies or half-truths.” I certainly wasn't told the truth at Buffalo. And, based on my reading of some of John Money's books, and ISNA literature, I now suspect that I have androgen insensitivity, that surgeons at Buffalo Children's removed my *testes*, and that all the staff there conspired to lie to me, telling me that I was female, but my (nonexistent) ovaries and uterus were “underdeveloped.”

The most important thing that I think could be done for intersex kids is to put together groups for them, so they can see

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that they aren't "the only one in the world." The counselors at Buffalo Children's Hospital told me that there were others, but they never let me see one! If there were a group, kids could talk about their feelings, about how they cope.

For instance, I remember "sex education" classes at school, around sixth grade. They separate the boys and girls, and tell about physical changes that "will happen to you," but nothing about sex itself.

I knew I was different, that what I saw didn't apply to me, but I couldn't talk about this with my parents, who were conservative Christians, and I couldn't talk about it with the counselors at Buffalo Children's. The counselors just laid out for me what was going to happen to me, but I really couldn't talk about how I felt, or ask them questions. I was always uncomfortable in the counseling sessions, I would tell them almost anything so that I could just get out of there.

I remember, during high school, I read about hermaphrodites in Greek mythology and knew that it had to do with me, but I just locked it away deep in my mind, I couldn't discuss it. After all, who was I gonna talk to about that?! I couldn't talk to my Mom and Dad. There were the counselors at Buffalo Children's, but those sessions always followed the counselor's agenda. She would just explain what was going to happen to me.

Occasionally she would tell me, "we want to know what you're experiencing, what you're feeling." But there just wasn't a space there to talk about these kinds of things. She's talking about "when you get married..." I guess I could talk with these counselors more than with anybody else, but I just couldn't open up. I was sometimes suicidally depressed, especially with the hormone pills, but I just answered, "fine," when they asked how I was.

I feel in between male and female. I don't really know what "masculine" feels like, but I don't feel like the "femi-

nine" that I see in my Mom and my sisters, either.

Because my family was so against homosexuality, I always tried to deny my lesbianism. I hoped to marry, adopt children, as the counselors at Buffalo Children's suggested. But I was never really attracted to men, and then I would see a girl, and feel this intense attraction. There was only one person at Buffalo Children's who mentioned this possibility to me. She was a surgeon, and she once mentioned, while doing a physical exam on me, that some intersex patients would turn out to be lesbian, and "that's OK." Some would have surgery and marry, and "that's OK for them, too."

Years and years after the fact, I wondered why she had chosen to tell me that. Was something noticeably different about me? Did she have her doubts that I would continue playing the "straight girl?"

Doctors should put together support groups for parents, so that they can talk about their experience with their intersex kids, know what to expect next, and get the encouraging feedback that they are not alone in dealing with this problem. My parents never spoke to me about my intersexuality, or about sex or sexuality in general. Even now, though I believe my mother suspects that I am a lesbian, she doesn't ask and I don't volunteer. My Mom and I get along better now that I've moved 3,000 miles away.

They shouldn't have these parades of interns, of surgeons, examining us and talking about us. A new physician wanting to learn about intersex should be interned to just one doctor, so that children will not have to be exposed to these big groups of students. Just one student, with one doctor.

I feel that they should encourage communication in the family, help them not to keep secrets. Kids are going to have questions, and they need to be told as much of the truth as they can handle at the time. As they get older and start to realize, "Hey, I'm different," they need honest explanations and the opportunity to decide what they want to do next.

It's wrong to rush the child off to surgery during infancy or early childhood because "everyone has to be either a boy or a girl"—but not intersexed. Surgery should be delayed until puberty, when the child can make a decision for him/herself.

Of course, the only way a child is going to be able to make this decision and voice an opinion is if they have been made to feel comfortable in dealing with these issues, and can trust the honesty and support of family and doctors. ■

Scientists question

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refused to grow into a woman, and now lives as an adult man. She didn't feel or act like a girl. She often discarded the estrogen pills which were prescribed at age 12, and she refused additional surgery to deepen the vagina surgeons had constructed at 17 months of age, despite Hopkins staff's repeated attempts to convince her that life would be impossible without it. "You're not gonna find anybody unless you have vaginal surgery and live as a female," the twin recalls a Hopkins physician telling her.

