

Introduction to Intersex Activism

A Guide for Allies

THE SECOND EDITION



Members of The Transexuam Menace joined intersex activists in the historic demonstration at the 1996 American Academy of Pediatrics annual meeting

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Introduction to Intersex Activism (The Second Edition)

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Introduction

What it means to become an ally to the intersex movement

Welcome to the Second Edition of *Introduction to Intersex Issues*, and thank you for your interest in the intersex movement. I developed the first edition for Intersex Society of North America (ISNA) two years ago, but much of its information (including my ISNA email address) has become outdated. That is why Intersex Initiative (the organization I now run) is publishing this updated and expanded (and nicer-looking) edition.

Intersex movement is a young movement; in fact, it has been only ten years since the founding of ISNA, the first broad patient advocacy group in the United States. From the beginning, we have worked together with our allies—LGBT activists, academics, students, disability activists, progressive medical professionals, writers, and others—who shared their resources, made phone calls on our behalf, spoke out in medical school classroom, spread our stories, carried signs with us at our actions, and cried with us.

An ally is someone who may not herself or himself have intersex conditions/histories/experiences, but who is committed to creating the world free of shame, secrecy, and isolation that are imposed on intersex children. It is our family members, partners, friends, neighbors, colleagues, teachers, service providers. One does not have to have the intersex condition/background to be able to do good activism.

This booklet has two main goals. The central goal of this booklet, obviously, is to educate readers about how they could become allies to the intersex movement. But there is another goal that is just as important, that is to give *permission* for our allies to *do something*. There are a lot of people who are interested in becoming allies but are afraid of actually making the move fearing that they might misrepresent the issues or otherwise inadvertently cause damages to the movement that they are trying to help. This booklet is intended to provide enough information for our allies so that they will feel comfortable and confident speaking out about intersex issues.

As I write this, Intersex Initiative, along with Bodies Like Ours, ISNA, and other activists are working together to create an annual “day of intersex activism” (official name undecided) which we envision as something similar to Take Back the Night march, Pride parade, International Women’s Day, or the National Coming Out Day. Through building this event in 2004 and beyond, we hope to begin building a strong grass-roots support for the intersex movement (see Appendix A for more information about this project).

That is one of many ways you can be involved. If you have thought about getting involved in the intersex movement, now is the time. We welcome your participation wherever you are.

Emi Koyama (emi@ipdx.org), Director
Intersex Initiative (www.ipdx.org)

Medical Abuse of Intersex Children & the Child Sexual Abuse

by Emi Koyama, Intersex Initiative Portland

The notion “genital mutilation” evokes an image of the traditional, ritualistic cutting of young women’s bodies in Africa, but its equally ritualistic high-tech version is widely practiced in the U.S. and other Western countries in relative secrecy. Since 1950s, children born with intersex conditions, or physiological anomalies of the reproductive and sexual organs, have been “treated” with “normalizing” surgeries that many survivors say are damaging to their sexual and emotional well-being.

Contrary to the popular mythology, intersex people do not have “both sets of genitals”; they simply have body parts that are different from what is considered “normal”—large clitoris, penis with a urethra on its underside, missing vagina, mixed gonads, etc. Even though it has been practiced for many decades, there is no long-term study that shows that “corrective” surgery is safe, effective, nor necessary.

One of the biggest problems with this “treatment” is that it sets in motion a lifelong pattern of secrecy, isolation, shame, and confusion. Adult intersex people’s stories often resemble that of those who survived childhood sexual abuse: trust violation, lack of honest communication, punishment for asking questions or telling the truth, etc. In some cases, intersex people’s experiences are exactly like those of child sexual abuse survivors: when they surgically “create” a vagina on a child, the parent—usually the mother—is required to “dilate” the vagina with hard instruments every day for months in order to ensure that the vagina won’t close off again.

Even so, many intersex adults report that it was not necessarily the surgery that was most devastating for their self-esteem: for many, it is the repeated exposure to what we call “medical display,” or the rampant practice where a child is stripped down to nude and placed on the bed while many doctors, nurses, medical students, and others come in and out of the room, touching and prodding and laughing to each other. Children who experience this get the distinct sense that there is something terribly wrong with who they are and are deeply traumatized.

In the past decade, the movement to challenge these medical abuses of intersex children grew from complete obscurity into an international network of intersex individuals, scholars, supporters, and some sympathetic medical professionals. Still, it is estimated that five children per day continue to undergo the medically unnecessary and irreversible surgeries in the United States. Progressive activists need to work with the intersex movement in order to end the ritualistic sexual abuse of children in our own society, not just in other continents.

Frequently Asked Questions About Intersex Activism & Intersexuality

by Intersex Initiative Portland

What is intersex?

Technically, intersex is defined as “congenital anomaly of the reproductive and sexual system.” Intersex people are born with external genitalia, internal reproductive organs, and/or endocrine system that are different from most other people. There is no single “intersex body”; it encompasses a wide variety of conditions that do not have anything in common except that they are deemed “abnormal” by the society. What makes intersex people similar is their experiences of medicalization, not biology. Intersex is not an identity. While some intersex people do reclaim it as part of their identity, it is not a freely chosen category of gender—it can only be reclaimed. Most intersex people identify as men or women, just like everybody else.

What do intersex activists want?

We are working to replace the current model of intersex treatment based on concealment with a patient-centered alternative. We are not saying that intersex babies are better off left alone; we want there to be social and psychological support for both the parents and intersex children so that they can deal with social difficulties resulting from being different than others. In the long-term, we hope to remove those social barriers through education and raising awareness. See Alice Dreger’s chart contrasting the two paradigms in the Appendix of this handbook.

Are intersex conditions harmful?

In general, intersex conditions do not cause the person to feel sick or in pain. However, some intersex conditions are associated with serious health issues, which need to be treated medically. Surgically “correcting” the appearance of intersex genitals will not change these underlying medical needs.

How common are intersex conditions?

