

Introduction to Intersex Activism

A Guide for Gay, Lesbian, Bisexual and Trans Allies



Intersex activists and allies from Transsexual Menace working together at the historic 1996 demonstration at the annual meeting of the American Academy of Pediatrics.

October 2001 Edition

compiled by **Emi Koyama** <emi@isna.org>
for **Intersex Society of North America**

Table of Contents

What is included in this Booklet

| | |
|--|----|
| Table of Contents | 2 |
| Mission Statement | 2 |
| About the Editor | 2 |
| Basic Information (FAQ) | 3 |
| Myths & Facts | 4 |
| Notes on Treatment of Intersex | 8 |
| Talking Points | 10 |
| Suggestions for Coalition Building | 11 |
| Sample Resolution | 12 |
| ISNA Store Catalogue..... | 13 |
| Resources | 15 |
| Order Form | 16 |

Mission Statement

Purpose of Intersex Society of North America



Our mission is to create a world free of secrecy, shame and unwanted genital surgery for intersexed people.

About the Editor

Who is responsible for this booklet

Emi Koyama joined Intersex Society of North America as the Activist-in-Residence (i.e. intern) for Summer 2001, and since then her title became more boring Program Assistant. She has also co-authored another booklet, ***Teaching Intersex Issues***, which is targeted toward college-level instructors in Women's, Gender and Queer Studies. To read more of Emi's work, search ISNA's web site at <http://www.isna.org/> for "koyama" or visit <http://eminism.org/>. Emi can be contacted at emi@isna.org. Some of the materials compiled in this booklet have been produced by Alice Dreger and other activists affiliated with ISNA.

Basic Information

Frequently Asked Questions about Intersex & ISNA

.....

Basic Questions:

What is intersexuality?

Simply put, intersexuality is a set of medical conditions that feature congenital anomaly of the reproductive and sexual system. That is, intersex people are born with “sex chromosomes,” external genitalia, or internal reproductive system that are not considered “standard” for either male or female. Intersex children are routinely “treated” with surgeries and other medical interventions to make their bodies appear more “normal,” although the evidence such treatments are needed or even desirable is scarce.

How common is intersexuality?

No one knows exactly how many intersex children are born because of the secrecy and deception surrounding their conditions, and estimates range widely depending largely on where you draw the line. It is however estimated that one in 2000 newborn babies exhibit enough physical signs at birth to be considered an emergency requiring surgical and other medical intervention.

How is intersex different from “hermaphrodite”?

Although these two terms are sometimes used interchangeably, we feel that “hermaphrodite” is a stigmatizing and misleading word. “Hermaphrodite” implies that a person is born with two sets of genitals - one male and one female - and this is never the case. There is a growing momentum to eliminate the word

“hermaphrodite” from medical literature when referring to human intersexuality.

Questions about Gender Issues:

How do we know the correct gender of an intersex child?

We won’t know the child’s gender until she or he is old enough to communicate to us. We recommend that the child be given a gender based on our best prediction, and allow her or him to determine for herself or himself once she or he is old enough to do so. Irreversible surgeries on infants should be avoided in order to give them the widest range of choices when they are older. This principle, of course, should apply not only to intersex people, but to every child.

Are there five sexes?

The notion of “five sexes” was popularized by Anne Fausto-Sterling’s article *The Five Sexes* (1993). In this largely tongue-in-cheek piece, she wrote that three

subcategories among “intersex” should be considered as three additional sexes aside from male and female. Unfortunately, the “five sexes” theory does not help intersex people. In addition to exoticizing and sensationalizing intersex people, the distinction between three additional “sexes” - merm, ferm and herm - were artificial and did not mean anything for intersex people’s well-being. Fausto-Sterling herself declared that she was “no longer advocating using discrete categories such as herm, merm or ferm, even tongue in cheek” in *Sexing the Body* (2000).

Are intersex people “third gender”?

Many intersex people identify comfortably as a man or as a woman, like many non-

intersex people. There are some intersex people who identify as a member of an alternative gender, like some non-intersex people. While we support everyone's right to define her or his own identities, we do not believe that intersex people should be expected to be gender-transgressive just because they are intersexed.

Is intersex part of “transgender” community?

While some intersex people also identify as transgender, intersex people as a group have a unique set of needs and priorities besides those shared with trans people. Too often, intersex people's unique needs are made invisible or secondary when “intersex” becomes just a subcategory of “transgender.” It is for this reason that we prefer to have “intersex” spelled out explicitly rather than have it “included” in “transgender.”

Is intersex part of “queer” community?

It is difficult to answer this question because it is not clear what it is asking. One thing that is clear is that the term “queer” needs to be redefined beyond sexual orientation, gender identity and sexual preferences if it were to be inclusive of intersex.

Questions about Intersex Society of North America (ISNA):

What does ISNA do?

