

intersexcritiques

notes on intersex, disability, and biomedical ethics



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Intersexcritiques: Notes on Intersex, Disability, and Biomedical Ethics
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to a doctor who suggested that we agree to disagree

march 13, 2003

it is not because
of your ignorant comments, or
flawed logic or the disagreement
between us that
i felt betrayed by you

it is that you
refused to play out the role
of the evil mastermind, that you
refused to answer questions i
was never allowed to ask,
that you refused to explain the whole
grand plan, that you
refused to be the mad scientist I
remembered my childhood
doctors as, that you refused
to
be
anything
but a regular rich straight white
male that you actually are

table of contents

A Letter to Intersex Society of North America 2

Statement on ISNA/BDRC Research Collaboration..... 4

What’s Wrong With “Male, Female, Intersex”:
A Letter to Outside In 8

Writing Our Own Monologues 10

Eugenides Wins Pulitzer for *Middlesex* 12

The Onion Parody Almost Realistic for Intersex Kids 13

Intersex Info Censored at Public Libraries?..... 14

Oregon Begins Mandatory Screening for CAH 15

Double Standard and Eugenic Impulse in the
Embryonic Research Debate 16

Early Detection of Swyer’s:
How Will the Information Be Used?..... 17

Conjoined Twin “Tragedy”: Was Ladan Bijani Murdered? 18

Doctors Receive \$1.2 mil to Study
“What’s Wrong With Intersex” 20

FDA Approves Injecting Growth Hormone
for Healthy, Short Children 21

Letter to *Daily Illini*: Non-Discrimination Policy
Is Not Enough for Intersex 22

Letter to *The New York Review of Books* 23

About Intersex Initiative / About Emi Koyama 24

A Letter to Intersex Society of North America

“We envision early in utero detection in pregnancies of families at risk and possible correction of defects... Better still, detection of carriers may reduce the incidence of such anomalies.”

— Dr. Patricia Donahoe (pediatric endocrinologist)

July 2, 2003

Dear ISNA Board Members,

First of all, thank you for your past and ongoing work on behalf of intersex children, adults, and family members. Over the past decade, Intersex Society of North America has drastically and positively impacted many lives, including mine.

I am writing this letter to you as a fellow intersex activist and a former ISNA employee/staffer who is concerned about the current direction of the organization, in particular the recently announced collaboration between ISNA and Birth Defects Research for Children, Inc.

Looking over BDRC’s web site, I cannot help but notice that the basic ideologies of BDRC are incompatible with the goals and missions of the intersex movement, which is to end shame, secrecy, and unwanted genital surgeries on children born with intersex conditions.

Like many other disability-related organizations that are NOT run by disabled people, BDRC is geared toward prevention and cure—thus, elimination—of disabled bodies. The contemporary disability movement, on the other hand, believes in challenging and transforming social structures and institutions that “disable” bodies that the society deems “abnormal.”

There is a historic conflict between disability-rights organizations that seek to liberate disabled people, and disability-control organizations that promote elimination and assimilation of the disabled body. The former is run by disabled people themselves who demand autonomy, empowerment, and equal access; the latter is run by parents and doctors of disabled people, and can be traced back to the eugenics movement.

The efforts of the latter movement frequently run contrary to the interests of the disabled people. For example, there is an organization that claims to support people with mental illness but are in reality made up of parents and professionals, which has extensively lobbied State legislatures to promote forced medication and forced institutionalization of mentally ill people under the guise of caring for them.

ISNA that I used to work many hours for belonged to the former group: it sought social change, not the “cause” or “cure” of intersexuality. It was surgeons and endocrinologists who want to rescue us by surgically eliminating our difference that belonged to the latter. Today, I fear that ISNA is now slipping into the latter group.

As an intersex activist, I am concerned about the eugenicist impulse behind BDRC’s desire to prevent “birth defects”—a phrase that came from the long tradition of eugenics movement, fueled by the hijacking of lived experiences of disabled people by the parents and doctors who manage and control their lives. While I have no reason to oppose removal of harmful toxins from the environment, that is not the kind of social change that intersex activists have been working for.

I question the notion that the scientific research on the environmental causes of intersexuality (which itself is a valid area to research) would reduce stigma or improve quality of life for people born with intersex conditions; I believe it is systemic social change and education that will. I question that the collaboration with disability-control organizations such as BDRC would actually contribute to the ISNA’s long-term goal of ending shame, secrecy, and unwanted genital surgeries. I feel that supporters and constituents of ISNA deserve an explanation as to its rationales for its association with this particular project, and how it would ensure that ISNA remains an activist organization dedicated to social change.