No one knows exactly how many children are born with intersex conditions because of the secrecy and deception surrounding it, and also because there is no concrete boundaries to the definition of “intersex.” It is nonetheless estimated that about one in 2,000 children, or five children per day in the United States, are born visibly intersex, prompting early intervention.

What is the difference between “hermaphrodite” and “intersex”?

In biology, “hermaphrodite” means an organism that has both “male” and “female” sets of reproductive organs (like snails and earthworms). In humans, there are no actual “hermaphrodites” in this sense, although doctors have called people with intersex conditions “hermaphrodites” because intersex bodies do not neatly conform to what doctors define as the “normal” male or female bodies. We find the word “hermaphrodite” misleading, mythologizing, and stigmatizing. Although some intersex activists do reclaim and use this term to describe themselves, it is not an appropriate term to refer to intersex people in general. In short, snails are the hermaphrodites; humans are not. Also, please avoid using the word “intersexual” as a noun; we prefer “intersex people” or “people with intersex conditions/experiences.”

Can’t they just do a test to find out babies’ true sex?

Medicine cannot determine the baby’s “true sex.” For example, chromosomes do not necessarily dictate one’s gender identity, as it is obvious from the fact that most people born with androgen insensitivity syndrome live as women despite their XY chromosomes. In other words: science can measure how large a clitoris is, but cannot conclude how large or small it needs to be. That is a social determination.

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. It is recommended that the child be assigned 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. Performing surgeries will not eliminate the possibility that our prediction is wrong.

Are there five sexes?

The notion of “five sexes” was popularized by Anne Fausto-Sterling’s article “The Five Sexes: Why Male and Female Are Not Enough” published in 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 people with intersex conditions. In addition to exoticizing and sensationalizing intersex people, the distinction between three additional “sexes”—merm, ferm and herm—are artificial and useless in improving the lives of intersex people. Fausto-Sterling later wrote in *Sexing the Body* (2000) that she was “no longer advocating” these categories, “even tongue in cheek.”

Are intersex people “third gender”?

Many people with intersex conditions identify solidly as a man or as a woman, like many non-intersex people. There are some 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 people with intersex conditions should be expected to be gender-transgressive just because of their condition.

Is intersex part of “transgender” community?

While some people with intersex conditions also identify as transgender, intersex people as a group have a unique set of needs and priorities beyond those shared with trans people. Too often, these unique needs are made invisible or secondary when “intersex” becomes a subcategory of “transgender.” For example, people who discuss about intersex in the context of transgender often stress the risk of assigning a “wrong” gender as an argument against intersex genital mutilation, which overlooks the fact that intersex medical treatment is painful and traumatic whether or not one’s gender identity happens to match her or his assigned gender. It is for this reason that we prefer to have “intersex” spelled out explicitly rather than have it “included” in “transgender” umbrella.

What is the correct pronoun for intersex people?

Pronouns should not be based on the shape of one’s genitalia, but on what the person prefers to be called. For children too young to communicate what her/his preference is, go with the gender assignment parents and doctor agreed on based on their best prediction. Do not call intersex children “it,” because it is dehumanizing.

How can I help intersex movement?

Join us! In addition to volunteering for or making donations to intersex activist groups such as Intersex Initiative Portland, you can help by talking to your friends and family members about the intersex movement. The idea is that the more people are aware about us, the less likely they will accept surgery as the only option when they or someone they know have an intersex baby. Get your community, church or school group together and show documentary films about intersex (available from Intersex Society of North America) or invite us to present.

Where can I read more about intersex movement?

Please see other sections of this handbook.

Shifting the Paradigm of Intersex Treatment

by Alice Dreger, Ph.D. <dreger@isna.org>

for Intersex Society of North America

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Key points of comparison	Concealment Centered Model	Patient Centered Model
What is intersex?	Intersex is a rare anatomical abnormality which is highly likely to lead to great distress in the family and great distress for the person with an intersex condition. Intersex is pathological and requires immediate medical attention.	Intersex is a relatively common anatomical variation from the “standard” male and female types; just as skin and hair color vary along a wide spectrum, so does sexual and reproductive anatomy. Intersex is neither a medical nor asocial pathology.
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, hormones, and/or prenatal life are/were like.	Both, surely, but that isn’t the point. The point is that people with intersex conditions 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, and freedom from discrimination. Physicians, researchers, and gender theorists should stop using people with intersex conditions in “nature/nurture” experiments or debates.
Are intersexed genitals a medical problem?	Yes. Untreated intersex is highly likely to result in depression, suicide, and possibly “homosexual” orientation. Intersexed genitals must be “normalized” to whatever extent possible if these problems are to be avoided.	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 concerns should be treated medically, but intersexed genitals are not in need of medical treatment. There is no evidence for the concealment paradigm, and there is evidence to the contrary.

<p>What should be the medical response?</p>	<p>The correct treatment for intersex is to “normalize” the abnormal genitals using surgical, hormonal, and other technologies. Doing so will eliminate the potential for parents’ psychological distress.</p>	<p>The whole family should receive psychosocial support (including referrals to peer support) and as much information as they can handle. True medical problems (like urinary infections and metabolic disorders) should be treated medically, but all non-essential treatments should wait until the person with an intersex condition can consent to them.</p>
<p>When should treatments designed to make a child’s genitals look “normal” be done?</p>	<p>As soon as possible because intersex is a psychosocial emergency. The longer you wait, the greater the trauma.</p>	<p>ONLY if and when the intersexed person requests them, and then only after she or he has been fully informed of the risks and likely outcomes. These surgeries carry substantial risks to life, fertility, continence, and sensation. People with intersex conditions should be able to talk to others who have had the treatments to get their views.</p>
<p>What is motivating this treatment protocol?</p>	<p>The belief that our society can’t handle genital ambiguity or non-standard sexual variation. If we don’t fix the genitals, the child with an intersex condition will be ostracized, ridiculed, and rejected, even by his or her own parents.</p>	<p>The belief that the person with an intersex condition has the right to self determination where her or his body is concerned. Doing “normalizing” surgeries early without the individual’s consent interferes with that right; many surgeries and hormone treatments are not reversible. The risks are substantial and should only be taken if the patient has consented.</p>
<p>Should the parents’ distress at their child’s condition be treated with surgery on the child?</p>	<p>Yes, absolutely. Parents can and should consent to “normalizing” surgery so that they can fully accept and bond with their child.</p>	<p>Psychological distress is a legitimate concern and should be addressed by properly trained professionals. However, parental distress is not a sufficient reason to risk a child’s life, fertility, continence, and sensation.</p>