Because our resources are limited, we prioritize organizing efforts that would achieve systemic changes rather than simply providing service directly to intersex people and their family members. To that end, we focus our resources strategically on educating medical professionals as well as the general society about issues faced by intersex people.

Who are involved in ISNA?

ISNA has a small staff and a board of directors, in addition to a growing pool of donors, volunteers, and supporters, both intersex and non-intersex. ISNA is not a closed club for intersex people only - it is an activist and educational organization made up of many unique individuals, intersex or otherwise. You can receive our newsletters several times each year by making a donation of \$35 or more, or volunteer to do some work!

What alternative does ISNA propose to the current treatment procedure?

ISNA supports the patient-centered model of care for intersex people as opposed to the concealment-based one currently employed by the medical community. See the chart contrasting these two models later in this booklet.

Does ISNA distribute educational materials?

Yes! Our web site, which is at www.isna.org is packed with news, articles, resources, and even more frequently asked questions. In addition, we sell books and video tapes that

specifically address intersex issues. Please take a look at our web site as well as the catalog section of this booklet.

How can I contact ISNA?

Email: info@isna.org
Telephone: (707) 283-0036
FAX: (707) 283-0036
Postal: PO Box 301, Petaluma CA 94953

Note: This “Frequently Asked Questions” are excerpted from the edition found on our web site. Please see <http://www.isna.org/faq/> for the complete FAQ.

Myths & Facts

“Top ten myths about intersex” by Alice Dreger

.....

Top ten myths about intersex

by Alice Dreger

Reprinted from ISNA News, Feb. 2001

MYTH #10: Intersex is extremely rare.

First we need to acknowledge that it's hard to say exactly how frequent intersex is, because the sex spectrum is like the color spectrum; nature provides us with a range where one “type” blends imperceptibly into the next. For our linguistic and social convenience, we break that spectrum into categories. It makes it easier to talk about “that blue car” or “that man over there.” But nature doesn't tell us that there are 7, or 10, or 100, or ten million colors, and nature doesn't even know that there are two sexes. We humans, with our words and our cultures, decide how many categories to delineate. While the “male” and “female” types are relatively common, nature presents a full range of sex types, and people decide where the line should be drawn between “female” and “intersex” or “intersex” and “male.”

That said, we do know that about 1 in 2,000 children is born with genitals that are pretty confusing to all the adults in the room. We know this from the statistics of how many newborn babies are referred to “gender identity teams” in major hospitals.

But wait, you say, 1 in 2,000 sounds rare! Well, if only 1 in 2,000 persons is intersexed, then intersex is more common than cystic fibrosis, a condition most people have heard of. In fact, as Sherri Groveman (now the Treasurer of ISNA) pointed out in her article in *Intersex in the Age of Ethics*, if you do the math, you realize that there are more intersexed people in the world than there are Jewish people!

And if all of the intersexed people of voting age had voted for a single presidential candidate, the outcome of the election would have never been in doubt. (Not that we're telling you who you should have voted for - though you might want to know for future reference that Al Gore made a public, educated statement about intersex at a meeting of lgbt leaders. We were unable to find out from the Bush team the

Republican platform on intersex.)

In fact, maybe it's time to print t-shirts that say, “I'm intersexed, and I vote!”

But wait, are you intersexed? That leads us to . . .

MYTH #9: Only “true hermaphrodites” are really intersexed.

The term “true hermaphrodite” is a nasty Victorian term invented in an effort to make intersexuality go away. (My first book, *Hermaphrodites and the Medical Invention of Sex*, is all about this.) The term “true hermaphroditism,” a term that sounds fancy and special, refers simply to the condition in which one person has both ovarian and testicular tissue, whether or not that tissue is functional physiologically. But it is silly to count only these folks as intersexed! Their internal and external anatomy varies all over the place, and many of them look less “ambiguous” than other folks. Some of them have xx chromosomes, some of them xy, and some of them have mixes or variations on those themes. Keep in mind that nobody has two full sets of sex organs, as some people mistakenly imagine. People with ovarian and testicular tissue, like other intersexed people, have one set of genitals, though they may be kind of in-between in appearance.

In practice, the term “intersex” is used to refer to anybody who was born with anatomy other than what the Powers That Be define as “standard male” or “standard female.” What counts as “standard”? Check your phall-o-meter (purchase online at ISNA's website), and stay tuned for a later newsletter, which will explore the deep and oh-so-hot question, “Who really is intersexed?”

For now, on the topic of who is intersexed, let's move on to dispel . . .

Myth #8: If you're transsexed, then you're intersexed.

This myth comes from our nutty cultural notion that your identity has to find its basis in your anatomy. It's just like the old-fashioned (sexist)

idea that if you're a strong woman, you must really be a man inside. In fact, it's the same kind of stereotype that assumes that all black people are lazy. Aren't we past the point of believing that one type of anatomy necessarily maps to only one type of identity? Get over it!