Even though I find BDRC’s underlying ideology problematic, I feel that there is still some room to work with them on some of its projects. For example, we can help BDRC improve the kind of information it provides to parents of intersex children, which will benefit both parents and intersex children. I also understand that sometimes we are forced to compromise our core principles to meet immediate needs. However, as an organization devoted to the patient-centered (and not biomedical, eugenicist, or parent-centered) model of medical treatment, ISNA needs to carefully evaluate the dangers of co-optation by those who view our queerly different bodies as defective or aberrant.

Back in the late 1990s, when I was finally putting together my thoughts around what had been done to my body, Cheryl Chase and others taught me through their words and actions that my body was just fine as I was born, that the doctors were wrong when they decided otherwise. We need to keep sending the same message until it becomes so obvious that nobody would question it.

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

Statement on ISNA/BDRC Research Collaboration

July 24, 2003

INTRODUCTION

On June 16, Intersex Society of North America (ISNA) announced its research collaboration with Birth Defects Research for Children, Inc. (BDRC), an Orlando, Florida non-profit organization that provides information to parents of children with “birth defects.” The goal of the collaboration was to find the link between the presence of synthetic chemicals in the environment and the rate of intersex births. The announcement surprised many intersex activists and supporters, because in the past ISNA had always advocated for the social acceptance of intersex bodies, not the “cause” or “cure/prevention” to eliminate them. Has ISNA changed its mission or lost focus?

After speaking with our core volunteers, advisors and supporters, Intersex Initiative (ipdx) director Emi Koyama wrote a letter to ISNA board members on July 2 expressing her and ipdx supporters’ concern over the announcement. ISNA board members Esther Leidolf and Alice Dreger responded on July 12 defending the collaboration. After reading ISNA’s response, we are still not comfortable with the project, and at this point we felt that it was the time to make this discussion public—so that intersex activists and supporters outside of ISNA/ipdx will be able to join in and voice opinions.

One thing we want to make clear is that we are not trying to attack ISNA or urging other intersex activists and allies to withdraw their support for ISNA; in fact, Emi Koyama is planning to perform in a benefit show for ISNA planned this November, just as she did last October. Instead, we are hoping for a greater dialogues within intersex activist communities and among our allies from disability, queer, and feminist activist communities. In the end, we hope that the discussions will help lead our intersex movement into better directions.

In the following sections, we broke down our concerns into three categories: what/why, how, and with whom. In each section, we discuss what part of the announced collaboration we find problematic, and propose alternatives or ways ISNA could improve the situation.

1) WHAT & WHY

In this collaboration, ISNA and BDRC are working to find out the extent to which synthetic environmental chemicals increase the rate of

certain intersex conditions. If there is a connection between synthetic chemicals and physically debilitating medical conditions, it would add support to the argument for a better regulation of synthetic chemicals.

However, intersex conditions are not what debilitate intersex people; it is the society's preoccupation with the concept of normalcy that does. While it is true that some intersex conditions are associated with physically debilitating medical conditions (and researches on prevention and cure for these conditions are completely valid), studying the causes of intersex with an organization that studies "birth defects" gives the wrong impression that intersex itself is limiting or undesirable.

British disability theorist Michael Oliver distinguished impairment, which is the limitation directly caused by the lack of limb or function in a body, and disability, which is the limitation placed on people with impairments by social structures and institutions. ISNA has traditionally focused on challenging the social structures and institutions that "disable" intersex bodies—those medical and social systems that deem intersex bodies unacceptable and freakish. The new announcement from ISNA shifts the focus away from this core mission, and fails to make this important distinction between impairment and disability clear.

Worse, when any relationship between the rate of intersex births and the exposure to synthetic chemicals is reported, we fear that it is not the concern for people living with debilitating medical conditions, but the society's perception of intersex as freakish and monstrous that will persuade the public that environmental toxins must be controlled. Rather than breaking down myths and stigmas associated with intersexuality, we fear that the process will inevitably benefit the environmental health movement at the expense of intersex people.

We also fear that people accessing ISNA's web site today—which includes intersex people and parents of newly diagnosed intersex children—will get a message that is the opposite of what many of us did when we first found ISNA in the past. With the announcement of ISNA's collaboration with BDRC prominently posted on the top page, we are afraid that ISNA is now sending the message that intersex bodies are undesirable and aberrant, however unintentionally.

2) HOW

In England, the research team led by Sarah Creighton and Catherine Minto have been working extensively with British CAH and AIS support groups for the last several years to produce amazing scholarship regarding the real-life impacts of early surgical treatment on intersex. As part of their cooperation with patient advocacy groups, they developed an intersex clinic, where patients receive intersex-related medical care from experts who are not only knowledgeable about intersex conditions,

but are also supportive of their different bodies and respectful of their right to dignity and self-determination. Research models such as these are clearly beneficial to the intersex movement as well as to individual participants.