<p>How do you decide what gender to assign a newborn with an intersex condition?</p>	<p>The doctors decide based on medical tests. If the child has a Y chromosome and an adequate or “reconstructable” penis, the child will be assigned a male gender. (Newborns must have penises of 1 inch or larger if they are to be assigned the male gender.) If the child has a Y chromosome and an inadequate or “unreconstructable” penis according to doctors, the child will be assigned a female gender and surgically “reconstructed” as such. If the child has no Y chromosome, it will be assigned the female gender. The genitals will be surgically altered to look more like what doctors think female genitals should look like. This may include clitoral reduction surgeries and construction of a “vagina” (a hole).</p>	<p>The parents and extended family decide in consultation with the doctors. This approach does not advocate selecting a third or ambiguous gender. The child is assigned a female or male gender but only after tests (hormonal, genetic, diagnostic) have been done, parents have had a chance to talk with other parents and family members of children with intersex conditions, and the entire family has been offered peer support. We advocate assigning a male or female gender because intersex is not, and will never be, a discreet biological category any more than male or female is, and because assigning an “intersexed” gender would unnecessarily traumatize the child. The doctors and parents recognize, however, that gender assignment of infants with intersex conditions as male or female, as with assignment of any infant, is preliminary. Any child may decide later in life to change their gender assignment; but children with intersex conditions have significantly higher rates of gender transition than the general population, with or without treatment. That is a crucial reason why medically unnecessary surgeries should not be done without the patient’s consent; the child with an intersex condition may later want genitals (either the ones they were born with or surgically constructed anatomy) different than what the doctors would have chosen. Surgically constructed genitals are extremely difficult if not impossible to “undo,” and children altered at birth or in infancy are largely stuck with what doctors give them.</p>
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<p>What should the person with an intersex condition be told when she or he is old enough to understand?</p>	<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 vague language, like “we removed your twisted ovaries” instead of “we removed your testes” when speaking to a woman with AIS.</p>	<p>Everything known. The person with an intersex condition and parents have the right and responsibility to know as much about intersex conditions as their doctors do. Secrecy and lack of information lead to shame, trauma, and medical procedures that may be dangerous to the patient’s health. Conversely, some people harmed by secrecy and shame may avoid future health care. For example, women with AIS may avoid medical care including needed hormone replacement therapy.</p>
<p>What’s wrong with the opposing paradigm?</p>	<p>Parents and peers might be uncomfortable with a child with ambiguous genitalia. Social institutions and settings like locker rooms, public restrooms, daycare centers, and schools will be brutal environments for an “abnormal” child. The person with an intersex condition might later wish that her or his parents had chosen to have her or his genitals “normalized.”</p>	<p>The autonomy and right to self determination of the person with an intersex condition is violated by the surgery centered model. In the concealment model, surgeries are done without truly obtaining consent; parents are often not told the failure rate of, lack of evidentiary support for, and alternatives to surgery. Social distress is a reason to change society, not the bodies of children.</p>
<p>What is the ideal future of intersex?</p>	<p>Elimination via improved scientific and medical technologies.</p>	<p>Social acceptance of human diversity and an end to the idea that difference equals disease.</p>
<p>Who are the proponents of each paradigm?</p>	<p>John Money and his followers, most pediatric urologists and pediatric endocrinologists, and many gynecologists and other health care practitioners.</p>	<p>Intersex activists and their supporters, ethicists, some legal scholars, medical historians, and a growing number of clinicians.</p>

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For additional reading or to download a copy of this comparison chart, please visit the website of the Intersex Society of North America: <http://www.isna.org/>

Resources for Further Learning

Books

Intersex in the Age of Ethics by Alice Dreger (ed.)
Intersex and Identity: Contested Self by Sharon Preves
Hermaphrodites and the Medical Invention of Sex by Alice Dreger
Lessons from the Intersexed by Suzanne Kessler
As Nature Made Him by John Colapinto

Booklets/Journal Issues

“Intersex: Awakening” issue of *Chrysalis* (available from ISNA)
A Speaker’s Handbook for Intersex Activists & Allies by Intersex Initiative
Teaching Intersex Issues by Intersex Initiative

Films (available from ISNA)

Hermaphrodites Speak! by ISNA
Intersex: Redefining Sex
Is it a Boy or a Girl?
First, Do No Harm by ISNA
Mani’s Story

Web Sites

Intersex Activism:
Intersex Initiative <www.ipdx.org>
Bodies Like Ours <www.bodieslikeours.org>
Intersex Society of North America <www.isna.org>
UK Intersex Association <www.ukia.co.uk>

Condition-Specific Support:
MRKH <www.mrkh.org>
AIS Support Group UK <www.medhelp.org/www/ais>
AIS Support Group Australia <home.vicnet.net.au/~aissg>
CAH Our Voices & Our Stories <www.cahourstory.net>

We picked these sites because they have a lot of articles and personal stories. Many other sites are linked from them as well.

Items marked “available from ISNA” can be ordered from ISNA’s online store at <www.isna.org/store>. To order items from Intersex Initiative, see the Appendix B.

Being Accountable to an Invisible Community

by Emi Koyama, Intersex Initiative

Intersex conditions are relatively rare, but not that rare. To give you an idea, there were about 8,000 intersex people living in the state of Florida alone during the 2000 Presidential Election, which means that intersex people could have tipped the election to Al Gore if they voted in a block! (To which my liberal friend said, “but if intersex people were voting in a block, they will find a way to disqualify intersex votes.”)