The twin was not convinced. "These people have got to be pretty shallow, if that's the only thing I've got going for me. That the only reason people get married is because of what's between their legs. If that's all they think of me, I've gotta be a complete loser," the 14 year old thought.

By age 14, the twin was able to convince her local physicians, if not the specialists at Hopkins, to help her to live as a male once again. He received a mastectomy and a phalloplasty, he began a regimen of male hormones, and he adamantly refused to ever return to Hopkins.

Although the Hopkins staff were aware of the twin's resistance to medical intervention intended to make a woman of him, for nearly two decades they have dismissed questions about the outcome of this important case because the twin was "lost to follow-up." In discussion following Diamond's presentation, sex-

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Scientists question

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ologists expressed shock and dismay that they had been allowed to continue to teach and to write that the penectomized twin had been successfully transformed into a woman, for twenty years after the care providers involved knew that the experiment had been a tragic failure. Vern Bullough, the distinguished histo-

rian, stood to denounce the Hopkins team and John Money as having acted unethically in the matter.

“Medical standards allow penises as short as 2.5 cm to mark maleness, and clitorises as large as 0.9 cm to mark femaleness. Infant genital appendages between 0.9 cm and 2.5 cm are unacceptable.” The audience laughed, but Kessler had accurately summarized mainstream

medical practice in “managing” infants and children with unusual genitals. At most hospitals, surgeons will remove clitoral tissue from a child born with such in-between genitals, to produce more acceptable female genitals. In others, surgeons transfer tissue from other parts of the body to try to build a larger penis. No one has ever performed studies to determine the long term effect on sexual function of these genital surgeries.

Letters



Healing begins...

I would like to pass along some of my impressions of my first ISNA meeting.

I don't really know what I expected when I flew into town for the meeting. Having read some of the medical books dealing with conditions that cause intersexuality, perhaps I was expecting to see a room full of freaks and monsters. I was really pleased to see that this was not the case, that everyone there appeared normal (on the outside at least). I remember listening to Cheryl talk about some of the things that she had been doing the week before and about things that were being planned for ISNA in the future.

I sat and listened in rapt wonder as others talked effortlessly about things that I had kept hidden from everyone, even myself. Near the end I was able to talk briefly about some of my problems. Later, staying with local members of the group, I was able to unburden myself of some of the emotional baggage that I've been carrying around for most of my 34 years.

I'm still trying to sort out my impressions and feelings about this last weekend but I can say one thing for certain: ***I really needed this vacation.*** It's helped me regain my focus in school, sort out

long-range plans that were ambiguous, open myself to others as I've never been able to do before, and it's even put a spring in my step and lightened my burdens. I'm really looking forward to finishing my computer networking program here in school and giving what ever help I can to the group and others in general.

I know that with the help, love, and support of my intersexed brother/sisters I and others will be able to see this work go forward.

I am in the process of obtaining my medical records so I hope to have more information to share with you all at a later date.

I'm also going to start a dialog with my parents, who up to this point in time haven't been very supportive or open about my problems. I feel that information from ISNA, and my finally being able to bring these dark secrets out into the open, is going to help my relationship with my parents. And if not, well then I guess I'll look for my family within the Intersex community.

Peace to all and Bright Blessings,

Heidi Walcutt

Kessler noted that physicians and parents refer to such genitals as “deformed” before surgery and “corrected” after surgery. In contrast, many of those who have been subjected to surgery label their own genitals as having been “intact” before surgery, and “mutilated” afterward. These individuals are beginning to come together to form an intersex advocacy movement, most notably ISNA.

Kessler presented a poll of college students' feelings about “corrective” genital surgery. Women were asked to imagine that they had been born with a larger than normal clitoris, and that physicians had recommended surgery to reduce its size. One fourth of the women indicated that they would not have wanted their parents to allow the clitoral reduction surgery under any circumstance; one half would have wanted surgery only if the clitoris caused health problems, and the remaining one quarter would have wanted the size of their clitoris reduced only if the surgery would not have entailed any reduction in pleasurable sensitivity.

Men were to imagine that they had been born with a smaller than normal penis, and physicians had recommended reassigning the boy as female and surgically altering the genitals to appear female. All but one man indicated that they would not have wanted surgery under any circumstance. They seem to be saying that they believe they could live as men in our culture, even with tiny penises.