If ISNA were to begin taking greater part in researches involving intersex people, it needs to establish a clear guideline that would be used to determine which research projects ISNA needs to get involved, and with whom. It would ensure that any research it participates in would directly address concerns of people living with intersex conditions (rather than those of doctors, scientists or parents), and that finding out the result would directly benefit the intersex movement.

Studies by Minto, Creighton, and colleagues meet both of these criteria; it is questionable if BDRC's meets either. As ISNA engages in more research projects, it needs to stress firmly that patient-centered research does not simply mean that researchers focus on the patient, but it means, more importantly, patients have the power to set priorities for and monitor the designs of any research in which they participate.

3) WITH WHOM

BDRC describes itself as a non-profit organization that “provides parents and expectant parents with information about birth defects and support services for their children.” So, three weeks after ISNA's collaboration with ISNA had been announced, we placed a request for the information about congenital adrenal hyperplasia (CAH) and “ambiguous genitalia” from BDRC in order to find out how exactly they assist parents of intersex children. The result was hugely disappointing: we received a BDRC brochure, a cover letter, and two short print-outs from the MEDLINE, a free online scientific database maintained by the National Library of Medicine.

For example, the information sheet BDRC has sent us lists “abnormal female external genitalia” as one of the “complications” of CAH, and states that “reconstructive surgery for girls with masculine external genitalia is usually performed between the age of 1 and 3 months,” without mentioning any potential physical, emotional or sexual harm we feel are caused by the childhood genital constructive surgeries. The information sheet on “ambiguous genitalia” includes the following passage: “It is often easier to treat (and therefore raise) the child as a female (it is easier for a surgeon to make female genitalia than it is to make male genitalia)...” Nowhere in the entire packet does BDRC include materials from ISNA, or even mention the existence of the patients' movement against cosmetic genital surgeries and the medical professionals who question the current protocol of the treatment.

If BDRC is indeed a partner of ISNA, and had been so for at least

three weeks before putting together this packet, shouldn't we expect more? This is one of things that make us question whether or not ISNA actually took the time to educate BDRC about our missions and goals to ensure that we are on the same page before jumping in a research project with them.

We were disappointed by the content of the packet we received from BDRC, but we did not find it shocking. Based on our reading of BDRC's web site, we knew that it was an organization by and for parents and doctors who "manage" disabled people, rather than the one dedicated to empowering people with disabilities. Disability activists have historically criticized organizations like BDRC for failing to challenge social structures and institutions that "disable" their bodies by focusing on finding causes or cure of their impairments, and for lacking critical awareness of their historical root in the eugenics movement.

Assuming that ISNA has not yet budged its commitment to social change, the core ideology of BDRC is incompatible with the mission statement of ISNA. BDRC may be able to improve the information packet it sends to parents of intersex children, and we should definitely help them do so before they send out another packet like the one they sent us, but fundamentally they do not share our movement's radical critique of social and medical institutions that shape our queer bodies and lives. By affiliating ourselves with BDRC and other groups like them, we fear that ISNA is turning its back on our ideologically more compatible allies and supporters from disability, queer and feminist movements, each of which have challenged the pathologization and biomedical control of our bodies in unique ways, paving the way for the intersex movement to come along.

CONCLUSION

We feel that ISNA entered into the collaboration with BDRC prematurely, but we believe it can be made better. First, ISNA needs to have a serious discussion with BDRC about the information it distributes to parents of intersex children and provide materials. Second, ISNA can make concerted effort to address the distinction between the "intersex" genitals that are merely "socially problematic" and the medically debilitating conditions in all communications, especially in relation to this project. Third, ISNA can institute a more rigorous protocol by which it evaluates which research projects it should participate in the future and with whom. Lastly, the intersex movement needs to firmly align itself with disability activists and others who wholeheartedly understand that intersex bodies are not freakish or monstrous, than with those groups that come from the opposite point of view. Within the environmental health movement, we should seek out new allies that are more compatible with our missions.

What's Wrong With “Male, Female, Intersex”: A Letter to Outside In

Below is an email sent to Outside In, a Portland, Oregon organization serving low-income people and homeless youth.

July 24, 2003

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 when I first came into the clinic, 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 its clinic, but it is wrong to list “intersex” as a sex. Here are some reasons:

* Vast majority of people born with intersex conditions live normally 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 “are you intersex?”

* Most people who would check “intersex” are probably not intersex, but transgender or genderqueer people who do not know what intersex is. 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-educates the general public.

* In the standard medical treatment, physicians view intersexuality primarily as a problem of gender, which is why they narrowly define successful intervention 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 found below, and let me know if there is anything else I can do to help Outside In a safe clinic for people born with intersex conditions.

<http://www.ipdx.org/articles/medicalabuse.html>
<http://www.ipdx.org/articles/intersex-faq.html>
<http://www.ipdx.org/articles/hermaphrodites.html>

By the way, the rest of my visit to the clinic went really well and I appreciate it a lot, since I had learned to fear medical settings from many years of exposure to abusive medical attention. Thank you.