Transsexed people are sometimes people who were born intersexed, but far more often they are people who were born with "standard" male or female anatomy. By a common definition, transsexed people are people who were assigned a gender that doesn't work for them. ISNA supports the right of all people, regardless of what their body looked like when they were born, to assume the gender identities that makes sense to them. This leads us to . . .

Myth #7: ISNA advocates doing nothing and raising intersexed babies in a third gender.

Sorry, gender warriors, that's not us! We certainly would like to see people become less gender-phobic, but we don't think dumping intersexed kids into a gender-phobic world with no gender or with a "third gender" is the way to go. We believe there are two problems with trying to raise kids in a "third gender."

First, how would we decide who would count in the "third gender"? How would we decide where to cut off the category of male and begin the category of intersex, or, on the other side of the spectrum, where to cut off the category of intersex to begin the category of female? (See Myth #1.)

Second, and much more importantly, we are trying to make the world a safe place for intersexed kids, and we don't think labeling them with a gender category that in essence doesn't exist would help them. (Duh, huh?)

ISNA recognizes that it can be damned hard to be intersexed, or to have an intersexed child. That's why we exist. That's why we don't advocate "doing nothing." What we do advocate is providing parents of intersexed newborns - and within a couple of years, intersexed children themselves - with honest and accurate information about intersex, psychological counseling by professionals who are not gender-phobic, medical help for any real medical problems, and especially referrals to other people dealing with the same issues. Time and again researchers have found that, no matter what the condition - being gay, dealing

with a serious disease - peer support, even if informal, saves families and lives.

ISNA believes that intersexed children and adults should not be subject to surgeries designed to "make the genitals look normal" without their explicit consent. (And consent of your parents isn't the same as your consent.

Think about it - would you want your parents making medically unnecessary decisions about your sexuality?) Some people think surgery is the only possible medical response to intersex. Not so! Everyone agrees that intersex is a psycho-social issue, so why not deal with it as a psycho-social issue first and foremost? This leads us to . . .

MYTH #6: You can't raise an intersexed child as a boy or girl without surgery.

Of course you can! When people ask me whether my baby is a boy or girl, do I have to show them his genitals to answer their question? No, I tell them, "He's a boy." To gender a child, we give that child the label of "boy" or "girl" and thereby float them into the (admittedly often problematic) gender stream of our culture.

How would we decide what gender to give an intersexed baby? Doctors and parents should consider an intersexed baby's genitals and physiology and, using the best knowledge they have of various intersex conditions and our culture, decide which gender the child is most likely to grow up to have. Sure, this requires recognizing that the child might express a different gender later. But the fact is that even with "corrective" surgery designed to "lock in" one gender, many intersexed children transition gender later.

We also have to recognize that everyone's gender assignment is preliminary. Mine was, yours was, so is my son's. Intersexed people are more likely than others to transition genders, but everyone, intersexed and not, has that potential. And it is worth remembering that the idea of "locking in" a gender using "corrective" surgery feeds into . . .

MYTH #5: Surgery makes normal-looking genitals.

This simply isn't true in the vast majority of cases. As Cheryl Chase, the Executive Director of ISNA, noted in *Intersex in the Age of Ethics*, "Surgery is good at removing structures . . . it is much less useful for creating structures." ISNA

believes that medically necessary surgeries should be employed when a child or adult's physical health is threatened. We believe that, for example, if a child's urine is not draining in a healthy way, the child should receive medical treatment for that problem. But "cosmetic" surgeries designed to make genitals look "normal" are not medically necessary.

Intersexed genitals are not diseased! They just look different. And don't go giving into . . .

MYTH #4: Once surgery is better, we won't have to worry about intersex.

When is it ever going to be ok to risk a baby's future sexual function, fertility, and even life, just because her genitals force you to realize gender and sex aren't simply dichotomies? Who are you to decide she wouldn't be happy with the genitals she was born with?

If it is true that intersex cosmetic surgeries are getting better (and we lack the data to know), then why not let the intersexed person himself decide when, in his own opinion, the likely benefits to him of the surgery outweigh the burdens and risks to him of that surgery?

Keep in mind, too, that surgeries designed to "correct" intersexed genitals will always, by definition, carry with them the message that intersex is shameful and bad. And we don't think intersex is shameful or bad. Nevertheless, we keep running into . . .

MYTH #3: "Corrective" cosmetic surgeries make parents forget their kid was born different and undoes all their confusion, shame, guilt, and fear.

Hello? This might work if the surgery being done was a lobotomy on the parents. "Normalizing" surgery just gives parents this message: Your kid is a freak, we had to correct it, don't talk to anyone about it because this is a really scary, shameful condition.

There is no question that the parents I talk with whose children had "normalizing" surgery still have all the confusion, shame, guilt, and fear after the surgery. Some parents say they are even worse off. Some have ended up with kids with permanent damages. Others have wound up with more guilt after realizing they risked their children's sexual function and fertility. Many worry openly that their kids will later accuse them of not accepting them as they were.

