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Teaching Intersex Issues

A Guide for Teachers in Women's, Gender & Queer Studies

THE SECOND EDITION

Intersex activists at a conference in the Midwest:
(Back from left to right) Max Beck, Kristi Bruce, Angela Moreno
(Front from left to right) Martha Coventry, David Vandertie

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"From Social Construction to Social Justice: Transforming How We Teach About Intersexuality" © 2003 Emi Koyama and Lisa Weasel

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"Shifting the Paradigm of Intersex Treatment" © 2003 Alice Dreger

Special thanks to: Lisa Weasel, Alice Dreger, and Cheryl Chase
Cover photo courtesy of ISNA.

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.

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Introduction to Intersex Activism: A Guide for Allies

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Hypospadias

Hypospadias refers to the condition in which the urethra is located along the underside, rather than at the tip of the penis. In some hypospadias, the urethra may be located in the glans. In more pronounced hypospadias, the urethra may be open from mid-shaft out to the glans, or the urethra may even be entirely absent, with the urine exiting the bladder behind the penis.

Klinefelter's Syndrome

Individuals with Klinefelter's syndrome are phenotypical males with XXY chromosomes. Some people with Klinefelter's syndrome may have small penis and testes or experience breast development at puberty.

Mayer-Rokitansky-Kuster-Hauser Syndrome (MRKH)

MRKH is a condition where vagina and/or other internal reproductive organs are partially or wholly missing for an unknown cause in otherwise "normal" XX females. Women with MRKH have functional ovaries and can produce egg. While non-surgical alternative is available to deepen vagina, sometimes surgery is necessary to discharge the menstruation.

Micropenis

Micropenis is a perfectly normal in shape and function, except it is much smaller in size than the "normal" penis. Under the belief that one cannot grow up to be an emotionally adjusted healthy male without a "normal" size penis, surgeries have been performed on micropenis to make the child into girls. When micropenis is left intact and the patient is raised as a boy, he typically receives androgen to achieve masculinizing puberty.

Turner's Syndrome

Individuals with Turner's syndrome has the karyotype of XO, which means they are missing a chromosome. People with Turner's syndrome have female genitals, but do not have fully developed ovaries.

5-Alpha Reductase Deficiency Syndrome (5ARD)

5-alpha reductase deficiency syndrome affects XY individuals. While individuals with 5ARD have "normal" testes, they lack the enzyme necessary to convert testosterone to dihydrotestosterone (DHT), and develop penis and scrotum that resemble female genitals. People with 5ARD experience a typical male puberty, as DHT is no longer essential for masculinizing the body at that stage.

Information in this list has been taken from web sites of Intersex Society of North America, MRKH.org, and Johns Hopkins University Medical School.

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Thank you for reading the second edition of *Teaching Intersex Issues: A Guide for Teachers in Women's, Gender & Queer Studies*.

This project began in summer 2000, when I approached Dr. Lisa Weasel, the Assistant Professor of Biology at Portland State University, to talk about the frustrations I had been feeling regarding how the topic of intersexuality is treated in many Women's, Gender and Queer Studies classrooms, including the "Women's Health Issues" course Lisa was teaching.

My frustration was that just about every time the subject of intersexuality is brought up, it appeared, it is used solely to make a point or two about the social construction theory, and not to address any actual concerns or issues faced by people born with intersex conditions. Intersex people are reduced to their peculiar organs, then are further diminished into a pure theoretical devise, the exhibit A in the case against essentialism and for social constructionism. In other words, people's bodies were used to support abstract theories, rather than social theories being used to support the people.

At first, I only speculated that this was a widespread problem. In order to substantiate my concern, I consulted with Lisa to develop a simple survey to find out how other scholars and universities are handling the topic of intersex. The survey was conducted in early 2001, and the result supported my prediction: most of the scholars who responded to the survey reported that they use intersex to teach about social construction theory, while few bother to actually use materials written by intersex individuals or about their lives.

In the summer of 2001, I was offered a position at Intersex Society of North America (ISNA), first as an intern then as a staffer, partly due to this project. During my one-year tenure at ISNA, Lisa and I expanded this project to include guidelines on how teachers can improve the way they handle intersex issues in their classrooms, produced the first edition of this booklet, and presented our findings and guidelines at the National Women's Studies Association conference.

In addition, I designed and taught the world's first interdisciplinary Intersex Studies course at Portland State University (Spring 2002 and Summer 2003). Lisa and I also co-authored a paper that was published in *Women's Studies Quarterly* on this subject.

In this booklet, you will find many of the materials about intersex activism that are relevant to your Women's, Gender and Queer Studies courses. I hope that you find them useful—and please do not hesitate to contact me if you have any questions or comments regarding this booklet or about intersex activism in general.

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

MEDICAL FACTS PREMIER

by Intersex Initiative

Information here is provided to you not because you need to know each of these in order to address human and civil rights violations faced by intersex people, but so you can understand how "intersex" is made up of wide variety of conditions. In fact, **we strongly discourage you from distributing this list or discussing specifics** in your class: it will only feed into the audience's voyeuristic curiosity without adding anything to the discussion. Keep in mind that the focus should be on the hand holding the knife, not the genital itself. Also, remember that this is not a complete list of intersex conditions, nor are they complete description of any.

Androgen Insensitivity Syndrome (AIS)

Androgen insensitivity syndrome is a genetic condition in which XY individuals do not respond to androgens. In "complete" AIS (CAIS), testes remain in the abdomen while the external genitals appear female. At puberty, CAIS individuals grow breasts but do not menstruate. The testes are sometimes removed from the abdomen because they may develop cancer. Partial AIS (PAIS) is marked by a limited response to androgens. The external genitals are ambiguous. Depending on the selection of hormone treatment, PAIS individuals may exhibit partial male or partial female development at puberty.

Congenital Adrenal Hyperplasia (CAH)

Congenital adrenal hyperplasia is the most prevalent cause of intersexuality amongst XX people. It is caused when an anomaly of adrenal function causes the synthesis and excretion an androgen precursor, initiating virilization of a XX person in-utero. Because the virilization originates metabolically, masculinizing effects continue after birth. Sex phenotype varies along the full continuum, with the possible added complication of metabolic problems which upset serum sodium balance. The metabolic effects of CAH can be counteracted with cortisone. The long term use of cortisone itself produces significant dependance and other side effects.