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

Writing Our Own Monologues

Originally written for the newsletter of Intersex Society of North America.

Two years ago, I went to see the play “The Vagina Monologues” for the first time. It was held at a local university, and was for a good cause: the production was part of the V-DAY national initiative to end violence against women and girls. As a long-time activist against domestic and sexual violence, I was happy that V-DAY was raising awareness about these issues as well as funds for organizations that confront them.

But there was a problem with the script: while the play portrayed the ritualistic cutting of young women’s genitals in Africa in a serious tone, it depicted the ritualistic cutting of intersex genitals in our society as a light-hearted “fairy-tale”: “One girl in Oklahoma told me how she had been born without a vagina, and only realized it when she was fourteen. [...] On the way from the doctor, in a noble attempt to comfort her, [the father] said, ‘Darlin’, we’ve got an interesting situation. You were born without a vagina. But the good news is we’re gonna get you the best homemade pussy in America. And when you meet your husband, he’s gonna know we had it made specially for him.” Later I found out that V-DAY specifically requested producers of the play to “be careful that the father is not portrayed as insensitive or ignorant,” because the story was “meant to be sweet,” according to the V-DAY document.

I felt invalidated by how the play’s depiction trivialized negative consequences of “normalizing” surgeries performed on intersex children often without their informed consent, and offended by the sexist and heterosexist presumptions made about women’s bodies. So on that evening two years ago, I went home crying and feeling alone. But in reality, I was not alone: many intersex activists and allies have written Eve Ensler, the play’s author, to express their concerns, although there was no immediate reaction from her or from V-DAY.

Lacking reactions from Ensler, I coordinated a nationwide campaign last year in which I emailed all 500+ individual campuses participating in V-DAY to ask them to support the intersex movement’s goal to end genital mutilation in our society as well. The reaction this time was enormous: not only did dozens of schools write back to thank us for the information and pledged to do something to raise awareness about intersex, but also I received a voicemail from the Executive Director of V-DAY suggesting that we work together. I called back, which eventually resulted in V-DAY’s endorsement of Intersex Society of North America’s mission to end shame, secrecy and unwanted genital mutilation.

Then later that year, I was informed by a third party that Ensler had apparently removed the entire section containing the “fairy-tale” from the 2003 version of the script, but without replacing it with a different intersex

monologue. On one hand, I was happy to see that Ensler finally took our concerns seriously; on another, I felt that there was still a need for intersex stories in V-DAY, considering the fact that one of its missions was to end genital mutilation of girls and young women. Hence the second nationwide campaign to promote intersex awareness at campus V-DAYs began.

This year, we were able to take advantage of the change in the script that allowed additional monologues to be plugged in by campus producers: we provided them with two of our own monologues (written by Thea Hillman and Esther Morris), which were performed at several campuses. In addition, many schools distributed our fliers, showed ISNA's films, and/or donated their proceeds to ISNA. In fact, I went to see the play at Portland State University, which decided at the last minute to include Esther's monologue.

And as I was hearing her piece being performed, I was thinking, wow, what a difference two years of activism had made. And I also realized that this little success is a mirror of successes we've achieved in other areas. In medicine, academia, pop culture, and pretty much everywhere, we were once laughed or theorized about but never treated as whole humans. Some of that may still continue, but we are also telling our stories now. As the crowd applauded at the end of Esther's monologue, I thought about how much progress we have made, and was filled with appreciation for those who came before me and those who are still working with me. Needless to say, I cried through my way home this time again.

Eugenides Wins Pulitzer for *Middlesex*

ipdxWIRE Intersex News (www.ipdx.org/news)

April 11, 2003

Jeffrey Eugenides won this year's Pulitzer prize in fiction for his novel "Middlesex," whose protagonist is an intersex person. While we find some of the things the author has said in interviews and at book readings problematic, we do nonetheless feel that the book raises public awareness of intersex issues in a way that hasn't been possible in the past.

Gay newsmagazine "The Advocate" posted an article about the Pulitzers on its online edition, but its title stated "Transgender novel Middlesex wins Pulitzer." So Emi wrote them an email--and within five hours, their web site is changed! The title was changed to "Intersex novel, gay playwright win Pulitzers," and the paragraph was re-written. Below is BEFORE and AFTER of the key paragraph:

BEFORE: "The fiction prize for Middlesex almost surely marks a milestone in Pulitzer history: the first book so honored to be narrated by a hermaphrodite, loosely defined as someone with both male and female sexual organs. Calliope Helen Stephanides is born a girl. As a teenager she begins growing a mustache and otherwise turning more than 'a little bit freakish.' Eugenides got the idea for Middlesex after reading a book by French philosopher Michel Foucault that contained a memoir by a 19th-century hermaphrodite. 'She could hardly describe the experience. She wrote around it,' he told the Associated Press in an interview last fall."