I don't have a smooth transition to the next

myth, so let's move on to . . .

MYTH #2: John Money is responsible for all of the troubles that have befallen intersexed people.

Psychologist John Money became widely known through John Colapinto's book, *As Nature Made Him*. Money often argued that you could make any kid a girl or a boy, as long as you made the genitals look "right." It turns out gender identity is much more complicated than that, but unfortunately legions of doctors thought Money was right and did "normalizing" surgeries in an attempt to make intersex go away.

While it is true that a lot of doctors justified their work via Money's own work, it is also true that burning Money in effigy won't make any difference in the lives of the five girls who today had their clitorises cut down by a surgeon who thinks no one can live with intersexed genitals. Every time you sit around and blame Money, ask yourself what you've done today to try to see that tomorrow there will be only four children subjected to medically unnecessary surgeries on their genitals.

What can you do? For starters, don't give into . . .

MYTH #1: My little contribution to ISNA can't possibly make a difference.

What? You doubt our powers to change the world on a shoestring budget! Consider the fact that in the last year, with just a few thousands of dollars, we have provided educational material to tens of thousand of people, supported doctors and activists working for positive reform, put intersex on the national agenda, and helped a few wonderful intersexed people realize that they are not alone.

Remember what Margaret Mead, that gender maven, said: "Never doubt that a small group of thoughtful committed citizens can change the world: Indeed it's the only thing that ever has."

We're sure that right after that, she added, "Send money!" Help us now end shame, secrecy, and unwanted genital surgeries for people born with atypical sex anatomies. With your help, we can make the world a safer place for people born intersexed.

Paradigm Shift

Point-by-point comparison of new and old models

.....

Notes on the Treatment of Intersex

Prepared by Alice Dreger, Michigan State University (dreger@msu.edu)

| Key points of comparison | Older paradigm of treatment (CONCEALMENT-CENTERED) | Reform paradigm of treatment (PATIENT-CENTERED MODEL) |
|--|--|--|
| Who are the proponents of each paradigm? | John Money, most pediatric urologists and pediatric endocrinologists, many gynecologists (including the physicians Patricia Donohoe, Kenneth Glassberg, etc.) | Intersex activists (including Cheryl Chase), most involved ethicists (including Alice Dreger, Edmund Howe, Robert Crouch), a few physicians (including Bruce Wilson, William Reiner, Justine Schober) |
| What is intersex? | Intersex is an anatomical abnormality which is highly likely to lead to great distress in the family and great distress for the intersexed person. Intersex is pathological and requires medical attention. | Intersex is an anatomical variation from the "standard" male and female types; just as skin and hair color varies along a wide spectrum, so does sexual anatomy. |
| Is gender determined by nature or nurture? | Nurture. Virtually any child can be made into a "boy" or a "girl" if you just make the genitals look convincing. It doesn't matter what the genes, brain, pre-natal life are/were like. | Both, surely, but that isn't the point! The point is that intersexed people ought to be treated with the same basic ethical principles as everyone else -- respect for their autonomy and self-determination, truth about their bodies and their lives, etc. Physicians and researchers should stop using intersex people in "nature/nurture" experiments. |
| Are intersexed genitals a medical problem? | Yes. Untreated intersex is highly likely to result in depression, suicide, possibly "homosexual" orientation. Intersexed genitals must be normalized if these problems are to be avoided. (Note: There is no solid evidence for this position, and there is evidence to the contrary.) | No. Intersexed genitals are not a medical problem. They may signal an underlying metabolic concern, but they themselves are not diseased; they just look different. Metabolic (medical) concerns should be treated medically, but intersexed genitals are not in need of medical treatment. |
| What should be the medical response? | The correct treatment for intersex is to "normalize" the abnormal genitals using cosmetic surgical technologies, cosmetic hormone technologies, and so on. Doing so will eliminate the potential for psychological distress. | The whole family should receive psychological support (including referrals to peer support groups) and as much information as they can handle. True medical problems (like urinary infections) should be treated medically, but all cosmetic treatments should wait until the patient can him/herself consent to them. |
| When should cosmetic "normalizing" treatments be done? | As soon as possible. The longer you wait, the greater the trauma. | ONLY if and when the intersexed person requests them, and then only after she/he has been fully informed of the risks and likely outcomes. S/he should be able to talk to others who have had the treatments to get their views of them. |
| Why should intersex be treated this way (the way your side advocates)? | Because our society can't handle genital ambiguity or non-standard sexual variation. If we don't fix the genitals, the intersexed child will be ostracized, ridiculed, rejected, and so on. | Because the intersexed person has the right to self determination where her/his genitals are concerned. Doing surgeries early interferes with that right; many surgeries and hormone treatments are not reversible. In addition, the risks from cosmetic treatments are substantial (risks to sensation, continence, fertility, risks of pain, scarring, etc.) and, given that the goal is cosmetic, these risks should only be taken if the patient him/herself has consented. |
| Who should counsel the parents when an intersexed child is born? | The surgeons, endocrinologists, and maybe a genetic counselor. The parents need to be told their child <i>does</i> have a sex (male or female), but that we haven't figured it out yet. We will "figure it out" (in reality, the doctors will <i>decide</i> what sex they will assign) and advise you as soon as possible. | A trained psychologist (including one familiar with the grief process common to parents facing traumatic surprises in newborns) and peer support groups. In addition, we should make information about intersex as widely known as possible so that all expectant parents will have heard of intersex, just as they have heard of cleft palate. Parents, intersexed people, and the public need to be provided with non-pathologizing images of intersexed people. |