Gonadal Dysgenesis

Gonadal dysgenesis is a condition where gonads do not develop or function fully because of a genetic mutation. Complete gonadal dysgenesis in XY individuals is known as Swyer's syndrome and result in female-appearing genitals due to lack of androgens. In the case of partial gonadal dysgenesis in XY individuals, some androgen is produced and thus the genitals appear ambiguous. Individuals with Turner's syndrome (XO), who have female genitals, also have gonadal dysgenesis.

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.

From Social Construction to Social Justice: Transforming How We Teach About Intersexuality

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A version of this paper has been published in Fall/Winter 2002 issue of *Women's Studies Quarterly*.

Introduction

Over the past decade, the topic of intersexuality has received increasing attention from feminist scholars investigating the nature of sex, gender, and sexuality. However, not all academic interest in the intersex "phenomenon" has been constructive or helpful to the lives of intersex people themselves, as scholars most commonly treat intersexuality as a convenient theoretical standpoint to demonstrate the social construction of the sexed/gendered body and only sometimes as a lived experience and a site of systemic erasure and resistance.

This paper analyzes how intersex issues have been taught in Women's Studies and other related fields (Gender Studies, Queer Studies, etc.) and proposes a new model that integrates activist and academic approaches to centering perspectives of intersexuality and lived experiences of intersex people in feminist classrooms.

Background Information

Intersex is technically defined as a group of medical conditions that involve "congenital anomaly of the reproductive and sexual system." In other words, intersex people are those born with physical conditions that result in atypical internal or external reproductive anatomies or chromosomal anomaly. (Koyama 3) Intersex is thus not a single diagnostic category, but includes a wide range of conditions and syndromes such as congenital adrenal hyperplasia (enzyme deficiency resulting in overproduction of androgen and virilization in genetic females) and androgen insensitivity syndrome (inability for the body to respond to androgen in genetic males, often resulting in female appearance), just to name two. The estimated frequency of intersex conditions varies depending on how the definition is applied, but it is assumed that one in 2,000 babies in the United States (or approximately five babies per day) are born visibly intersex, prompting early diagnosis and treatment.

Today, the standard treatment for intersex conditions involves surgical

and hormonal interventions that are designed to alter the appearance of the body so as to make it more visually "normal," but do not necessarily address any particular health issues (although these may also be present). These surgeries are often performed in early childhood, when the child is too young to understand or consent to what is being done to them, and they are rarely told the truth about their medical history even after they grow older. (Dreger 16).

Even though these surgeries have been performed for the last fifty years, there is little evidence that they are effective and safe in the long-term; on the contrary, several recent studies have confirmed that early surgical treatment on genitals often results in psychological and sexual problems rather than better social adjustment (Creighton et al. 124); (Creighton 219); (Zucker, et al. 300); (Alizai, et al. 1588). The social power and authority of the medical establishment combined with fear and lack of awareness in general public allowed these surgeries to go on unquestioned, inflicting lifelong pain on these defined as intersex.

In 1993, several intersex people created Intersex Society of North America (ISNA), the first advocacy group for people with intersex conditions, to connect with other intersex people and to take back the control over their own bodies. ISNA states: "We believe that intersex is not something so shameful that it has to be concealed medically and socially. We believe that intersex people have the right to know all the information currently available about conditions we experience, and determine for ourselves what is done to our bodies… We oppose the idea that eliminating our physical differences is the way to address social issues we may encounter; rather, we believe in addressing social difficulties intersex people may experience through social and psychological interventions."

Intersex in Women's Studies: Where We Are Now

There has been a growing interest and attention to the topic of intersexuality in Women's Studies in the recent years. To investigate how intersex issues are being integrated into Women's Studies classrooms, we conducted a small internet-based survey of 24 self-selected scholars in Spring 2001 on how they teach about this topic in their courses. Invitation to participate in the survey was distributed through academic mailing lists that deal with Women's Studies, Queer Studies, and other related fields. Responses were collected through the specially designed web site, and were analyzed for themes. While not relying upon a controlled research design and primarily exploratory in nature, the preliminary results of this pilot study nonetheless confirmed our prediction that intersex existence is understood and presented largely as a scholarly object to be studied in order to deconstruct the notion of binary sexes (and thus sexism and homophobia) rather than a subject that has real-world implications for real people.

Our survey found that the approach to intersex issues taking place in Women's Studies classrooms is severely limited, despite instructors'

Appendix B

Writing Guidelines by Emi Koyama

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.

What should the person with an intersex condition be told when she or he is old enough to understand?	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.	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.
What's wrong with the opposing paradigm?	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."	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.
What is the ideal future of intersex?	Elimination via improved scientific and medical technologies.	Social acceptance of human diversity and an end to the idea that difference equals disease.
Who are the proponents of each paradigm?	John Money and his followers, most pediatric urologists and pediatric endocrinologists, and many gynecologists and other health care practitioners.	Intersex activists and their supporters, ethicists, some legal scholars, medical historians, and a growing number of clinicians.

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/

good intentions. For example, only four out of 24 respondents use materials written or produced by known intersex people, despite the fact these materials have become widely available in the last few years and would provide a perspective on intersexuality central to any theoretical discussion.

According to our survey, Anne Fausto-Sterling's 1993 classic, "The five sexes: why male and female are not enough" continues to be the favored text among our respondents, with 15 instructors reporting using it; 19 of 24 instructors use this and/or other works by Fausto-Sterling. Other non-intersex scholars cited by more than once were Suzanne Kessler (6), Alice Domurat Dreger (3), Judith Butler (2), and Kate Bornstein (2). Intersex writers mentioned were ISNA (3), Cheryl Chase (2), Angela Moreno (1), Morgan Holmes (1), and Martha Coventry (1).

In response to the question regarding their selection of materials, only one of the respondents reported a conscious effort to give voices to intersex people by using sources produced by intersex people themselves. A respondent who included multiple works by intersex authors reported that they were brought to her attention by her students, who found them on the Internet. Because few intersex people have access to publication in academic journals, incorporating non-academic sources such as magazine articles and web sites seems to be a good strategy.

Several respondents seem to be confusing or conflating intersex issues and transsexual/transgender issues, as in response to this question they mentioned some works by or about transsexual/transgender individuals such as Kate Bornstein that do not address intersex issues in depth. While it is not an uncommon to associate intersexuality issues with transsexual or transgender issues, this is nonetheless a misperception that overlooks very specific ways intersex people's right to self-determination and informed consent are taken away under the guise of providing necessary medical treatment.