AFTER: The fiction prize for Middlesex almost surely marks a milestone in Pulitzer history: the first book so honored to be narrated by an intersexed protagonist, a person whose reproductive organs and other physical characteristics are of indeterminate sex. In the novel, Calliope Helen Stephanides is born a girl. As a teenager she begins growing a mustache and otherwise turning more than 'a little bit freakish.' Eugenides got the idea for Middlesex after reading a book by French philosopher Michel Foucault that contained a memoir by a 19th-century 'hermaphrodite,' as the intersexed were then called. '[The intersexed person] could hardly describe the experience. She wrote around it,' he told the Associated Press in an interview last fall."

The changes seem somewhat awkward, but we're glad that they are making an effort to get the story right.

The Onion Parody Almost Realistic for Intersex Kids

ipdxWIRE Intersex News (www.ipdx.org/news)

April 20, 2003

The April 16 issue of *The Onion* contains an interesting article titled “New Children’s Book Helps Kids Deal With Pain And Isolation Of Plastic Surgery.” The article is obviously made-up just like any other in this parody publication, but it seems almost realistic in the context of plastic surgeries on intersex children.

The article states: “As a pediatric plastic surgeon, Dr. Jessica Krieg changes little faces and lives for the better. Yet for all the good she does, she is all too aware that rhinoplasty and liposuction can be difficult, scary experiences for a child. With her new book, *Norah’s New Nose*, she hopes to change all that. ‘These children, on the threshold of becoming something—and someone—beautiful, are often scared and unsure of what’s about to be done to them,’ Krieg said. ‘In *Norah’s New Nose*, I try to show them there’s nothing to fear, and that when it’s over, there’s no need for shame.’”

Few would consider it necessary to perform rhinoplasty or liposuction on young children in order for her or him to grow up with a healthy self-esteem, but many doctors are so convinced that it is unthinkable for a child to grow up healthy with an intersex genitalia intact that they would recommend invasive cosmetic surgeries on children as young as six month old.

Granted, it is difficult to grow up when you are different. But is it worth causing irrevocable scars on the child’s physical, emotional, and sexual well-being just to make her or him “fit in”? We as the society need to address shame and isolation associated with intersexuality through honest communication and education, rather than using medical technologies to eliminate “shameful” bodies.

Intersex Info Censored at Public Libraries?

ipdxWIRE Intersex News (www.ipdx.org/news)

June 30, 2003

On Monday, June 23, the U.S. Supreme Court restored the Children's Internet Protection Act, which had been passed in 2000 but overturned in the appeals court. The ruling now allows the Congress to require public libraries to install software on their computers that filter out adult content in order to receive federal technology grants.

The next day's edition of *The Orange County Register* reports about the impact of this ruling on people researching about intersex issues. The paper says: "Sandie Kloszewski, 36, of Santa Ana is worried about losing access to legitimate Web sites [...] Kloszewski said she uses the Santa Ana library's adult computers only youth computers have filters to read about hermaphrodites. But she recently was denied access to similar Web sites when she logged on at the Orange Public Library."

It is inevitable that any "filtering" software is flawed, to the detriment of people who are legitimately seeking potentially life-saving information on such socially taboo subject as sexual orientation, transgender issues, abortion, safer sex, and yes, intersex. Adults and youth—including intersex youth, who are rarely told about the complete truth about who they are and what that means for them—deserve access to those valuable information on the internet at school and public libraries.

To read more about issues involved in internet blocking/filtering, visit Electronic Frontier Foundation's site:

<http://www.eff.org/Censorship/Censorware/>

Oregon Begins Mandatory Screening for CAH

ipdxWIRE Intersex News (www.ipdx.org/news)

July 7, 2003

This month, Oregon joined 34 other states that mandate routine infant screening for congenital adrenal hyperplasia (CAH), arguably the single most common condition associated with intersexuality, or “ambiguous genitalia.” On the surface, this is a good news for children born with CAH, because children with the severe form of CAH experience “salt-losing shock” which at worst lead to death unless they are treated with medication.

However, some intersex activists are concerned that the mandatory early screening would result not just in the early detection and treatment of bona fide metabolic problems, but also in the more aggressive medical interventions to “cure” aspects of CAH that need not be medicalized, under the guise of “saving children.” This is particularly important since females with CAH are associated with queerly different physiology (e.g. large clitoris) and relatively high frequency of lesbian, bisexual and trans identity formation.