(continued)

| | | |
|---|---|---|
| How do you decide what gender to assign an intersexed newborn? | <p>The doctors decide. They do genetic and other tests immediately.</p> <p>If the child has a Y chromosome and an adequate penis (or "reconstructable") penis in the eyes of the doctors, the child will be assigned a male gender.</p> <p>If the child has a Y chromosome and an inadequate penis (or "unreconstructable") penis in the eyes of the doctors, the child will be assigned a female gender and surgically "reconstructed" as such. (Newborns must have penises of 1 inch or larger if they are to be assigned the male gender.)</p> <p>If the child has no Y chromosome, it will be assigned the female gender. The genitals will be surgically altered to look what the doctors think female genitals look like. This will include clitoral reduction, construction of a "vagina" (a hole), and so on.</p> | <p>The doctors in consultation with the family decide. They do genetic and other tests immediately. Then, given what is known about the child in question and about the aggregate histories of intersexed people with various conditions, they will assign the gender most likely to be accepted by the family and child.</p> <p>The child is assigned a male or female gender.</p> <p>The doctors and parents recognize, however, that this gender assignment (like ALL gender assignments) is preliminary. The child may decide later to change it. That is why medically unnecessary surgeries should not be done without the child's consent; the child may want the flesh later to construct genitals different than the ones the doctors would have chosen.</p> |
| What should the intersexed person be told when s/he is old enough to understand? | <p>Very little, because telling all we know will just lead to gender confusion that all these surgeries were meant to avoid. Withhold information and records if necessary; use euphemisms (like "we removed your twisted ovaries" instead of "we removed your testes" when speaking to a woman with AIS).</p> | <p>Everything we know. The intersexed person has the right and responsibility to know as much about her/his condition as her/his doctor does.</p> |
| What's wrong with the opposing paradigm? | <p>Parents might be uncomfortable with a child with ambiguous genitalia.</p> <p>The intersexed person might later wish that her/his parents had chosen to have her/his genitals "normalized".</p> | <p>The autonomy and right to self determination of the intersexed person is violated by the surgery-centered older model.</p> <p>In the older model, surgeries are done without truly obtaining consent; parents are not told the failure rate of, lack of evidentiary support for, and alternatives to the surgery approach.</p> <p>Children assigned "male" and those assigned "female" are treated according to sexist asymmetrical lines in the older model.</p> <p>Lying to or deceiving patients and parents is wrong, even if done with beneficent intentions.</p> |
| What is the ideal future of intersex? | <p>Elimination via improved scientific and medical technologies.</p> | <p>Social acceptance and the recognition that sexual categories are socially constructed.</p> |

Further reading: See the website of the Intersex Society of North America: <http://www.isna.org>

Dreger, Alice. 1998. When Medicine Goes Too Far in the Pursuit of Normality. *New York Times*, 28 July, Science Times. Available from <http://www.nytimes.com/library/national/science/072898sci-essay.html>.

Dreger, Alice. 1998. Special issue on intersexuality. *Journal of Clinical Ethics* 9 (4).

Dreger, Alice. 1999. *Intersex in the Age of Ethics*. Hagerstown Maryland: University Publishing Group.

Dreger, Alice Domurat. 1998. "Ambiguous Sex" -- or Ambivalent Medicine? Ethical Issues in the Medical Treatment of Intersexuality. *Hastings Center Report* 28 (3):24-35. <http://www.isna.org/dregerart>.

Talking Points

Six additional points to keep in mind

.....

Talking Points: Six points to remember when talking about intersex

by Emi Koyama

1. Intersex is not a freely chosen identity.

While some intersex people indeed reclaim intersex as part of their identities, this is not true for all or even most people who have intersex conditions or who have gone through intersex medicalization.

2. Intersex is not about gender.

Some intersex people experience gender issues, while others don't. Some intersex people are unhappy with the gender assignment they were given, and many aren't. Some intersex people identify outside of traditional male-female genders, many don't. That only means that intersex people's experience of gender is just as diverse as non-intersex people's experience. Everybody should have the right to determine her or his gender identity and expression whether or not s/he is intersexed.