Finally, Kessler presented communications from parents of girls whose clitorises had been deemed “too large” by physicians, and surgically reduced. In

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some cases, the parents had noticed nothing unusual about their daughters' clitoral size; physicians had to teach the parents that the clitoris was unusual enough to warrant genital surgery.

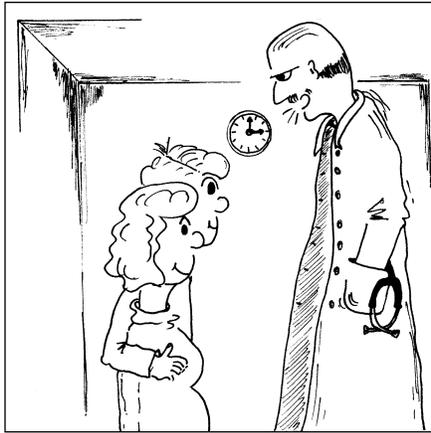
Meyer-Bahlburg defended the practice of genital surgery on children. Without surgery, he said, they are likely to be rejected by their parents, and teased by other children. He offered the example of one infant whose father was so disturbed by her large clitoris that he attempted to rip it off with his fingers, resulting in a trip to the emergency room. An ISNA representative stood to denounce the father's action as child abuse, which cannot justify surgery on the infant.

Medical intervention has been predicated on the notion that quality of life is possible only for individuals who conform to male or female sex and gender. But in recent years, the possibility of a third gender, of non-conformance, has come to the fore. There are several threads to this discourse. Anthropologists and ethnographers have identified third gender categories in many cultures, such as the Berdache in Native America, the Hijra in India, the Xanith in Oman, and many others. Non-conforming gender roles are also in evidence in the growing transgender movement, which has rebelled against medical policy which offered services to transsexuals only if they conformed adequately to mainstream heterosexual male or female roles.

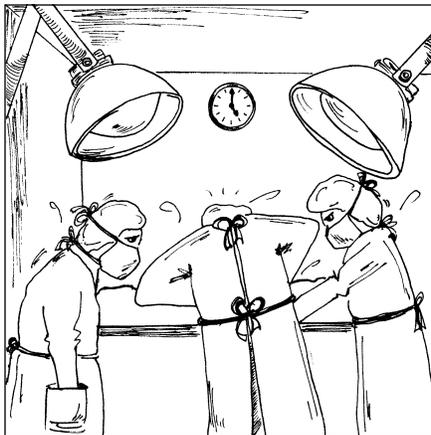
But most important, Meyer-Bahlburg acknowledged, is the growing intersex advocacy movement. This movement, represented most forcefully by ISNA, is beginning to speak out against the harm of genital surgery and of secrecy and taboo surrounding intersexuality. "I believe that this new third gender philosophy is going to have a beneficial and quite profound effect on medical intersex management, but that it will take quite a while," said Meyer-Bahlburg. In response to a question from the audience, he indicated that he would begin to advocate less surgery for "minor" cases of genital abnormalities. ■



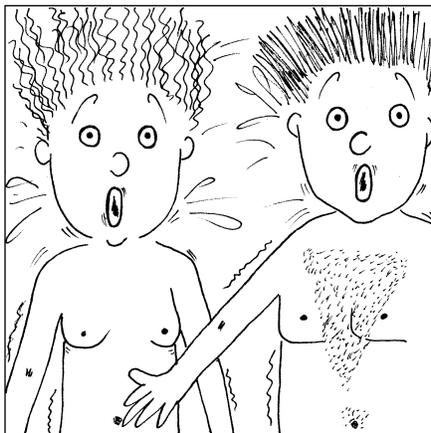
Ambiguous genitals?!
 Boy or girl??
 What will Grandma say?
 What will the sitter say?



Don't worry!
 With some modest cosmetic surgery WE can assure that the child will look just like you.
 Here - sign this consent form.



Hurry now!
 This is an emergency!
 You take this - no, put that there - wait, take that out - is this big enough?
 Is this small enough?
 Shave a bit off over here and attach it there



Yikes!!
 We didn't consent to surgery - on ourselves!
 We thought you were going to fix the kid!

idea by David
 illustrations by Revonne

Treatment raises ethical questions

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ers—although perhaps well-meaning—have done more harm than good. By and large, their clinical situation has been summarized in three commonly published words: “lost to follow-up.” And we, as caregivers, are the ones who lost them.