For example, Save Babies Through Screening, an organization that lobbies for mandated newborn screening programs, states: “prenatal therapy with a synthetic hormone called dexamethasone throughout pregnancy can allow proper development of the external genitalia in female fetuses... [they] are then born with normal external genitalia and do not require corrective surgery.” SBTS does not mention any potential risks of using the synthetic hormone throughout pregnancy, nor does it explain how having an “ambiguous genitalia” is a medical problem that “require[s] corrective surgery” on babies. In general, these surgeries do not serve any practical purposes except to prepare children to have “normal” heterosexual intercourse many years down the line.

Given the slew of studies that associate CAH females with typically male-gendered behaviors (playing with boy toys, seeking career over family life, sexual interest in other women, etc.), I fear that those girls found to have not so severe forms of CAH would be subjected to over-medication and increased parental pressure in the society’s attempt to prevent not just genuine medical complications but also these gender and sexual transgressions.

Thirty years after homosexuality was officially de-pathologized out of “Diagnostic and Statistical Manual of Mental Disorders” by the American Psychiatric Association, queer bodies—intersex bodies—continue to be regulated by medicine. We ask our queer friends and supporters to embrace newborn screening of CAH even as we stay skeptical as to how it is implemented.

Double Standard and Eugenic Impulse in the Embryo Research Debate

ipdxWIRE Intersex News (www.ipdx.org/news)

July 8, 2003

Dr. Norbert Gleicher from the private fertility clinic group Centers for Human Reproduction shocked the world on July 2 when he announced that his team had created a human chimera embryo that was “part male, part female” by deliberately inserting the 3-day old male embryo into the 3-day old female embryo. Gleicher has stated that this research could lead to the treatment for genetic diseases, a claim that many scientists question. The embryo was viable and could have developed into healthy a fetus (which may or may not have been intersexed—nobody knows), but was destroyed.

All this is interesting, but as an intersex activist, I’m more interested in the reasons behind the widespread public outcry against this particular experiment. For one thing, researches on human embryos aren’t news—in fact, many of the fertility “experts” who condemn this research as “irresponsible” and “deeply flawed” earned that title by doing embryonic researches themselves. The comment from Dr. Françoise Shenfield, as quoted in *Ananova*, is telling: “The aim [of Gleicher’s research] is to create a chimera to correct a defect, but it seems a little illogical because nobody has any idea how much of the embryo would be normal.” Translation: intersex embryo is abnormal.

Even worse, the *United Press International* (UPI) wire published in *The Washington Times* states in the headline: “Test-tube ‘monster’ condemned.” So apparently, it is not even the scientists who study embryos who need to be condemned. The “monster” reference is supposedly made in reference to the linguistic root of the word “chimera”—the “Greek monster that was part lion, part serpent and part goat”—but seem to also imply that anyone whose body is not completely male or completely female are abnormal and monstrous, an idea that has led to the medically unnecessary mutilation of the healthy genitals of intersex children.

In 1991, pediatric endocrinologist (and an author of a popular medical textbook chapter on intersex surgery) Dr. Patricia Donahoe suggested this final solution to the intersex problem: “We envision early in utero detection in pregnancies of families at risk and possible correction of [intersex] defects... Better still, detection of carriers may reduce the incidence of such anomalies.” (“Clinical Management of Intersex Abnormalities.” *Current Problems in Surgery* 28: 519-579.) In other words, Donahoe is calling for a kinder and gentler type of scheme, reminiscent of the eugenics movement, to eliminate the monstrous intersex bodies.

Both Gleicher and his critics seem to share this narrow desire to “treat”

“abnormalities” out of existence, but, as Donahoe’s case indicates, sometimes it is more important or at least as important to address social attitudes and structures that make certain bodies “abnormal” and in need of “treatment.” Scientists and bioethicists should pay more attention to the practical impact of any “treatment” (and the languages that describe them) on those who already live with that particular condition, and how such lives are limited by the social conception of normalcy and abnormality, rather than profusely debating whether or not experimenting on male-female chimera is more “unethical” than creating a chimera from embryos of the same sex.

Early Detection of Swyer’s: How Will the Information Be Used?

ipdxWIRE Intersex News (www.ipdx.org/news)

July 13, 2003

July 13 edition of *The Age*, an Australian newspaper, reports about the country’s scientists’ discovery of the mechanism behind Swyer syndrome, or “pure XY gonadal dysgenesis,” in which the patient has a 46 karyotype, female external genitalia, and streak gonads. Reporter Liz Gooch interviews two of the researchers involved in the study published earlier in *Proceedings of the National Academy of Sciences*, an American scholarly journal.

The discovery could be used to identify and monitor individuals with Swyer syndrome for the risk of developing gonadal cancer, for which they have a much higher than average risk, but the article describes other ways researchers think this information could be used: “We can do hormone treatments and it’s possible to perform operations if people have got ambiguous genitalia so that people can have a ‘normal life.’”