As for the reasons for including materials addressing intersexuality, nearly all respondents stated that one of the main purposes was to deconstruct one or more conventional understandings of human sexes, genders, and sexualities. In many cases, this revelation is then used to deconstruct gender roles, compulsory heterosexuality, and even scientific objectivity. Our respondents use the subject of intersex as a gender issue, and a way to illustrate the social construction of gender, without explicitly addressing medical ethics or other issues with direct real-life implication to the lives of intersex people.

That is not to say that none of the respondents thought about raising awareness around intersex issues, as a small number of respondents indicated raising awareness of intersex issues as one of their goals. However, even in these cases, there are mismatches between this stated goal and the kind of materials they selected for use in the courses. For example, Fausto-Sterling had not spoken with any intersex person at the time she wrote "The five sexes," and thus only discussed historical cases. Rather than increasing awareness of intersex issues and affirming

students who are themselves intersexed, use of such outdated materials in the absence of more contemporary materials by intersex people may further mythologize and exoticize intersex existence and make it seem like an anomaly of the past. In another example, one respondent wrote: "[Intersex] issues are marginalized and need to be given more attention. Here I often direct students to the writings of transsexuals such as Kate Bornstein and Leslie Feinberg" Although the goal is to raise awareness of intersex issues, neither Bornstein nor Feinberg is known to be intersexed and it is unclear how these writings provide more attention to intersex issues. Most likely, this problem arises from the confusion surrounding intersexuality and its distinction from transsexual/transgender issues discussed above.

Furthermore, beyond the assumption that a greater visibility will eventually lead to the liberation of a marginalized group, a carry-over from lesbian/gay/bisexual/transgender (LGBT) politics, there seems to be little thought around how advocating for intersex people might take a different form or require a different set of priorities than advocating for LGBT communities. As one intersexed speaker said during the National Gay and Lesbian Task Force's Creating Change conference in November 2000, "if virtually all gays and lesbians were forced to undergo reparative therapy against their will, and it was done in complete silence and secrecy so that none of them knew each other, visibility would be last on their agenda." While LGBT communities can certainly provide forum for addressing intersex issues, conflating or collapsing intersexuality into LGBT agendas fails to acknowledge the specific and urgent issues facing intersex people.

Because the existence of intersex people is under pervasive marginalization and erasure, there is a concern that classroom discussion about intersexuality could wind up reinforcing exoticization and objectification of intersex people. This is particularly damaging to students who are themselves intersexed, whether or not those around them are aware of their intersex status. We included in this survey a question about how instructors maintain a safe learning environment for students who may be intersexed because we wanted to stimulate awareness of these students' existence among instructors as much as to determine their answers.

In response to this question, nearly half (11) of respondents reported that they believed the general "ground rules" for the class address this issue sufficiently (although these ground rules were often not explicitly detailed). In addition, six respondents said that intersex issues would not stand out because transgender issues and other gender-related issues are also discussed in the course.

Strategies specific to intersex issues included citing statistics to show that there are many intersex people in their campus or that any of the students could be intersexed and not know it (8), as well as asking hypothetical questions like "what would you do if you had an intersexed child?" (2). These strategies are designed to demystify and de-stigmatize

How do you decide what gender to assign a newborn with an intersex condition?	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 1inch 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).	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.

What should be the medical response?	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.	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.
When should treatments designed to make a child’s genitals look “normal” be done?	As soon as possible because intersex is a psychosocial emergency. The longer you wait, the greater the trauma.	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.
What is motivating this treatment protocol?	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.	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.
Should the parents’ distress at their child’s condition be treated with surgery on the child?	Yes, absolutely. Parents can and should consent to “normalizing” surgery so that they can fully accept and bond with their child.	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.

intersex existence, but may actually contribute to further objectification of intersex people because they seem to assume that no students already know themselves to be intersexed or have intersexed family members. In addition, the former approach also runs the risk of reducing the category of intersexuality and the medical interventions to an interesting biological trivia rather than a site of intimate physical violation.

A more troubling tendency we noticed is that some (6) respondents are actually addressing in their responses ways they make the classroom more comfortable for non-intersex students rather than actually considering classroom safety issues for students who are intersexed. A respondent wrote: “I try to connect the issue to gender, which many are more comfortable discussing… It eases them into the challenge to their own preconceptions about sex (and gender) as fixed, binary categories.” There are two problems with this approach: first, it reinforces the invisibility of intersex people, and second, it prioritizes the privileged group over the marginalized one. By interpreting the question to apply to non-intersex people, these respondents further reinforced the notion that the stigmatization of intersex people is normal and legitimate.

In addition, two respondents reported that they had not had to deal with this issue because they have never had any student come out as intersexed. The lack of disclosure by intersex students in their classrooms merely indicates the intensity of erasure and silencing against intersex people in this society as well as in their classes, rather than their actual lack of existence.

Four instructors admitted that they needed further education on the issues intersex people face in order to become more sensitive to the needs of students who are intersexed, and two reported that they use first person materials written by intersex people in a non-objectifying manner. These responses are compatible with the goals and priorities of the intersex movement. In response to these stated needs, ISNA has prepared a teaching kit to help instructors incorporate intersex issues into classroom teaching in a way that addresses the lives and realities of intersex people and the social and ethical justice issues relating to surgical interventions. Additional resources address the social construction of binary sex while incorporating voices of intersex individuals and organizations with a critique of the unnecessary and traumatic impacts of medical intersex surgeries (Preves). Given the growing awareness and incorporation of intersex topics into Women’s Studies classroom, it is important for instructors to gain understanding of not only the theoretical dimensions of intersexuality, but also the urgent practical issues facing intersex individuals.

Given the fact that virtually all respondents introduce intersex issues in order to address theories about social construction of sex and gender, as discussed above, it is not surprising that a majority (13) of respondents reported students’ learning of social construction theory as the primary result of their instruction. It is encouraging that some respondents did report that students are seriously considering the ethical “dilemma” of

whether or not surgery is warranted (5), that some became interested in learning more about intersex people (4), or are appalled at the medical abuse of intersex children (3), after the initial shock(12).