Of course, there has never been an intersex voting block, or even an intersex political action committee. Indeed, despite the fact that there are tens of thousands of intersex people in this country, only a small number of people have publicly come out as “intersex.” Where are the rest of intersex people?

Some do not know that they have an intersex condition, either because they have not been properly diagnosed or have not been told by their doctors and parents about their condition. Some do know about the condition that they have, but do not know that their condition may be considered part of intersex. Some reject the term “intersex” because of its negative association with “hermaphrodite” and other freaky imagery. For many, intersex is a site of pervasive physical and sexual violation, which they do not want to re-visit at all. Some wish to push away intersex as something that has happened in the past. Some are struggling hard just to stay alive. Some feel isolated and alienated by everyone around them, and do not feel that it is possible to “come out.”

When we talk about intersex, we are talking about a lifelong history of shame, secrecy and isolation that are imposed on children who were born with slightly different bodies. We are talking about childhood sexual trauma, dirty family secret, repeated stripping in examination rooms, and the knowledge that whatever body you were born with was defective on arrival. It is not surprising that most people born with intersex conditions do not identify as “intersex” either publicly or privately.

As a result, the demographics of the few intersex activists who “come out” is skewed to be: mostly white, often college-educated, often LGBT or genderqueer (because queer people are already familiar with the process of coming out and doing activism, and also because they are more willing to go outside of standard sex/gender categories). This group, however, does not necessarily represent the rest of the people who are born with intersex conditions.

I personally do not consider “intersex” to be part of my identity. I feel that intersex is something that was done to me, not who I am. Nonetheless I am publicly “out” as an intersex activist, because I feel that taking such position is useful politically. Once people recognize me as an intersex

activist, I can then start talking about what I actually feel about the label.

This creates a problem for the people who want to become allies to the intersex movement. If the few “out” intersex activists do not represent the rest, where should allies draw guidance as to what to do? How can allies act responsibly to the people who do not speak out?

As a relatively well-known intersex activist, I have come in contact with many people with intersex conditions who are not otherwise “out” as intersex or do not identify as intersex. Some of these people participate in condition-specific (such as CAH and AIS) support groups, while others are completely isolated. Even with the insight coming from these meetings, I am still unsure sometimes if certain things I say or do is actually in the best interest of intersex people as a whole.

There are some things that I am absolutely certain, such as that clitoral genitoplasty and vaginoplasty on a child is a bad idea. This is supported by many stories I have heard as well as the latest medical researches. But on other topics, such as when there was a discussion about whether or not to include “intersex” in PFLAG, I have had to make a judgment call based on everything I know about the situation and my own personal conviction.

As an ally, you will not get to hear from 99% of the people you are working to advocate for. But you are still accountable to them, as I am to my less vocal peers. Your best guide, aside from what “out” intersex activists will tell you, is your common sense.

Common sense should tell you that intersex people are regular people just like everyone else. Some are male, some are female, and there are few who explore alternative gender categories—just like the non-intersex population. Some are gay or lesbian, some are bisexual, and some are straight. It makes no sense to assume that someone is gay or transgender because s/he is intersex, because a) there are gays and transgender people who aren't intersex, and b) there are intersex people who are not gay or transgender.

Common sense should tell you that whether or not one's genitalia matches her or his gender identity is not the only thing that matters. The problem with the intersex surgery is that it's harmful and in violation of the child's right to self-determination. The risk of assigning the “wrong gender” is not the only argument against this surgery, nor is it the biggest one.

Common sense should tell you that using intersex babies to argue for some abstract theory or someone else's agenda, such as the social acceptance of a “third gender,” is wrong. Most intersex people live happily as women or men just like everyone else, although they may be unhappy about the shame, secrecy and isolation that were imposed on them through medicine. If we were to advocate for the social acceptance of “third gender,” that should be the responsibility of adults, whether intersex or not, rather than that of intersex children.

This is just the beginning. Use your common sense and focus on how to improve the lives of people with intersex conditions now and in the future. Ask us questions, but sometimes be willing to question the answers coming from the few “out” intersex activists including myself.

Why I Am Speaking About Intersex Issues

by Tara Medve, Intersex Initiative

When Emi asked me to give presentations about intersex, I felt very excited and honored. However, I also felt nervous about speaking publicly about intersex because I am not intersexed and I was afraid that I might mislead or give inaccurate information to the audience. We thought that others might have similar fears and apprehensions as myself, hence the reason for this essay.

I first became interested in intersex while in college. To receive my B.A. in Women's and Gender Studies, it was required that I write a Capstone paper on a topic of my own choosing. I had heard a little about intersex, and like many other non-intersex academics before me, I wanted to use the concept of intersex to make an argument for social constructivism and gender performativity—and against biological determinism. Once I began researching, I realized that I was into something far greater than I had originally anticipated. My mind was suddenly opened to avenues not yet explored in my understandings of sex, gender, sexuality, and identity. With this, however, came the realization that the paper I had envisioned writing would be virtually impossible. My topic was way too large and vague, and it was imperative for me to narrow it down.

After a few false starts and lots of brainstorming, I decided to analyze narratives written by intersex people about their experiences, and to transform my project into a sort of ethnography. Looking back, I wonder why I chose to focus on narratives, when originally I was interested in theory. The most obvious reason that comes to mind is that after reading several narratives, I realized that many of the common issues faced by intersex people would be neglected in a paper on gender theory because intersex is not about gender identity. I found that theories on intersex were not grounded in the lived experiences of intersex people; therefore, they could not, in good conscience, be the starting off point for my paper.

I was so incredibly moved by the stories that I had read- and so shocked and appalled at the treatment of intersex people in the U.S. society—that it made sense for me to focus my paper on intersex people and their experiences. Also, I remember feeling angry and frustrated with the absence of intersex voices in the academic discourse on intersexuality, and I did not want to produce another text written by a non-intersex person theorizing about the societal and cultural implications of the treatment of intersex. I wanted my Capstone to be a place where the voices of intersex people could be heard, not ignored.