But how can you have a “normal life” when surgeons are cutting up your genitals? How can you feel normal when doctors think that your are so abnormal that you need to be fixed by a knife? Strikingly, none of the researchers mention that social and psychological support can be made available to make it easier for people with Swyer syndrome to live with their unique bodies.

Conjoined Twin “Tragedy”: Ladan Bijani Murdered?

ipdxWIRE Intersex News (www.ipdx.org/news)

July 8, 2003

The first-ever brain separation surgery on adult conjoined twins was performed by an international team of experts on July 7, which resulted in the tragic death of both sisters, Laleh and Ladan Bijani. Doctors and newspapers assure that Bijani sisters had been fully informed of the potential consequences of this risky procedure, including the chance of death of one or both of the sisters, before consenting to it. However, a close examination into surgeons' comments about the failed “treatment” raises an ethical question regarding what went on in the operation room.

According to all sources, the critical component of this surgery was how to deal with the thick vein that drained blood from their brain to their hearts. Several teams of experts had previously declined to operate on Bijani sisters because they shared this important vein, which meant that the chances of both sisters surviving the separation surgery was “almost nil,” according to Madjid Samii, president of the International Neuroscience Institute in Hanover, Germany. Samii had evaluated possibilities for separating the Bijani sisters in as early as 1988, but had decided against the procedure because it was “virtually impossible.” In 1997, another team of doctors in Germany also decided against surgery because they “thought one of the twins would die and the other would be at risk” since there was only one vein.

The team that actually operated on Laleh and Ladan attempted to solve the vein problem by using the vein grafted from Ladan's inner thigh in her brain, and “reroute” the shared vein inside Laleh's head. But soon, Ladan's grafted vein congested, signaling failure for this plan. *Associated Press* reports:

... surgeons Monday night considered whether to call off the rest of the operation and leave the twins joined or “continue with final stage of the surgery, which we knew would be very, very risky,” [Dr.] Loo said.

“The team wanted to know once again what were the wishes of Ladan and Laleh,” Loo said. “We were told that Ladan and Laleh's wishes were to be separated under all circumstances.”

“Very, very risky”? They knew that Ladan could not survive without the vein she was sharing with her sister, and the replacement (grafted vein from her thigh) did not work as hoped. That means that doctors knew for 100% certain that Ladan would die if they “continue[d] with final stage of the surgery.” At that point, by choosing to go forward with the procedure that has absolutely no potential of improving Ladan's health, doctors made a conscious decision to murder Ladan in order to secure the vein for Laleh, instead of leaving them joined and alive. News stories that state that Ladan died 90 minutes before

Laleh are not telling the whole truth: doctors focused on saving Laleh after they had made a conscious choice not simply to abandon Ladan, but to actively murder her, which resulted in the 90 minute gap.

The medical procedure in which one of the conjoined twins is deliberately murdered in order to give the other a “normal life” is not unheard of. According to Alice Dreger, the medical historian from Michigan State University, at least nine such surgeries have been attempted on conjoined children, although none of them “resulted in any long-term, healthy survivor.” In all of these cases, Dreger states, none of the twin “chosen to survive ever actually survived to go home or even life free of a ventilator.” Pragmatic difficulties aside, it is obviously in violation of every ethical code to intentionally sacrifice a patient’s life in a medical procedure that have no potential whatsoever to help her or him. “It is unethical to treat children with unusual anatomies according to a different set of ethical guidelines than other children,” says Dreger, who is also known as the expert on ethical issues involved in the surgical “correction” of intersex genitals.

Ladan and Laleh demanded the highly risky surgery in hope that they would be able to follow their separate paths, and accepted the possibility that they might die from surgical complication. But did Ladan actually consent to being sacrificed in an avoidable procedure in which she had no chance whatsoever to survive? Did Laleh consent to having doctors kill her sister instead of staying alive together? Or, did doctors presume that life as a conjoined twin was not worth living? When Ladan and Laleh expressed their wish to be separated, did they actually say that they would rather be murdered than conjoined? Ladan and Laleh may have consented to a high-risk procedure which may inadvertently kill them, but does that mean that Ladan gave up her right not to be murdered in a procedure that has no potential merit for herself?

Laleh’s death was probably an unfortunate tragedy, but Ladan’s death is a murder, an intentional and avoidable killing of a healthy adult woman by the medical professionals who viewed her life as less valuable than their own. When conjoined twins’ lives are not valued as much as everybody else’s, neither will intersex children’s. Bijani sisters’ story reminded me of a presentation by a doctor, an intersex specialist, who first stated that genital surgeries on intersex children should wait until the child is at least six month old because anesthetic might kill the baby, and then added that earlier surgery was permissible if it reduced parents’ anxiety.