Four respondents reported an interesting by-product of addressing intersex issues: gay, lesbian and bisexual students felt more comfortable after discussing intersex issues in class. One respondent wrote, "several 'out' lesbian students thought this was the coolest thing in the world — seemingly somewhat mollified." Another said, "I have had many gays, lesbians and bisexuals tell me that they feel much better about themselves after taking my course and hearing alternative views such as Fausto-Sterling's." While this is a positive side effect, it appears that discussions about intersex within Women's Studies often get "stuck" in such discussions, as one instructor puts it, and do not address issues and concerns specific to the lives of intersex people.

But perhaps this is an inaccurate way to describe the situation; a better way to understand it may not be to assume that discussions are "stuck" prematurely, but that they are in need of a different framework that addresses issues of medical ethics, social justice, and erasure. What is needed are courses that treat intersex people as ends and not just means, and that start from the assumption that intersex people are experts and authorities of their own experiences and that their voices should be required materials .

While it is important and encouraging that feminist and LGBT communities are beginning to recognize and embrace the issue of intersexuality, and Women's Studies, Gender Studies and Queer Studies courses may be the only place where intersexuality is incorporated into the curriculum, the specific ways in which intersex issues are introduced in these classrooms should be strengthened and made more relevant to the social justice movement. Despite instructors' good intentions, a lack of awareness and attention to the realities of intersex lives biases the presentation of the topic, potentially unintentionally perpetrating the invisibiliyg and objectification of intersex people.

Guidelines for Teaching Intersex Issues

What follows below is the list of recommendations we have developed in order to address intersex issues in Women's Studies courses. While it is not definitive, we believe that it is a good starting point as it addresses some of the common problems we discovered in the survey.

- Give authority to intersex people. When teaching about intersex, introduce students to first-person narratives as well as academics writings by intersex authors, such as those found in Alice Dreger's *Intersex in the Age of Ethics* and on the web site of Intersex Society of North America (www.isna.org) while being careful not to indulge voyeuristic attitudes. If you are using materials created by non-intersex authors, make an effort to avoid presenting intersex voices as in need of legitimatizing or

Appendix A

Shifting the Paradigm of Intersex Treatment by Alice Dreger

Shifting the Paradigm of Intersex Treatment
Prepared by Alice Dreger, Ph. D (dreger@isna.org)
for the Intersex Socety of North America.
Reprinted with permission.

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.

Shifting the Paradigm
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VII. Films About Intersex

The following films are available from Intersex Society of North America <www.isna.org>:

Hermaphrodites Speak! (1997)
- *Filmed at the first-ever retreat for intersex people. Not professionally edited, but quite touching. About 30 mins.*

Is it a Boy or a Girl? (2000)
- *An hour-long documentary produced for the Discovery channel. Features Cheryl Chase, Howard Devore, and other intersex activists; Kenneth Glassburg represents the American Academy of Pediatrics.*

First, Do No Harm (2002)
- *Produced by Intersex Society of North America as the "alternative" training video for medical school, although it's accessible for the general audience as well.*

Mani's Story (2003)
- *Hour-long documentary that follows the life journey of Mani Mitchell, an intersex activist from New Zealand; also featuring Angela Moreno and David Vandertie, the U.S. intersex activists. Very impressive.*

VII. Web Sites

Bodies Like Ours <www.bodieslikeours.org>
- *Support-oriented intersex group in New Jersey.*

Intersex Initiative <www.ipdx.org>
- *Intersex activist group from Portland; has regularly updated "news" section.*

Intersex Society of North America <www.isna.org>
- *Leader in the medical reform movement; most complete list of links and literature.*

AIS Support Group <www.medhelp.org/www/ais>
- *Web site of the UK group; has many resources.*

MRKH.org <www.mrkh.org>
- *Support and information for women with MRKH/vaginal agenesis.*

Other sites can be found from "links" page of these organizations.

interpretation by non-intersex "specialists."

Do not exploit intersex existence for gender/sex deconstruction only; make sure to address real-life issues faced by intersex people. If the social construction theory needs to be addressed, do so in the context of exposing and resisting the oppression against intersex people. In other words, use theories to support people, rather than the other way around.

- Assume that intersex people are everywhere, including in your classroom. Do not ask hypothetical questions as if none of the students are intersexed or family members of an intersex person. Do not expect intersex students to "come out" in the class, or interpret the absence of openly intersex students as the absence of intersex individuals.

- Recognize that intersex movement may have priorities and strategies beyond those of gay and lesbian movement or transgender movement. Do not automatically treat intersex issues simply as an extension to LGBT issues, or intersex people as a subgroup within LGBT communities.

- Draw connections to many issues, not just LGBT issues. Consider implications of the intersex movement on dis/ability movement (normalization of bodies marked as different), psychiatric survivor movement, medical ethics (informed consent), health activism, feminist anti-violence movements (child sexual abuse, domestic violence, female genital cutting, etc.), reproductive rights, children's and youth rights, etc. and vice versa.

- Recognize that it is not the responsibility of intersex people to deconstruct binary gender/sex or to be used as guinea pigs to test out the latest theory about gender. Do not be disappointed that many intersex people are not interested in becoming a member of the third gender or overthrowing sex categories altogether, although we should support those people who happen to be interested in these things, whether they are intersexed or not.

- Engage yourself and your students in the actual activist work in support of the intersex movement. It is essential for feminist scholars to contribute something back to the movement they study rather than merely using it as an object of academic inquiry.

- Educate yourself about intersex issues. For example, learn which words and phrases are preferred or not preferred by intersex people and why.

Conclusion

Before the Second Wave of women's movement, the only published information about women's bodies and sexualities came from male doctors who claimed authority over them; the emergence of women's health movement and the publication of literatures such as *Our bodies,*

ourselves changed that, forever. Today's feminist scholars thus have the fundamental moral and scholarly obligation to support intersex people's struggle to regain their own voice and narratives by bringing them into the classroom, while critically interrogating feminist and medical perspectives on intersexuality. Indeed, there appears to be growing interest and attention to intersex issues in Women's Studies classrooms, providing a potential space to educate students and encourage activism around these issues.

Yet too often, exploration of the political and practical issues relating to intersex lives have been marginalized in feminist scholars' use of intersex existence in support of their theoretical and pedagogical deconstructions. While feminist scholars have been hard at work using the existence of intersex people to deconstruct gender in their theories and classrooms, the medical profession has been busy "reconstructing" intersex bodies through unnecessary and often damaging surgeries to fit those same binary norms and standards that feminists are attempting to dismantle. As with any feminist undertaking, it is essential that theory and practice must meet, that feminist scholarship and pedagogy must engage with activist strategies that address the real-life issues that intersex individuals face.