Since then, I have remained interested in the topic of intersex, and I have become an active ally in the movement. I am a firm believer in the idea of reciprocity in research, and for a while I felt that it was my duty to give something back. After all, these individuals had published their stories that I could use; the least I could do is try to help them with their mission.

Plus, I have always believed that theory without action is impractical and useless, and there is so much opportunity for activism in the intersex movement.

I am still learning, through speaking and other means, about intersex. I am in no way an expert on intersex, but I do know a lot more than most people. It is my responsibility to use my education and knowledge in a way that is beneficial to others, and educating others about intersex issues is a wonderful and rewarding way for me to do so.

Tips for Non-Intersex People Speaking About Intersex

by Tara Medve, Intersex Initiative

Below is a list of tips and guidelines that we should keep in mind as allies when speaking about intersex issues. I felt that it would be useful to have these guidelines so that we can avoid some of the common mistakes people make when we try to speak about issues that do not directly impact us.

1. **Remember to center the voices and experiences of intersex people** in your discussions of intersex issues.
2. **You are not an expert on intersex experiences** and you should not pretend to be one. There is nothing wrong with saying that you do not know the answer to a question.
3. When speaking or writing about intersex, **it is important to portray intersex people as complete human beings**, and not to reduce them to their medical conditions.
4. **Be honest about who you are and why you are involved in intersex activism.** This includes thinking and talking about how intersex informs your own life and the society you live in.
5. **Speak responsibly and cautiously.** Your speech might be the first exposure to the topic of intersex that members of the audience have had.
6. **Stay on topic** as much as possible. So many people conflate the experiences of LGBT people that you will most likely have to field many questions regarding gender and sexuality. It is important to remind yourself that you are speaking on intersex, and to keep the discussion on topic. For example, even though I have a fairly solid grip on gender theory and thoroughly enjoy talking about it, a speech on intersex is neither the time nor the place to do so.
7. I am **continually learning how to become a better ally.** A large part of being a good ally is being open to criticism and guidance from intersex people.

8. Always **give your audience resources** for further learning.

9. **Do not use intersex to forward your own political agenda.** Being an ally requires you to focus on the issues most important to the people you are supporting, not the issues most interesting to you. Stopping the medical abuse of intersex people is the primary mission of intersex activism, and one should not lose sight of this while speaking about intersex.

10. **Do not assume that there are no intersex people in the room** just because nobody has come out as such. Do not ask hypothetical questions that take for granted that none of the people in the room is intersex or that none of them has a family member or friend who is.

Suggested Guidelines for Non-Intersex Individuals Writing About Intersexuality & Intersex People

By Emi Koyama, Intersex Initiative Portland

Inspired by Jacob Hale's "Suggested Rules for Non-Transsexuals Writing about Transsexuals, Transsexuality, Transsexualism, or Trans____." Editing suggestions by Cheryl Chase.

1. **Recognize that you are not the experts about intersex people,** intersexuality, or what it means to be intersexed; intersex people are. When writing a paper about intersexuality, make sure to center voices of intersex people.

2. **Critically approach writings by non-intersex "experts"** such as doctors, scientists, and academics about intersexuality or intersex people if you decide to quote or cite them. That is, consider what the author's perspective and agenda are, and where his or her knowledge comes from.

3. Do not write about intersex existence or the concept of intersexuality without talking about the **lives and experiences of intersex people** as well as issues they face. Do not use intersex people merely to illustrate the social construction of binary sexes.

4. **Do not judge the politics and narratives of intersex people or movement** based on how useful they are to your political agenda (or agendas). Intersex people are no more responsible for dismantling gender roles or compulsory heterosexuality than anyone else is.

5. Be aware that writings by intersex people are often part of conversations within the intersex movement and/or with other communities, including the medical community. **Realize that intersex people's words may be addressing certain constituencies or political agendas** for which you do not have access to the full context.

6. **Do not conflate intersex experiences with lesbian, gay, bisexual or trans (LGBT) experiences.** You may understand what it might feel to grow up “different” if you are part of the LGBT community, but that really does not mean you understand what it means to grow up intersexed.

7. **Do not reduce intersex people to their physical conditions.** Depict intersex people as multidimensional human beings with interests and concerns beyond intersex issues.

8. Focus on what looking at intersexuality or intersex people tells you about yourself and the society, rather than what it tells you about intersex people. **Turn analytical gaze away from intersex bodies or genders** and toward doctors, scientists, and academics who theorize about intersexuality.

9. **Do not represent intersex people as all the same.** How people experience being born intersex is at least as diverse as how people experience being born non-intersex, and is impacted by various social factors such as race, class, ability, and sexual orientation, as well as actual medical conditions and personal factors. Do not assume that one intersex person you happen to meet represents all or even most intersex people.

10. **Assume that some of your readers will themselves be intersex,** and expect that you may be criticized by some of them. Listen to intersex people when they criticize your work, and consider it a gift and a compliment. If they thought that you had nothing to contribute, they would not bother to engage with you in the first place.

11. **Remember: five children are being mutilated every day** in the United States alone. Think about what you can do to help stop that.

Part Three

Additional Readings for Building Alliances

Interrogating the Politics of Commonality: Building a Bisexual, Trans and Intersex Alliance

By Emi Koyama, Intersex Initiative Portland

Below is the keynote speech presented at the “Transcending Boundaries” conference at Yale University on October 21, 2001. The theme of the conference was about bisexual, trans and intersex activists working together.

First of all, I’d like to thank the organizing committee for hosting this groundbreaking conference and for providing me this opportunity to speak at this concluding plenary session.

This conference is about alliance. It’s about how we, as bisexual, trans, intersex, all of the above and more, can work together to increase visibility, transform institutions, and enhance our lives.

I want to start off my speech by talking about how bisexual, trans and intersex politics emerged within the broader so-called LGBT (and sometimes I) movement and why it was necessary, or to put it more bluntly, what was wrong with the single-issue identity politics of the “gay movement.”