3. We oppose the treatment paradigm based on concealment, of which surgery is a big part but only a part. We advocate patient-centered paradigm. We are not anti-surgery,

but we are pro-choice. It is wrong to perform unnecessary surgeries on the genitals of infants and young children because it would take away their freedom of choice, as do institutionalized secrecy and shame surrounding the issue.

4. The problem with surgery is not just that sometimes they predict the patient's gender incorrectly.

It's still wrong even if they could predict patients' future gender identity 100% of the time.

5. Intersex people should not be used to support some abstract theory or someone else's agenda. Intersex people are real people with real lives and concerns, and do not exist so that they can be used to illustrate the social construction of sexes, or how heterosexuality should not be the only option, for example.

6. Anti-discrimination laws and hate crime laws are extremely

inadequate as a mechanism to defend intersex people's civil rights,

because the violence intersex people face is very different from those faced by GLBT people. Adding "intersex" to the pre-packaged GLBT agenda is not true "inclusion."



Max Beck, intersex activist, at the 1996 protest.

True Alliance

Suggestions for coalition building

.....

Suggestions for Ally-Building

by Emi Koyama

1. Do not let non-intersex “experts” such as doctors, therapists and academics speak on behalf of intersex people. Listen to intersex people themselves.

2. Do not ask intersex people about their diagnosis or medical conditions merely out of curiosity. For many intersex people, unwanted attention to their physical difference was the problem in the first place.

3. Educate yourself. Realize that there are very few “out” intersex activists around, and they are often overworked. Do your homework before contacting them for a

question so that you won’t burden them with the responsibility to educate you.

4. Do not automatically include intersex people in “queer” or “trans” categories. Many intersex people do not feel included or represented by these movements, mostly because they aren’t. At the same time, always remember that some intersex people also identify as gay, lesbian, bisexual or trans.

5. If your organization decides to include intersex in its name or mission, actually practice inclusion. Educate your members

about intersex through videos, literature, and guest speakers (you have our number, right?), and start taking actions.

6. Do not exploit intersex existence for the sake of deconstructing homophobia, biphobia or transphobia. If you mention intersex, make sure to discuss issues intersex people face.

7. Recognize that the intersex movement

needs to set its own priorities and agendas, some of which are different from that of GLBT politics.

8. Pass resolutions in your organizations stating support for intersex activists’ work.

Make sure to word the resolution so that you are honoring the leadership of intersex activists

rather than making recommendations about something you are not even familiar with.

9. Join ISNA and/or make donations. You can also help ISNA financially by ordering books and video tapes about intersex through ISNA.

10. Do not expect one organization to speak for all intersex people, because intersex people are just as diverse as any other group. Support intersex activists who are not part of ISNA as well.



Intersex activists Howard Devore, Cheryl Chase, Kristi Bruce, and Sam Ferguson speak to medical students at UC Berkeley.

Resolution

Make a public statement of support

.....

If you want to help the intersex movement advance civil rights for intersex people, get your organization to adopt a resolution similar to the sample. When you do, make sure to let us know so we can keep track of the list of groups that support us.

Ending Shame, Secrecy, and Unwanted Surgery for Children Born with Atypical Sex Anatomy: A Sample Resolution

WHEREAS, at least one in 2000 children is born with notably atypical sex anatomy; and

WHEREAS, these children are frequently subjected to repeated and medically unnecessary display to satisfy the curiosity of medical professionals; and

WHEREAS, intersex children are frequently subjected, before they are old enough to provide informed consent, to invasive surgical and hormonal procedures to make their bodies more closely approximate what doctors consider “normal”; and

WHEREAS, parents of intersex children are rarely given full and accurate information about the child’s condition and risks involved in these procedures, or referrals to supportive information and resources; and

WHEREAS, intersex children and adults are frequently not given full and accurate information about their own condition and medical history; and

WHEREAS, many intersex people grow up feeling hurt, isolated and ashamed due to these violations of their bodily integrity and their systemic erasure;

WHEREAS, in recent years many intersex people have come forth to report that these medical interventions have been the source of

physical, emotional, and sexual harm;

WHEREAS, legal and social assignment of sex do not require “normalizing” sexual surgeries; and

WHEREAS, since 1993 the Intersex Society of North America (ISNA) and other organizations have been formed by intersex people to end secrecy, shame and unwanted genital surgeries on children born with atypical sex anatomy;

THEREFORE BE IT RESOLVED that *ORGANIZATION* supports the rights of children too young to consent to be free of unnecessary medical display and of cosmetic procedures including surgical and hormonal interventions which influence the sexual appearance of their bodies; and

BE IT FURTHER RESOLVED that *ORGANIZATION* supports the rights of people old enough to make an informed choice to choose procedures including surgical and hormonal interventions which influence the sexual appearance of their bodies; and

BE IT FURTHER RESOLVED that *ORGANIZATION* supports the leadership of ISNA and other intersex advocacy groups in their struggle to end secrecy, shame and unwanted genital surgeries on children except in cases where there are genuine health reasons requiring surgeries;

BE IT FINALLY RESOLVED that *ORGANIZATION* urges the medical community to establish and adopt a patient-centered treatment protocol in conjunction with patient advocacy groups under which patients are not made objects of curiosity, full and accurate information is disclosed and supportive resources and information, including referrals to support groups of adult intersex people, are provided to parents of intersex children.