References

Alizai N, Thomas D, Lilford R, Batchelor A, Johnson N. "Feminizing genitoplasty for congenital adrenal hyperplasia: What happens at puberty?" *Journal of Urology* 161 (1999):1588-91.

Creighton S. "Surgery for intersex." *Journal of the Royal Society of Medicine*, 94 (2001):218-220.

Creighton S, Minto C. "Managing intersex : most vaginal surgery in childhood should be deferred." *BMJ,* 323 (2001):1264-5.

Creighton S, Minto C, Steele S. "Objective cosmetic and anatomical outcomes at adolescence of feminizing surgery for ambiguous genitalia done in childhood." *The Lancet* 358 (2001): 124-5

Dreger AD. *Intersex in the Age of Ethics*. University Publishing Group, 1999.

Intersex Society of North America Website. 28 December 2001 <http: //isna.org/faq/faq-medical.html> .

Intersex Society of North America (2001). *Feminism and intersex movement : this is our vagina monologue*. Leaflet available from Intersex Initiative, PO Box 40570, Portland OR 97240.

Koyama, E. (2001). *Introduction to intersex activism : a guide for allies*. Booklet available from Intersex Initiative, PO Box 40570, Portland OR 97240.

Zucker, K., et al. "Psychosexual development with congenital adrenal hyperplasia." *Hormones and Behavior* 30 (1996): 300-318.

• *A textbook chapter actually used in medical schools; with a lot of illustrations depicting how to "correct" intersex genitals.*

Corpron CA, Lelli JL (2001). "Evaluation of pediatric surgery information on the internet." *Journal of Pediatric Surgery*. 36(8):1187-1189.

• *Reviews what kind of information about intersex is available online by typing a few keywords into search engines; argues that surgeons should protect parents from intersex activist sites that do not agree with the doctors.*

VI. Reform Movement within Medicine

Wilson B, Reiner W (1999). "Management of intersex: A shifting paradigm." Dreger (1999).

• *Former practitioners of intersex surgeries change their position.*

Creighton S, Alderson J, Brown S, Minto CL (2002). Medical photography: Ethics, consent and the intersex patient. *BJU International*. 89:67-72.

• *Analysis of how photos of intersex children are taken without patients' consent; ethical issues connected to psychological trauma.*

Minto CL, Liao L-M, Woodhouse CRJ, Ransley PG and Creighton S (2003). "The effect of clitoral surgery on sexual outcomes in individuals who have intersex conditions with ambiguous genitalia: A cross-sectional study." *Lancet*. 361: 1252-57.

• *Shows sexual difficulties experienced by people whose clitoris has been cut off or trimmed.*

Liao LM (2003). "Learning to assist women born with atypical genitalia: journey through ignorance, taboo and dilemma." *Journal of Reproductive & Infant Psychology*. 21(3): 229-238.

• *Important development in research, considering that, as more children escape surgeries and grow up with visibly intersex bodies, it becomes more and more important that we provide appropriate social and psychological support.*

Rangecroft L, British Association of Paediatric Surgeons Working Group (2003). "Surgical management of ambiguous genitalia." *Archives of Disease in Childhood*. 88:799-801.

• *Not completely in agreement with intersex activists, but it's noteworthy that even surgeons began to reconsider intersex treatment.*

Dreger A (2003). "Shifting the paradigm of intersex treatment." Available from Intersex Society of North America <www.isna.org>

• *Chart that contrasts "concealment-based" (traditional) treatment versus the "patient-centered" model.*

Clare E (2003). "Gawking, gaping, staring." *GLQ: A journal of lesbian and gay studies*. 9(1-2): 257-261.

Blumberg L (1994). "Public stripping." Shaw B (1994). *The rugged edge: The experiences from the pages of the first fifteen years of The Disability Rag*. Advocado Press.
- *Important literature that discusses sexually traumatic medical "routines" applied to children with disabilities. Very similar to intersex experiences.*

IV. Scholarly Articles by Intersex People and Allies

Chase C (1999). "Surgical progress is not the answer." In Dreger (1999).

Chase C (2002). "'Cultural practice' or 'reconstructive surgery'?: U.S. genital cuttings, intersex movement, and media double standards." Robertson C and Stanlie J (2002). *Shades of othering: female genital cutting*. University of Illinois Press.

Chase C (1998). "Hermaphrodites with attitude: Mapping the emergence of intersex activism." *GLQ: A journal of lesbian and gay studies*. 4(2): 189-211.

Holmes M (1994). "Re-membering a queer body." *Undercurrents*; May, p. 11-13.

Koyama E and Weasel L (2002). "From social construction to social justice: Transforming how we teach about intersexuality." *Women's Studies Quarterly*; Fall/Winter.

Dreger A (1998). "'Ambiguous sex'—or ambivalent medicine?" *The Hastings Center Report*. 28(3): 24-35.

Dreger A (2000). "Jarring bodies: Thoughts on the display of unusual anatomy." *Perspectives in Biology and Medicine*. 43(2):161-172.
- *Uses of medical photography; objectification through medical gaze.*

Preves S (2002). "Sexing the intersexed: An analysis of sociocultural response to intersexuality." *Signs*. 27(2):523-556.

V. Traditional Medical Approach to Intersexuality

Texts in this section are included to show how intersexuality has been and still is treated within the traditional treatment paradigm.

Donahoe PK, Schnitzer J, O'Neill J (1998). "Ambiguous genitalia in the newborn." Rowe M, Grosfeld J et al. (1998). *Pediatric Surgery*. St. Louis: Mosby Yearbook. p. 1797-1818.

Medical Abuse of Intersex Children and 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 closely 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).

Devore H (1999). "Growing up in the surgical mealstorm." In Dreger (1999).
- *Story of having 16 surgeries to "fix" hypospadias throughout childhood.*

Hawbecker H (1999). "Who did this to you?" In Dreger (1999).
- *Parents rejected doctors' recommendation to remove his short penis and raise him as a girl; he now lives happily as a man.*

Moreno A (1999). "In Amerika they call us hermaphrodites." In Dreger (1999).
- *Also published in Libido magazine.*

Triea K (1999). "Power, orgasm, and the psychohormonal research unit." In Dreger (1999).
- *Experiences at John Money's Psychohormonal Research Unit at John Hopkins University.*

Chase C (1998). "Affronting reason." Atkins D (1998). *Looking queer: Image and identity of lesbian, bisexual, gay and transgendered communities*. Binghamton, NY: Haworth Press.