A common misperception about what is wrong with identity politics is that it is wrong because it excludes people who stand on the side of privilege. For example, feminism has been criticized as anti-male, and gay movement has been said to promote “special rights” over heterosexuals. These are not legitimate critiques of identity politics, because the whole point of having a movement is to empower groups with significant social, political and economic disadvantage.

The true reason single-issue identity politics is flawed is not that it excludes those in power - like men, white people, heterosexuals, the rich - but that it inherently reinforces the invisibilization and marginalization of people with multiple or mixed identities or backgrounds both within the movement and in the society.

I witnessed this effect of single-issue politics the last time I visited Yale University, which was in April this year. I had been invited by Yale Women’s Center to speak about third wave feminisms, so I took that opportunity to look around the campus and get to know people.

What happened was this: Yale University’s GLBT student organization had just held a week of events celebrating queer lives and issues. The problem was that almost all of presenters featured had been white, with little multi-racial or multi-cultural representation, reinforcing the myth that all queers are white. The group of queer people of color protested how it happened, and while the white organizers of the week acknowledged that racism may have played part in it, they also blamed queer people of color

for not attending meetings and giving their input.

The discussion went on and on without any concrete proposals to resolve the problem, so I asked them if they could have a weekly anti-racism training groups for white members of the group. Now, I didn't really expect that this would fly, and it didn't: white members complained that they were already extremely busy and there is no way they could fit another meeting to their schedule.

And that was my point: because of racism, queer students of color have to spend another hour, perhaps many more hours, every week in meetings and in personal support in addition to everything else white students do, and cannot be expected, realistically, to attend the GLBT meetings as much as white people do, unless of course white people also agree to spend certain amount of time every week dealing with the issue of racism.

What this shows is that any movement that only addresses one issue, in this case GLBT—but mostly gay and lesbian, is bound to represent the interests of those who only have to deal with that one issue. In other words, if you go to feminism, you have white straight women in the leadership; if you go to gay activism, you will find white gay men; and in anti-racism, you will see that straight men of color lead the groups.

So if you are like me, a fat Asian intersexed genderqueer bi-dyke with disabilities, you are out of luck. Because movements are so segmented, I would have to do more work than anybody else without gaining the recognition for the total of work that I do.

This would mean that the leadership of each of these movement would be made up of people who address only one issue, which will most likely result, for example, in the “gay” agenda that fails to recognize that factors such as race, class, gender, and nationality impact varied ways we experience homophobia.

This hold true not only for people with multiple identities, but also for people with mixed identities or backgrounds, which is the theme of this conference. We all know how bisexual people are asked by gay and lesbian activists to support same-sex marriage or domestic partnership registry, and yet given cold shoulder if we decide to date a partner of a different sex. Or how both bisexual and transsexual people are accused of exercising internalized homophobia for merely being true to who we are. Bisexual and trans people have been told that we are, or our partners are, not part of the “community” and are un-welcome at some of the events.

But what about intersex people? How do intersex people experience our “inclusion” in the greater GLBT movement? What are the problems, and how can it become a true inclusion, rather than just inclusion in the name?

A trans activist from New York City contacted ISNA about the proposed city ordinance designed to prohibit the discrimination against trans people. She asked us how to word the ordinance to include intersex people. But the protection from discrimination in employment, housing

and public accommodation is extremely inadequate to defend intersex people's civil rights, because much of the violation of our civil rights take place in other areas.

Two years ago, the president of the National PFLAG gave a speech in which he mentioned the existence of intersex people. He said that because there are people who are physically neither completely male nor completely female, heterosexuality cannot possibly be the only "natural" sexual options. Such use of intersex existence objectifies intersex people, and does not help the intersex movement.

A group for "female-assigned gender-variant" people in Portland conducted a survey about their experience with health professionals last year. The survey specifically included "intersex" as one of the groups asked to participate, and yet did not have any question related to intersex issues. Apparently, they intended to only include intersex people who are transitioning from female-to-male.

A gay and lesbian group in San Jose contacted ISNA this summer, asking us to do a presentation about the biological basis of sexes. They felt that it was necessary to know about biology in order to help intersex movement, but that would not have helped us. What we are dealing with here is civil rights, and it is not necessary to understand the biological basis for sex to advocate for intersex people any more than it is necessary to understand the biological basis of skin color to fight against racism.

A trans group in San Francisco distributed a "definition list" which included the explanation of "intersex" and how we are surgically operated on routinely. It talked about how horrible it is that doctors often get the gender identity of the child wrong, as if that is the only problem with the mutilation of children's genitals.

A GLBT political lobbying group surveyed candidates' positions on sexual minority issues for the election last year. The question asked whether or not the candidate would agree that intersex people should be labeled as neither male nor female, even though this is not the position taken by many intersex activists including ISNA. We believe that everybody, not just intersex people, should have the right to determine her or his gender, be it male, female, or anything else. We oppose using genital shapes to dictate one's gender rather than allowing each individual to decide for herself or himself.

These are just anecdotes, but I think they demonstrate the danger of collapsing gay, lesbian, bisexual, trans and intersex experiences into a single set of pre-defined agenda.

We frequently hear that bisexual, trans and intersex people are "natural allies" because we all share victimization from the dualistic view of sex, gender and sexuality. We all share the sense of being a "minority within the minority."

But I am here to say that, no, we are not "natural allies." Not only that, I'm willing to say that a bisexual person is not necessarily a "natural ally" to other bisexuals, and a trans person is not necessarily a "natural ally"

to other trans people, and an intersex person is not necessarily a “natural ally” to other intersex people. To suggest that any of us are “natural allies” to one another erases the specificity of our multiple and mixed identities and backgrounds.

If we are not “natural allies,” then, we need to work at it in order to build alliances. We need to actively listen and learn from each other, and be willing to celebrate our differences as much as our commonalities. We need to honor the leadership of each unique individuals to set priorities and agenda on issues that matter to us.

So, as the first act of such alliance building, I would like to ask everyone: will you stand for me, so that I can stand for you?