Catalogue

Order educational materials from ISNA

.....

Video Tapes

Hermaphrodites Speak! from ISNA (\$50)

Imagine growing up knowing you were different, not quite knowing why and feeling like you were the only person in the world like you. Meet Angela, David, Heidi, Tom, Mani, Cheryl, Max and Hida as they tell their stories of growing up intersexed. Share their joy at finally meeting other people who are intersexed. Be amazed as you witness intersex people speaking out for the first time in their lives! This is the first and only (so far) documentary made by and about intersex people.

Redefining Sex from City TV of Toronto (\$50)

Meet families of intersex people. Hear doctors on both sides. It is a great way to see for yourself some of the personal dynamics resulting from intersexuality and infant sex assignment surgery.

This touching film is perfect for showing in college classrooms, at community group meetings or at a house party.

Is it a Boy or a Girl? from Discovery Channel (\$50)

This one-hour documentary has been nominated for a GLAAD award for outstanding tv journalism.

From the moment of birth, everybody wants to know is it a boy or a girl? This question can be complicated when a

third option is introduced; one out of every two thousand children in America is born intersexual. Sometimes biology malfunctions and children are born with mixed sexual characteristics, in what is called an intersexual birth.

Many argue that the standard practice of sexual assignment by surgery in infancy should be discontinued giving the intersexual the right to choose or not to choose surgery once that person reaches adolescence. But whatever the surgical choice, intersexuals show us that gender is infinitely more complex than shape

of our genitals. (This summary prepared by Discovery)



Hida Viloria, Mani Bruce Mitchell, Martha Coventry, Max Beck, Heidi Walcutt, Suegee Tamar, and David Vandertie share a meal during the retreat where "Hermaphrodites Speak!" was filmed, 1996

Books & Journals

Intersex in the Age of Ethics

ed. by Alice Dreger (\$25)

Intersex in the Age of Ethics marks the first time an entire volume has been dedicated to the exploration of the ethics of intersex

treatment. It could not be more timely; professional conferences, gender clinics, and the popular media are abuzz with the controversy over how medicine and society should handle intersex and intersexuals. The volume will provide some much-needed perspective. The writings approach the issue of intersexuality and its treatment from numerous perspectives, including the personal, ethical, clinical, legal, anthropological, historical, sociological, and philosophical. University Publishing Group (1999).

Hermaphrodites and the Medical Invention of Sex by Alice Dreger (\$20)

Alice Dreger, Assistant Professor of Science and Technology Studies at Michigan State University and adjunct faculty at the Center for Ethics and Humanities in the Life Sciences, brings us this study of how and why medical and scientific men have construed sex, gender, and sexuality as they have. A 36 page long epilogue contains narratives of intersexuals treated according to the still-standard medical protocols developed in the 1950s and calls for change: "Surely, ...it will be familiarity rather than knowledge that finally takes away [intersexuals'] supposed 'strangeness.'" Harvard University Press, 1998.

Lessons from the Intersexed by Suzanne Kessler (\$20)

Fascinating in what it tells us not only about situations in which sex assignment is uncertain but about the astonishingly weak empirical foundations on which the medical orthodoxies of binary sex and gender are built. A must for anyone interested in the ways widely accepted social beliefs and scientific explanations generate and reinforce each other. Rutgers University Press, 1998.

Journal of Clinical Ethics: Special issue on intersexuality (\$35)

Winter 1998 issue of Journal of Clinical Ethics is devoted to the discussion of ethical issues involved in the treatment of intersex children. Articles from this issue have been incorporated into Alice Dreger's edited book, *Intersex in the Age of Ethics*.

Chrysalis: Intersex Awakening Special Issue (\$10)

Never-before-told true life stories! Revolutionary social change ignited before your very eyes! Intersex people speaking for themselves rather than depicted as medical specimens! Thrill to the stirrings of a new social agenda! This special issue of *Chrysalis: Journal of Transgressive Gender Identities* is guest-

edited by intersex activists and is completely devoted to addressing intersex issues.