Also, see the list of websites—there are a lot of stories there.

III. Disability Theory

Disability studies and theories have made important criticisms of the biomedical construction of physical human varieties. Here are some resources on disability theory that would be beneficial.

Davis L (1997). *The disability studies reader.* Routledge.
- *Good anthology to start learning about disability studies.*

Oliver M (1997). *The politics of disablement*. St. Martin's Press.
- *Classic by the accomplished disability theorist; good intro to social model of disability.*

Johnson HM (2003). "Unspeakable conversations, or how I spent one day as a token cripple at Princeton University." *The New York Times Magazine*; February 16; 152, p50, 9p.
- *On contemporary threats of eugenics against disabled people.*

Clare E (1999). *Exile and pride: Disability, queerness and liberation*. Cambridge: South End Press.
- *Addressing intersections and conflicts of disability, queer, class, anti-racist, and environmental organizing.*

Part Five

Suggested Resources for Students & Teachers

Intersex Bibliography for Women's/Gender/Queer Studies

Compiled and annotated by Emi Koyama

I. Books

Dreger A (1999). *Intersex in the Age of Ethics*. Maryland: University Publishing Group.

- *The only anthology to date that provide both personal stories and ethical discussions regarding intersex treatment.*

Preves S (2003). *Intersex and identity: The contested self.* Rutgers University Press.

- *Based on interviews with intersex people; uses identity theories.*

Dreger A (1998). *Hermaphrodites and the medical invention of sex.* Harvard University Press.

- *History of intersex medicalization from 18th century to present.*

Kessler S (1998). *Lessons from the Intersexed.* Rutgers University Press.

Gender theorist analyzes medical discourse of intersex management.

Fausto-Sterling A (2000). *Sexing the body: Gender politics and the construction of sexuality.* Basic Books.

- *Construction of gender and sexuality, especially around intersex.*

Colapinto J (2001). *As nature made him: The boy who was raised as a girl.* Prennial.

- *Note that this case is not actually intersex, but the child was treated similarly. Step back from the gender aspect and read how the child experienced medical attention intended to "cure" him. There are more important things to discuss than "nature vs. nurture."*

II. First-Person Narratives

Morris E (2001). "The missing vagina monologue." *Sojourner*; March. Also available from MRKH.org <www.mrkh.org>.

- *Response to "The Vagina Monologues" from a woman who was born without a vagina.*

Coventry M (1999). "Finding the words." In Dreger (1999).

- *Author of "Making the cut" found in March 2000 issue of Ms. magazine.*

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 comform 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 the resources section of this handbook.

girls: A girl's right to choose. Resolution at the annual NOW convention. 1-page document.

Book-length Items:

Eugenides, J. (2002). *Middlesex*. New York: Farrar, Straus & Giroux.

Colapinto, J. (2000). *As Nature Made Him: The Boy Who Was Raised as a Girl*. New York: Harper Collins.

Preves, S. and Preves, S. (2003). *Intersex and Identity: Contested Self*. Rutgers University Press.

8. Allies to Intersex People (Week 10)

Intersex Initiative Portland (2003). *A Speaker's Handbook for Intersex Activists and Allies*.

In-class: guest lecture by intersex allies from the community; a video lecture "History's Role in Intersex Movement" by Alice Dreger.

Assignments and Grading Methods

1. Journals (40% total). Students will write short (1-3 pages) informal journals on topics raised in the readings during weeks 1 thru 3. Journals are due once a week.

2. Class participation (30%). Attendance is essential, as much of the course is based on discussions. Attempts will be made to allow each students to share their input.

3. Critique (15% writing, 15% presentation). Students will produce a paper or series of papers critiquing at least two of the short medical, academic or popular culture texts provided or a book-length literature on intersexuality, from patient-centered perspective learned in the course. The papers will be graded on the basis of the student's ability to interpret the text and apply critical perspective to it. Critique paper is due by the finals date. Students will also present the paper to the class during the week 9. Alternatively, creative projects may be arranged with the instructor in lieu of a critique paper/presentation.

Grades are given based on percentage of the total number of points possible, using the standard percentage breakdown (A for 90-100%, B for 80-89%, C for 70-79%, D for 60-69%, and F for 0-59%).

2-page document.

b.
Fausto-Sterling, A. (1993). The five sexes: Why male and female are not enough. *The Sciences*, March/April 1993.
Fausto-Sterling, A. (2000). The five sexes revisited. *The Sciences*, July/August 2000.

c.
Natarajan, A. (1996). "Medical Ethics and Truth Telling in the Case of Androgen Insensitivity Syndrome." *Canadian Medical Association Journal*, 154: 568-570.
Kemp, D. and Groveman, S. (1996). "Sex, Lies and Androgen Insensitivity Syndrome." *Canadian Medical Association Journal*, 154: 1827-1834.

d.
Koyama, E. and Weasel, L. (2002). "From Social Construction to Social Justice: Transforming How We Teach About Intersexuality." *Women's Studies Quarterly*, 15 (3&4).

7. Patient-Centered Critique of Texts about Intersex: Praxis (Week 8-9)

Students will read these items (pick several short pieces, or one book-length material),write critiques, and present to the class.

Short Items:

Anonymous (2003). "The secret no doctor would tell me." *Redbook,* March 2003.

Apsell, P. (2001). Sex: Unknown (film/website). PBS NOVA Series.

Baker, R. (2002). "She's Worth It: Surgery Mends Hamden Infant's Disorder." *The New Haven Register,* March 3, 2002.

Burton, G. (2002). "General Discussion of Legal Issues Affecting Sexual Assignment of Intersex Infants Born with Ambiguous Genitalia." Paper presented at a bioethics conference.

Corpron, C. and Lelli, J. (2001). Evaluation of pediatric surgery information on the internet. *Journal of Pediatric Surgery*, v.26 no.8. p.1187-1189.

Greer, G. (1999). "Pantomime Dames." *The Whole Woman*, p. 70-80.

Hausman, B. (2000). Do boys have to be boys? *NWSA Journal*, vol. 3, 2000.