Thank you.

What is Wrong with “Male, Female, Intersex”

A letter by Emi Koyama, Intersex Initiative

Below is a letter I sent to Outside In, a community clinic, after I visited it to receive treatment for an infection. Later, I was invited to present about intersex at a staff meeting, which went really well. –ek

Hello Outside In,

My name is Emi Koyama and I am the director of Intersex Initiative, a Portland-based activist group working to end the medical abuse of children born with intersex conditions. I also came in the Outside In clinic as a client on June 23, which led me to write this letter to you.

On the first intake sheet I was made to fill out, I noticed a curious “inclusion” of “intersex” and “transgender” categories along with “male” and “female” sexes. I realize that this reflects the agency’s eagerness to acknowledge the diverse population that visit the clinic, but it is wrong to list “intersex” as a sex. Here are some reasons:

* Vast majority of people born with intersex conditions live as a woman or a man, and do not view themselves as a member of a different gender/sex category. Most people born with intersex conditions do not think “intersex” to be who they are; it is simply a medical condition, or a lived history of medicalization. Most people with intersex conditions would answer “no” if they are asked “is your gender/sex intersex?”

* Most people who would check “intersex” are probably not intersex, but transgender or genderqueer people who do not know what intersex means. I’m talking about the people who feel that they do not belong to either male or female gender who mistakenly think “intersex” describes who they are. This is a very common misperception among transgender and genderqueer people, which basically renders this portion of the

intake form useless.

* To list “intersex” along with “male” and “female” gives the false impression that one cannot be male or female if she or he has an intersex condition. This hurts people with intersex conditions who identify as male or female, and mis-informs the general public.

* In the standard medical treatment, physicians view intersexuality primarily as a problem of gender, which is why they narrowly define “successful treatment” as the surgical construction of “normal” appearing genitalia and the development of “normal” gender identity. Intersex activists oppose this point of view, arguing that the patient’s own perception of quality of life—which, by the way, is severely damaged by invasive surgical interventions—as the ultimate measurement of a successful treatment. To put down “intersex” as a gender or sex category negates intersex activists’ effort to question the view that intersexuality is primarily a problem of gender.

* Using “intersex” as a gender or sex category is not simply incorrect; it is hurtful because it makes intersex seem like a neutral, stigma-free category. Intersex activists feel that using “intersex” as a neutral gender or sex category trivializes the actual pain of medical abuse that people go through when they are labeled “intersex.”

I’m sure that you have heard conflicting information about intersex before, which is understandable because intersex activists have not had our own media to spread our message. In the past, a lot of information about intersex have been spread by people who are not intersex: first doctors, then gender theorists, transgender activists, and the media. Please see the additional information on <www.ipdx.org>, and let me know if there is anything else I can do to help make Outside In a safe clinic for people born with intersex conditions.

Emi Koyama
Director, Intersex Initiative
<http://www.ipdx.org/>

Adding the “I”: Intersex in the LGBT Movement

by Emi Koyama, Intersex Initiative

Should LGBT groups add the “I” (for intersex) to their names, mission statements, etc.? That is the question many people are asking, but there is no simple answer.

There are a couple of reasons for adding the “I” to LGBT. First, intersex bodies are pathologized and erased in a way that is similar to how homosexuality has historically been treated within psychiatry. Even though homosexuality has been officially depathologized for three decades, transgender people are still labeled as having “gender identity disorder” and thus treated as something abnormal rather than a natural human variety. From this point of view, intersex is just another sexual minority that is pathologized and treated as “abnormal.”

Another reason is that the surgical treatment for intersex conditions is heavily motivated by homophobia, transphobia, and misogyny. Western medicine defines “functional” male and female genitalia in terms of its ability to participate in a heterosexual intercourse, rather than how much sexual enjoyment patients can achieve—which is why removing a woman’s clitoris is medically acceptable according to (mostly male and straight) doctors, as long as her vagina is deep enough to be penetrated by a penis.

However, some concerns have been raised also about LGBT groups adopting the “I.”

First, some people fear that adding the “I” would give the wrong impression that all or most intersex people are lesbian, gay, bisexual, and/or transgender. Obviously, some intersex people are, and some aren’t—but when we are dealing with young children and their parents, there is a concern that the association with LGBT would drive away parents of intersex children who would otherwise seek out information and resources about intersex conditions.

Second, there is already a lot of conflation between LGBT and intersex in the society, and constantly being combined with LGBT might prevent intersex from getting its own visibility, or make it hard for intersex people to find intersex-specific resources. For example, if you search for the word “LGBTI” on the internet, most articles that would come up deal with LGBT issues—marriage, discrimination, hate crimes, etc.—with no mention of any issues that actually apply to intersex people.

Similar to this, there is also a concern that adding the “I” would make it appear as if what intersex people need is the same thing that LGBT people need. For example, adding intersex to the non-discrimination ordinance or hate crime law is completely insufficient to address the human rights issues faced by intersex people, but it gives the false impression that intersex people’s rights are protected.

Lastly, the model of organizing is very different. People with intersex conditions generally do not organize around the “identity” or “pride” of

being intersex; “intersex” is a useful word to address political issues, but there is yet to be an intersex “community” or “culture” the way we can talk about LGBT communities (although this may change in the future). In other words, adding the “I” does not necessarily make the organization appear more welcoming to intersex people. For many people, “intersex” is just a condition, or history, or site of horrifying violation that they do not wish to revisit.

If that is the case, what can be said about whether or not to add the “I”? I feel that we should take a pragmatic approach.

If adding the “I” would enable you to put your energy and resources onto doing more things that help the intersex movement, then by all means add the “I.” If adding the “I” will help you become a better resource for people with intersex conditions, then do it. You will not make everybody happy at the same time, but at least you are doing something concrete to help end shame, secrecy and isolation.

But do not think that adding the “I” is by itself an achievement. Adding “intersex” to an LGBT group must mean a commitment to take concrete actions to address the specific needs of intersex people; anything less is tokenism, or a mere fashion statement, which will not benefit the intersex movement.