Understandably, intersex patients are reluctant to participate in retrospective research. They don’t trust us—and I’m at a loss to explain to them why they should. Even as a member of the ISNA Board of Directors, as one who enthusiastically supports ISNA and what it stands for, I am excluded from the peer support group meetings and the Internet mailing list which permit them to exchange life stories and support each other. Not being intersexed, I am an outsider. Rather than trying to establish necessarily subjective rules to discriminate who among us in the “helping professions” is trustworthy, ISNA has felt it necessary to deny access to all of us, and I don’t blame them. I don’t think we have treated intersex patients particularly well.

Occasionally an ISNA member has sought me out and trusted me with his/her life story. I feel privileged and I am learning a great deal from these rare opportunities. I also feel frustrated and angry. Frustrated because I realize that it will take many more years, if ever, before treatment modalities are appropriately evaluated. Angry because I believe there are many in the treatment community who, sustained by their own arrogant belief that “procedures are getting better,” and paying lip-service in their publications to the need for follow-up studies without producing any, simply don’t give a damn. I have little faith that the intersexed adults of tomorrow—undergoing “state of the art procedures” today as infants and children—will be much better off physically or emotionally than their forebears. This is a human tragedy of enormous proportions.

Many of us in the treatment community have patronizingly assumed that intersex

patients are too unsophisticated to understand their diagnoses and treatment, or to participate in their own care. Responses to their queries for information have been met by a resounding silence or a mixture of fulsome fudge and downright prevarication.

Mental health professionals have routinely advised them to “let go” of their victim postures. Good advice—but it would be easier to follow if the victims could convince themselves that new victims were not being created daily

ISNA recommends “avoidance of harmful or unnecessary surgery.” Dr. Sandberg asks how one can know “in advance,” whether surgery will be harmful. It is axiomatic in medicine that the duty of the physician is “first, do no harm.” ISNA members are telling caregivers quite clearly that surgery in infancy and childhood was harmful to them. It is perilous for us, as caregivers, to disregard this information, coming from a substantial number of our patients.

members is that they are not helpful but harmful. If ISNA members are in the minority, it is the responsibility of treatment professionals to document that fact.

It is heartening to hear that Dr. Sandberg is asked to consult, as a qualified mental health professional, in the management of intersex cases at his institution. ISNA will certainly advocate for more widespread availability of such qualified mental health services and would be eager to help formulate training guidelines. Although I do not speak officially for the organization, it is my personal belief that minimum “Standards of Care” for intersex individuals must be developed and respected in practice.

Certain elements of the Standards of Care for gender dysphoric adults adopted by the Harry Benjamin International Gender Dysphoria Association (of which I am a member), are worth considering in this light. Under these Standards, surgery requires the recommendation of at least two qualified mental health professionals. Reputable surgeons

By the surgeons’ own admission, surgery attempts to alleviate a “psychosocial emergency,” rather than a medical one.

Dr. Sandberg points out that the “necessity” of surgery for intersex patients in infancy is an empirical question, and suggests a sound scientific prospective research protocol, comparing matched cohorts. Dr. Sandberg’s heart is obviously in the right place. But his proposal seems highly unlikely to materialize. Surgical attempts at management of intersexed infants and children has been going on for decades and we still have no reliable data. I am not aware that any such studies are planned for the future. Without such studies, how can management protocols for intersexed patients be considered anything but experimental?

The real burden of proof lies with those who implement and promote such treatments as useful, not with ISNA members. The collective experience of ISNA

will not undertake surgery for gender dysphoria without the recommendation of mental health professionals with special expertise in matters of gender.

By the surgeons’ own admission, surgery performed on intersexed children and infants attempts to alleviate a “psychosocial emergency,” rather than a medical one. And, unlike individuals contemplating sex reassignment surgery, intersex infants and children are given no opportunity to weigh the risks and benefits of surgery—to choose or to reject it.

I could not agree more strongly with Dr. Sandberg that working with the families of intersex children is of paramount importance. Such work can take a considerable amount of time, however, and
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rushing to “corrective” surgery can short-circuit the work forever.