National Organization for Women (2001). Freedom of choice for intersex

A Curriculum Unit on the Politics and Practice of Contemporary Intersex Issues

by Lisa Weasel, Ph. D.

Introduction to the Unit:

Feminists have devoted a great deal of scholarship to deconstructing binary definitions of gender, and have often drawn upon the existence of intersex people in support of their theoretical and pedagogical deconstructions. Yet all too often, exploration of the political and practical issues relating to intersex people and their lives have been ignored in this quest. While feminist scholars have been hard at work using the existence of intersex individuals to deconstruct gender in their theories and classrooms, the medical profession has been busy "reconstructing" the bodies of those classified as intersex through unnecessary and often damaging surgery to fit those same binary norms and standards that feminists are attempting to dismantle. As with any feminist undertaking, it is essential that theory and practice must meet, that feminist scholarship and pedagogy must engage with activist strategies that address the real-life issues that intersex individuals face. This unit will help to bring these issues to light through readings, discussions and exercises relating to intersex individuals' lives and experiences, helping us to understand the practical realities and real-life consequences of the social construction of a binary gender code.

Background Definitions and Terms

Because intersex lives and existence have been marginalized in our society, there is often confusion or misunderstanding of terms. The following definitions and terminologies can be useful to fully understand and engage with this curriculum unit.

Intersexuality: Contemporary Western social definitions of human sexual identification allow only a binary distinction between male and female. However, humans are born with a broad range of primary and secondary sex characteristics that do not always fit neatly into one of these two socially constructed categories. Because human anatomical development is a flexible, gradual process, involving many steps and intersecting processes, a full spectrum of physiological sex characteristics and combinations normally occur. Often, human bodies that do not tightly conform to the binary male-female definitions are surgically altered, through painful and medically unnecessary means performed while the individual is still an infant or young child, under the pretense of making these bodies fit into tightly controlled male-female categories. The denial of intersex existence has allowed these surgeries to continue, harming

the bodies and lives of countless individuals and blinding society to the full spectrum of human sexual physiologies. Recent intersex activism has drawn attention to these issues and has increased public awareness of intersex existence and issues.

Note: The term intersexuality refers to the sexual physiology of an individual, not to their sexual attractions, practices, or relationships (do not confuse intersexuality with bisexuality).

Primary sex characteristics: These sex characteristics refer to organs involved in producing gametes, or sex cells, such as sperm and eggs. In humans, primary sex organs are the ovaries and testes. Organs that produce gametes are often referred to as gonads.

Secondary sex characteristics: These sex characteristics involve functions other than the production of gametes. Examples include mammary glands, external genitalia such as the vagina and penis, hormones such as estrogen and testosterone, etc.

For more on terminologies and FAQ's, see the following websites:
1. Introduction to Intersexuality & Intersex Activism, from Survivor Project's website: http://www.survivorproject.org/is-intro.html
2. Frequently Asked Questions, from the Intersex Initiative Portland's website: http://www.ipdx.org/articles/intersex-faq.html

Unit readings:

These readings can be ordered or obtained via the Intersex Society of North America website: (http://www.isna.org). The ISNA website also contains a long list of additional reading materials and on-line resources which can be incorporated into classroom syllabi.

Main Texts:

Dreger, Alice. *Intersex in the Age of Ethics*. University Press Group, 1999.

Chase, Cheryl. "'Cultural Practice' or 'Reconstructive Surgery?' US Genital Cutting, the Intersex Movement, and Media Double Standards." In Robertson, C & S. James, *Shades of Othering: Female Genital Cutting: Representations and Implications for Transnational Sisterhood*. Champaign: University of Illinois Press. 2002.

Supplemental readings (see the "resources" section of this booklet also):

1. First person accounts pertaining to intersexuality:

Once a dark secret. *British Medical Journal* 1994; 308:542.

Gender identity in testicular feminization. *British Medical Journal* 1994: 308: 1041.

Hawbecker, H. (1999). Who did this to you? p.111-116 in Dreger.

Morris, M. (2001). The missing vagina monologue. *Soujourner*, March 2001. p. 19-21, 28.

Moreno, A. (1999). In Amerika they call us hermaphrodites. p.137-140 in Dreger.

…and other stories in Dreger.

Also: Disability Studies and the critical disability theory has a lot of implications for the intersex movement. The following articles are highly recommended to better understand the context for the intersex experiences:

Blumberg, L. (1994). "Public Stripping." Shaw, B. (ed.) *The Rugged Edge: The Disability Experiences from Pages of the First Fifteen Years of The Disability Rag*. Louisville, Ky: Advocado Press.

Clare, E. (1999). "The Mountain." *Exile and Pride: Disability, Queerness and Liberation*. Cambridge, Mass.: South end Press. p. 1-13.

In-class: guest lecture by intersex individuals living in Portland; guest lecture by a mother of a child with CAH; documentary films *Hermaphrodites Speak!*, *Mani's Story*, and *Born Queer: dear doctors*.

5. Reform Movement within Medicine (Week 5)

Dreger, A. (2003). *Shifting the Paradigm of Intersex Treatment*. (handout)

Wilson, B. and Reiner, W. (1999). Management of intersex: a shifting paradigm. p.119-136 in Dreger.

"The Statement of the British Association of Paediatric Surgeons Working Party on Surgical Management of Children Born with Ambiguous Genitalia."

Melton, L. (2001). New perspectives on the management of intersex. *The Lancet,* v. 357, issue 9274. p.2110.

Creighton, S., Alderson, J., Brown, S. and Minto, C.L. (2002). "Medical photography: ethics, consent and the intersex patient." *BJU International,* 89: 67-72.

6. Patient-Centered Critique of Texts about Intersex: Examples (Week 6-7)

a.
Marion, R. (2000). The curse of the Garcias. *Discover*, 21 (12), 42.
Groveman, S. (2000). Letter to Dr. Robert Marion. AIS Support Group UK.

Course Readings/Discussions

1. Introduction (Day 1)

In-class: presentation and film.

2. Biology of Sex Differentiation: Intersex as a Biological Reality (Week 1)

In-class: presentation.

Johns Hopkins Children's Center. *Syndromes of Abnormal Sex Differentiation: A Guide for Parents and Their Famillies.* (brochure)

Dreger, A. (1999). From the age of gonads to the age of consent. p. 5-22 in Dreger.