Others

"Teaching Intersex Issues" Kit (\$75)

Teaching Kit for Women's, Gender & Queer Studies Instructors. The kit packages everything a teacher needs to be able to introduce intersex issues in their classes appropriately:

- a 16-page booklet featuring an analysis of problematic ways in which the topic of intersexuality has been used, a sample ready-to-use course unit and an extensive list of recommended materials;
- a copy of "Hermaphrodites Speak!" (the first -- and only documentary film by and about intersex people);
- special intersex issues of two journals (*Chrysalis: Journal of Transgressive Gender Identities* and *Journal of Clinical Ethics*) guest edited by intersex activists and entirely dedicated to the discussion of intersex issues;
- a list of guideline for non-intersex writers writing about intersexuality and intersex people;
- the pamphlet "Introduction to Intersexuality and Intersex Activism: A Starting Point for Feminist, Queer and Trans Activists";
- the latest newsletter from ISNA and Survivor Project;
- original buttons made by

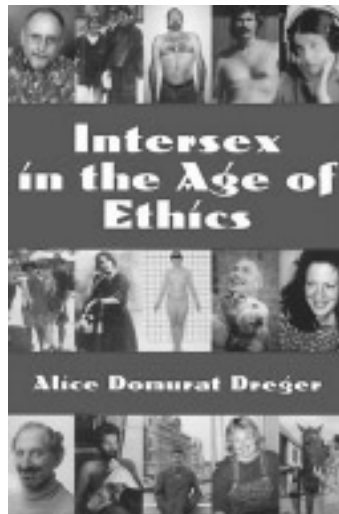
Eminism.org

- and more!

By purchasing this package, you save more than \$100 over the list price of the individual items.

Assorted Intersex Activist Buttons from Eminism.org (\$15)

Assorted 1" round buttons made by Eminism.org. Get five each of three different buttons (ISNA logo, "It's the consent, stupid," and "It's not a choice; we were mutilated that way"). Total 15 buttons.



Resources

For further information about intersex

.....

Books

Intersex in the Age of Ethics (Alice Dreger, ed.)

See the catalogue section.

Hermaphrodites and the Medical Invention of Sex (Alice Dreger)

See the catalogue section

Sexing the Body (Anne Fausto-Sterling)

See the catalogue section

As Nature Made Him (John Colapinto)

While not a book about intersex, this story is about a boy who was turned into a girl after an accident during circumcision. Don't get caught up in the "nature versus nurture" debate and pay attention to the child's voice.

Looking Queer (Dawn Atkins, ed.)

This anthology is about how queer people's body images, but devotes an entire chapter for intersex people's narratives (Cheryl Chase, Raven Kaldera, and Morgan Holmes)

Articles in Magazines

Making the Cut (Martha Coventry), *Ms.*, Oct./Nov. 2000

Introductory article about clitorrectomy in the United States. Includes author's own experience in a separate column.

The Missing Vagina Monologue (Esther Morris), *Soujourner*, March 2001

Author describes her experience of growing up with and being "treated" for MRKH, or

vaginal agenesis.

Academic Articles

Re-membering a Queer Body (Morgan Holmes), *Undercurrents*, May 1993

One of the first articles about intersexuality written by an intersex person. This article explores the heteronormative cultural imperatives that drive doctors to perform surgeries on intersex children.

Intersex Activism, Feminism, and Psychology (Peter Hegarty and Cheryl Chase), *Feminism and Psychology*, vol. 10

Subtitled "opening a dialogue on theory, research, and clinical practice," authors explore how to incorporate intersex and feminist activism in the discipline of psychology.



Intersex activists at NGLTF's Creating Change 2000

Web Sites

Intersex Society of North America

<http://www.isna.org/>

The UK Intersex Association

<http://www.ukia.co.uk/>

AIS Support Group UK

<http://www.medhelp.org/www/ais/>

AIS Support Group Australia

<http://www.vicnet.net.au/~aissg/>

CAH Our Voices & Our Stories

<http://www.cahourstories.net/>

MRKH.org

<http://www.mrkh.org/>

Hypospadias Association of America

<http://www.hypospadias.net/>

Survivor Project

<http://www.survivorproject.org/>

Order Form

Photocopy and fill in this form or order online

.....

☐ Here's my tax deductible gift of ☐ \$20 ☐ \$50 ☐ \$75 ☐ \$100 ☐ Other \$ _____

☐ *Hermaphrodites Speak!* (video) \$50

☐ *Redefining Sex* (video) \$50

☐ *Is it a Boy or a Girl?* (video) \$50

☐ *Intersex in the Age of Ethics* by Alice Dreger, ed. (book) \$25

☐ *Hermaphrodites and Medical Invention of Sex* by Alice Dreger (book) \$20

☐ *Lesson from the Intersexed* by Suzanne Kessler (book) \$20

☐ *Teaching Kit for Women's, Gender & Queer Studies* (package) \$75

☐ *Chrysalis* Special Issue (newsletter back issue) \$10

☐ *Journal of Clinical Ethics* Special Issue (back issue) \$35

Payment Options: ☐ Check / Money Order ☐ Mastercard ☐ Visa

Credit Card Number: _____

Expires: _____ / _____

Name: _____

Organization: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____

Email: _____

Address me as: ☐ first name ☐ Ms. ☐ Mr. ☐ Dr. ☐ Other _____

☐ Keep my donation anonymous

Make your check payable to "ISNA."

ISNA

PO Box 301

Petaluma, CA 94953

USA



W1B1001XXP