Above: Searching for “LGBTI” on Google.
Google’s smart spellchecker thinks that it’s a typo.

Appendix A: Getting Involved

“Intersex Awareness Day” Consortium

web: <www.intersex-awareness-day.org>
email: <info@intersex-awareness-day.org>

An online public consortium established to plan the annual day of intersex activism similar to Take Back the Night, Queer Pride parade, International Women’s Day and National Coming Out Day. Once you create an account, you can participate in the discussion forum and post news, events, photos, documents, links, and other things for everyone to share. We want to build this into a day of massive grass-roots action! Come to the web site and join in the organizing. An independent project endorsed by Bodies Like Ours, Intersex Initiative, and Intersex Society of North America.

Intersex in V-DAY Resources Project

web: <www.ipdx.org>
email: <vday@ipdx.org>

V-DAY is an international organization founded by Eve Ensler to end the violence against women and girls. Over 500 local V-DAY chapters organize events and fundraisers around the country every year. Because one of its goals is to end genital mutilation on girls and young women, we are working with V-DAY chapters to address the genital mutilation of intersex children (many of whom are assigned female at birth) in their programs. We need people to contact their local V-DAYS—if you are interested in helping us, please email. A joint project of Bodies Like Ours, Intersex Initiative, and Intersex Society of North America.

Intersex Initiative / Intersex Initiative Portland (ipdx)

PO Box 40570, Portland, Oregon 97240
web: <www.ipdx.org>
email: <info@ipdx.org>

Intersex Initiative is a network of intersex activists and allies working to stop the medical abuse of intersex children, and to challenge medical and social erasure of intersex existence through raising the awareness of issues faced by intersex people. We work both locally (Portland, Oregon) and nationally. Email for more information.

Bodies Like Ours

PO Box 416, Oldwick, New Jersey 08858

web: <www.bodieslikeours.org>

email: <info@bodieslikeours.org>

Bodies Like Ours seeks to end the shame and secrecy that surrounds people born with atypical genitals through community and peer support. Our goals are to make it okay to be born different and to recognize that we are not defined by what is between our legs. Instead, we seek to be defined by what makes us whole as human beings—our soul, our gender, and our presence.

Intersex Society of North America (ISNA)

4500 9th Ave. NE, Suite 300, Seattle, Washington 98105

web: <www.isna.org>

email: <info@isna.org>

Intersex Society of North America is devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female. We urge physicians to use a model of care that is patient-centered, rather than concealment-centered.

Appendix B: Ordering Materials from Intersex Initiative

Booklets

Intersex Initiative produces and distributes beautifully designed booklets for intersex activists and allies. The following booklets are currently available for \$5 a copy, or \$40 for ten copies.

Introduction to Intersex Activism: A Guide for Allies (this booklet) by Intersex Initiative

A Speaker's Handbook for Intersex Activists and Allies by Intersex Initiative

Teaching Intersex Issues: A Guide for Teachers in Women's, Gender and Queer Studies by Intersex Initiative

IntersexCritiques: Notes on Intersex, Disability and the Biomedical Ethics by Emi Koyama

Buttons

Our buttons pack our logo ("ipdx" in *Hoefler Text Black* typeface), mascot (the snail), and symbol colors (pink and maroon), and various slogans (10 patterns) in a 1-inch circle, and still keeps it legible. We sell the set of ten buttons (each has a different slogan) for \$10. Slogans are (subject to change without notice):



Kids & Knives Don't Mix
Take Back the Clit!
Five Babies A Day
No Cutting w/o Consent
Question Normalcy
Mutilation is Child Abuse
Fix Society, Not Babies
End Secrecy & Shame
First, Do No Harm
IGM is Homophobic

How to Order

Make a check or money order payable to Emi Koyama/IPDX, PO Box 40570, Portland OR 97240. Or, use Paypal.com to send the payment to: <info@ipdx.org>. Please use the form on the next page or make sure to include a note so that we can tell which item(s) you are ordering. Also, please consider adding some extra \$\$\$ for donation of any amount. We don't get big foundation grants, so we need grass-roots support from people like you. Thanks!

Intersex Initiative Order Form

Booklets:

Introduction to Intersex Activism \$ 5 x _____ copies = \$ _____

Teaching Intersex Issues \$ 5 x _____ copies = \$ _____

A Speaker's Handbook \$ 5 x _____ copies = \$ _____

Intersex Critiques \$ 5 x _____ copies = \$ _____

Booklets in Bulk Pack (10 copies):

Introduction to Intersex Activism \$40 x _____ packs = \$ _____

Teaching Intersex Issues \$40 x _____ packs = \$ _____

A Speaker's Handbook \$40 x _____ packs = \$ _____

Intersex Critiques \$40 x _____ packs = \$ _____

Buttons (10pc per set):

Intersex Initiative Assortment \$10 x _____ sets = \$ _____

Donation: = \$ _____

Total: = \$ _____

Send your check or money order to:

Emi Koyama/IPDX
PO Box 40570
Portland, OR 97240

If you have any questions, please feel free to email info@ipdx.org.

Intersex Initiative (Intersex Initiative Portland) is a network of intersex activists and allies working to stop the medical abuse of intersex children and to challenge the medical and social erasure of intersex existence. If you are interested in finding out more about intersex or getting involved (we are located in Portland, although we work with activists from across the country), or inviting our speakers to your campus or organization, please email info@ipdx.org or visit www.ipdx.org.

We welcome your feedback to this handbook. Please send your comments to: info@ipdx.org or PO Box 40570, Portland Oregon 97240.

Also available from Intersex Initiative:

Teaching Intersex Issues: A Guide for Teachers in Women's, Gender and Queer Studies

IntersexCritiques: Notes on Intersex, Disability and Biomedical Ethics

A Speaker's Handbook for Intersex Activists and Allies

Visit www.ipdx.org for more information.

ipdx
intersex initiative portland
www.ipdx.org