3. Medical Interventions: Intersex as a Social Emergency (Week 2)

Donahoe, K., Schnizter, J., O'Neill, J. (1998). Ambiguous genitalia in the newborn, in Rowe, M., Grosfeld, J, et al. *Pediatric Surgery*, St. Louis, MO, Mosby Yearbook. p.1797-1818.

American Academy of Pediatrics (2000). "Evaluation of the Newborn With Developmental Anomalies of the External Genitalia." *Pediatrics,* 106(1).

Joint LWPES/ESPE CAH Working Group (2002). "Consensus Statement on 21-Hydroxylase Deficiency from Lawson Wilkins Pediatric Endocrine Society and European Society for Paediatric Endocrinology." *Journal of Clinical Endocrinology & Metabolism,* 87(9):4048-4053.

In-class: presentation and film. (Note: this film, *Surgical treatment of ambiguous genitalia in female children* by Hurwitz, R., Applebaum, H., and Muenchow, S. (1990) is the actual medical training video designed to teach medical students how to "treat" intersex conditions. Because it contains graphic images of surgical procedures on infants, students may choose not to view this film. However, I feel that it is important to see this in order to understand exactly what it is that we are talking about here. For contrast, I'll show ISNA's 2002 medical educational video, *First, Do No Harm: Total Patient Care*, as well.)

4. Intersex People Speak: Intersex as a Lived Experience (Week 3-4)

There are other sources of stories that students could read—will discuss in class.

Devore, H. (1999). Growing up in the surgical maelstorm. p.79-82 in Dreger.

Be open and honest with sufferers. *British Medical Journal* 1994: 308: 1042.

This series of short articles and letters introduces students to the issues that surround the secrecy associated with intersexuality.

2. Decisions around intersex surgery for infants:

Kessler, Suzanne. 1990. The Medical Construction of Gender: Case Management of Intersexed Infants. *Signs* 16 (1): 3-26.

Abramsky, L; S. Hall ,J. Levitan and T.M. Marteau. 2001. What parents are told after prenatal diagnosis of a sex chromosome abnormality: interview and questionnaire study. *British Medical Journal* 322: 463-6.

Biesecker, B. 2001. Prenatal diagnoses of sex chromosome conditions (editorial). *British Medical Journal* 322: 441-2.

Phornphutkul, C, A. Fausto-Sterling, and P.A. Grupposo. 2000. Gender self-reassignment in an XY adolescent female born with ambiguous genitalia. *Pediatrics* 106: 135-137.

3. Background on the Biology of Sex Determination:

Fausto-Sterling, Anne. (2000). Of gender and genitals: the use and abuse of the modern intersexual. Chapter 3 in *Sexing the Body: Gender Politics and the Construction of Sexuality*. Basic Books.

Films and videos for classroom showing:

Mani's Story (60 minutes; available from ISNA)

Hermaphrodites Speak! (35 minutes; available through ISNA).

First, Do No Harm: Total Patient Care (20 minutes; available from ISNA)

Class Discussion Topics:

A. Personal narratives

1. What is missing if we leave out the voices of intersex people themselves from a discussion of intersexuality?

2. What are some of the key issues facing intersex people today? How did you come up with these issues?

3. Why has so much silence and secrecy surrounded the existence of intersexuality? What consequence has such silence had for the lives of intersex individuals?

B. Surgical decision making

1. What are some of the ethical issues involved in making decisions about surgery when infants are classified as intersex?

2. How do issues of power relating to the medical profession influence the ways in which decisions about surgery are made?

3. How could the training of medical professionals be changed to increase awareness about the consequences of surgery on intersex infants?

C. Biology and sex determination

1. How do hormones, chromosomes, environment and genes work together to shape the sexual physiology of humans?

2. What kinds of surgery are often performed on AIS girls, and why? Are these surgeries necessary? What are alternatives?

Supplemental Exercises:

1. After completing this class unit, read the following articles:

a) Fausto-Sterling, A. The Five Sexes: Why Male and Female are not enough. *The Sciences* (NY Academy of Sciences) March/April 1993: 20-24.
b) Marion, R. The Curse of the Garcias. *Discover*, 21 (12), 42.

Provide a critique of each of these articles. How are intersex individuals represented in each article? What ethical issues arise? What kinds of responses, interventions, actions can be taken in response to these issues? As a follow-up to critiques of each article, respectively, students can read:

a) Fausto-Sterling, A. The Five Sexes, Revisited.*The Sciences* (NY Academy of Science) July/August 2000, 18-23.
b) Groveman, Sherri. Letter to Dr. Robert Marion re: The Curse of the Garcias. http://medhlp.netusa.net/www/ais/DEBATES/GARCIAS.HTM

2. Research the information on intersexuality that is being provided to patients by healthcare providers. Contact a healthcare provider to discuss issues of intersexuality, what it is, how they would treat or counsel patients on such issues, where they get their information and training on intersexuality. What have you learned about how the medical profession approaches and deals with intersexuality? What are the implications for individual's lives? How can the training, education, actions of the medical profession be changed to promote a more ethical approach to intersex individuals?

A Sample Syllabus for Intersexuality: An Interdisciplinary Exploration

by Emi Koyama, Portland State University

Please note that this is a syllabus for a 10-week Intersex Studies course. Materials used in this syllabus may not be appropriate if your class has only one or two hours to discussing intersexuality. If you only have a small amount of time, please stick with the first-person narratives by intersex individuals and other materials that directly address real-life issues faced by intersex people.

Description

This course is an interdisciplinary exploration on social, medical, biological, and political issues surrounding intersexuality and the lives of intersex people. First, students will learn basic biological facts about intersexuality as well as the current treatment protocol on intersex conditions. Second, students will read about the patient-centered reform movement by intersex people as well as among medical professionals. Lastly, students will learn to critically analyze medical, academic, and pop culture texts written about intersexuality from the patient-centered point of view. The course centers around discussions on readings, but also incorporates lectures, films, and guest speakers.

Course Objectives

After completing this course, students will:

1. Have a broader awareness of intersexuality as a lived experience rather than merely a theoretical standpoint.

2. Develop critical perspectives on the way that the medical profession defines, approaches and intervenes in the lives of intersex people.

3. Be able to critically analyze medical, academic, and popular culture texts about intersexuality from the patient-centered point of view.

Main Text

Dreger, A. (1999). *Intersex in the Age of Ethics*. Hagerstown, MD: University Publishing Group.