I could not disagree more strongly, however, with a rationale that proposes that if parents, relatives, and family friends of intersexed children can “not accept the child whose genital appearance was not normalized through surgery,” the child should be subjected to cosmetic surgery to mollify them.

There are at least two problems with this approach. The first—a practical problem—is that the capacity of genital surgeries to “normalize” genitals is greatly oversold. Even in adults (e.g. transsexuals), who have significantly more tissue than infants or children as raw material for the surgeon’s work, the best of genital remodeling jobs I have seen (and in my practice as a clinical sexologist I have seen more than a few) look like remodeling jobs—these genitals simply do not appear to be “normalized.” The worst of these surgeries are simply cosmetically horrendous; functionally they don’t seem to be much better. Some individuals experience chronic pain. Few report satisfactory erotosexual functioning.

The real tragedy is that most intersexed individuals would likely have been erotically, if not procreatively, “normal” without cosmetic surgery. For many of these individuals, who because of their syndromes will be denied the opportunity to reproduce, to sacrifice sexual pleasure and the important role it plays in developing satisfying, intimate, pair-bonded interpersonal relationships as adults for some dubious “normality” of appearance which may get them by in the locker room seems a poor trade-off.

The second problem is an ethical one. None of us is the personal property of another, to do with as we will. There is no guarantee when parents become pregnant that a “perfect” child will result. And whatever in the world does a genitally “perfect” child look like? A child is not parental property; parents have no right to subject a child to cosmetic surgery whenever a body part is functional

but just doesn’t look right. Parents simply must come to an accommodation with the “imperfect” child with whom they are blessed. It is not unreasonable to expect that parents, given appropriate support and help from properly trained caregivers, can work through their initial emotional pain and support and nurture their child.

ISNA believes that genital anomalies which threaten a child’s well-being should be treated by the best methods available. ISNA recognizes that past surgeries have been less than optimal and that surgeons, bright and decent human beings that they are, are getting better at their work.

But cosmetic genital surgery, which attempts to “normalize” genital appearance, is another matter. Where has it been demonstrated that minor hypospadias is physically or emotionally harmful? As Dr. Sandberg correctly points out, hypospadias is a common condition. No one disputes that severe hypospadias requires surgical intervention. But for minor hypospadias, what’s the hurry? Functionally, why is a urethral meatus which opens dead center in the glans penis superior to one which is slightly eccentric? Yet even slightly eccentric meatuses, reported in the article co-authored by Dr. Sandberg as “minor deviation[s]... at the tip of the penis” are surgically “corrected.” Are these corrective plastic surgeries requested by parents—or by pediatric urologists?

Where is it written that a clitoris must be a certain length and no longer? What studies show that partners shy away from a woman whose clitoris is larger than two standard deviations from the mean, that meaningful, intimate erotosexual relationships are compromised? What research shows that a “too large” clitoris interferes with sexual functioning or leads to emotional distress? Where is the research that demonstrates that intersexed children should have their clitorides resected, recessed, or extirpated, sacrificing erotosexual function to cosmetic appearance? Time and again, ISNA members report that this is their experience.

Newer surgeries may be better than the older ones. But reliable physiological measures which demonstrate erotosexual capability are hard to come by. For example, it has become fashionable among surgeons to assume that preservation of the neurovascular bundle in childhood clitoral recession may permit normal sexual functioning in adulthood. This is, of course, a tacit admission that earlier surgeries, which did not preserve the neurovascular bundle, resulted in impaired sexual functioning. But the medical literature continues to promote various surgical approaches based primarily on the cosmetic outcome. If some surgeons have realized that earlier surgeries resulted in impaired adult sexual functioning, why have they not said so in print?

Furthermore, the mere existence of a patent neurovascular bundle—demonstrated, in one surgeon’s recent publication, by normative values in evoked potential studies—is no assurance of normal sexual function.

I, for one, wholeheartedly support Dr. Sandberg’s plea for more research and better training of mental health professionals with respect to the special needs and concerns of intersexed patients. I also wholeheartedly support ISNA’s recommendations that treatment professionals avoid harmful or unnecessary surgeries, and that patients whose medical condition does not demand immediate treatment be afforded the opportunity to wait until they can make appropriately informed decisions before undergoing surgery.

The time has come for much greater care in the selection of intersexed candidates for surgical intervention. We cannot, as treatment professionals, ignore the clear message from ISNA members that surgical intervention can be harmful as well as helpful. It is indeed gratifying to see that ISNA appears to be sparking a lively debate about the standards of care for intersexed patients by promulgation of its *Recommendations for Treatment*. ■

Counterpoint

Treatment Raises Serious Ethical Questions

H. Marty Malin, Ph.D., is Professor and Director of the Clinical Studies Program at the Institute for the Advanced Study of Human Sexuality in San Francisco. He was formerly the Manager of the Sexual Disorders Clinic at the Johns Hopkins Hospital and an Instructor in the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins Medical School. He is a Board Certified Clinical Sexologist, Sex Therapist, and Sex Educator, a Life Clinical Fellow of the American Academy of Clinical Sexologists and a member of the Board of Examiners of the American Board of Sexology. We are pleased to have Dr. Malin's services as a member of ISNA's Board of Directors.

There is much to applaud—and much to be troubled about—in Dr. Sandberg's comments on ISNA's "Recommendations for Treatment: Intersex Infants and Children." He quite appropriately calls for better research and asks, "Shouldn't

By and large, their clinical situation has been summarized in three commonly published words: "lost to follow-up."

this be a goal for ISNA?" The answer is, of course, that it is.

ISNA's members, while perhaps not representative of the patient population as a whole, are nevertheless well informed about intersex management practices, having been subjected to them. In most cases, without their concurrence, they have been experimental research subjects. Follow-up has been uniformly poor. Patients who want details of what was done to them in infancy or childhood have been frustrated in their attempts to obtain their medical records. Some have

been told that their records are not on file, though the hospital has not discarded other records from that era. They—and I—wonder why the records are missing.

Many believe they are being stonewalled. Published information about their cases has been sparse. Valuable information has been irretrievably lost. At least in the way this group interprets the outcome data, the experiment has been a miserable failure; their caregiv-

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Sexual scientists question treatment

Bo Laurent

The fate of intersexed children was the focus of debate when sexual scientists from around the world met in San Francisco in November. Before modern medical understanding of endocrinology and advances in surgical techniques, such individuals made their way in the world as best they could. For the past forty years, however, medical technologies have been widely used to force such unruly bodies to conform more closely to male or female shapes. This policy has been implemented almost entirely without public scrutiny, in hospitals throughout the US and other industrialized countries.

In a symposium titled "Genitals, Identity, and Gender," held at the annual convention of the Society for the Scientific Study of Sex, sex researcher Dr. Milton Diamond, of the University of Hawaii Medical School, and psychologist Dr. Suzanne Kessler, of the State University of New York at Purchase, found a recep-

Medical standards allow penises as short as 2.5 cm, and clitorises as large as 0.9 cm. Infant genital appendages between 0.9 cm and 2.5 cm are unacceptable.

tive audience for their criticism of medical treatment of hermaphrodites. Dr. Heino Meyer-Bahlburg, a member of the team which treats hermaphrodites at Columbia University's Presbyterian Hospital in New York, was on hand to offer the clinician's point of view.

Diamond had dramatic news for the assembled sexologists; he presented a follow-up on the famous case of the twin boys. One of these identical twins had lost his penis at age 7 months in a circumcision accident, in 1963. On medical advice, the boy was reassigned as a girl, plastic surgery used to make his genitals appear female, and female hormones administered during adolescence to complete the metamorphosis. The change of sex was facilitated and monitored at Johns Hopkins Hospital, a leading center for medical treatment of hermaphrodites.

In 1973 and 1975, Dr. John Money of Johns Hopkins, a leading expert in pediatric psychoendocrinology and developmental psychology, reported the outcome as favorable. In the ensuing twenty years, the case of the penectomized twin has taken on immense significance; it is cited in numerous elementary psychology, human sexuality, and sociology texts. Most importantly, the case influenced medical thinking about treatment of hermaphroditic infants. Medical texts now recommend that boys born with a penis that is "too small" be reassigned as girls, just as the twin was. Surgeons remove their penises and testes and construct a vagina, and a pediatric endocrinologist administers hormones to facilitate female puberty.

But in fact, according to Diamond's report, the penectomized twin steadfastly

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