Doctors Receive \$1.2 mil. to Study “What’s Wrong With Intersex”

ipdxWIRE Intersex News (www.ipdx.org/news)

July 17, 2003

According to *Australian Associated Press*, an international team of American and Australian doctors received a \$1.2 million grant from the National Institute on Health to study genetic causes of intersex conditions. Vincent Harley of the Prince Henry’s Institute of Medical Research in Melbourne and Eric Vilain of the University of California will study genetic makeup of “some 30 intersex patients... as well as genetically engineered intersex mice.” Harley told AAP: “We have a bank of patients and the aim ultimately is to understand what is wrong in those patients.” But intersexuality is a naturally occurring variation that is neither right or wrong; if anything, it is the society that deems intersex bodies shameful or offensive that is wrong.

Vilain further explains the purpose of this study: “When a baby is born intersex it’s quite traumatic for the family... Knowing the molecular explanation for this syndrome helps perform rapid diagnosis... so we can say to the patients... your baby will be more comfortable in a male or female gender.” Wow, so many flaws in just a couple of lines. Where should we even start?

First of all, they can’t tell the child’s gender identity by studying genetic makeup of the child--all gender assignments, including those on non-intersex babies, are therefore tentative until the child is old enough to express how they feel. Second, parents of intersex babies are not “patients”—there needs to be a limit to how they can have their children’s bodies medically altered. And lastly, parents’ anxiety is a real concern, which should be addressed by social and psychological support, as well as honest and factual communication. For doctors to pretend to know what they cannot know (i.e. which gender the child will be more comfortable in) is dishonest and does not serve any constructive purpose.

There are valid reasons doctors should study the genetic causes of intersexuality. However, no amount of causal knowledge shall be used to justify or rationalize otherwise unethical medical practices, such as medically unnecessary surgical “correction” of intersex babies, or dishonest communication with the parents of intersex children.

FDA Approves Injecting Growth Hormone for Healthy, Short Children

ipdxWIRE Intersex News (www.ipdx.org/news)

July 25, 2003

On July 25, the U.S. Food and Drug Administration approved the injection of human growth hormone to “abnormally short” children who are otherwise completely healthy. According to *Associated Press*, growth hormone “has been used for 16 years to treat children who are extremely short because their bodies don’t naturally produce the substance or because of a few other growth-stunting diseases,” but this is the first time the drug is approved for children who do not have any of these medical conditions but are simply short. The regimen involves six shots a week for years and will cost each family \$10,000 to \$25,000 per year.

Interestingly, doctors insist that “this is not cosmetic use.” Both FDA and Eli Lilly & Co., the manufacturer of the hormone, state that the goal of the treatment is to improve children’s quality of life by avoiding situations like “being ostracized in elementary school” for not being able to reach the water foundation, or being “too short to even reach a car’s pedals.” But the gender discrepancy inherent in the standard by which they decide a child’s eligibility for the hormone treatment—boys must be predicted to be shorter than 5-feet, 3-inches as adults, and girls shorter than 4-feet, 11 inches—itself is a proof that this is a highly invasive and costly medical intervention whose goal is to get around social stigmas rather than any actual physical condition.

Letter to *Daily Illini*: Non-Discrimination Policy is Not Enough for Intersex

Sent to *Daily Illini*, the student newspaper of University of Illinois.

March 10, 2003

Dear Editor,

It's interesting that after years of seeing "bisexual" and "trans" mentioned along with "gay and lesbian" without addressing any specific needs of bisexual and trans people, we are now seeing "intersex" (people born with atypical reproductive and sexual systems) being mentioned alongside "transgender/transsexual" in pretty much the same way.

According to your article [*Transgender Community Looks to Make Campus More Inclusive*, March 3, 2003], "members of the LGBT community" are demanding that "intersex status" added to the University's non-discrimination policy along with "gender identity," because intersex people, like transgender people, "might face more discrimination" than others in the LGBT community.

While LGBT activists' desire to advocate for intersex people is welcome, "including" intersex category in non-discrimination policies does little to protect the rights of intersex people.

This is because the intolerance of intersex people takes a very different form than that of transgender people: instead of being excluded from opportunities or assaulted on the street, intersex people are routinely surgically and hormonally "corrected" throughout childhood, often resulting in emotional, physical and sexual trauma, in the society's attempt to make them appear "normal," that is, non-intersex. Thus, addressing "discrimination" as a major issue facing intersex people would not only be inaccurate, but also trivialize specific experience of intersex people, which is about erasure rather than rejection.

In order to truly address the needs of intersex people, we must push for children's and patients' rights to self-determination and for social and psychological support, rather than creating non-discrimination policy. That is not to say that non-discrimination policy should not include intersex, but we need to recognize that the inclusion of "intersex" in non-discrimination policies is highly inadequate in securing intersex people's rights.

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

Letter to *The New York Review of Books*

Sent to Andrew Hacker, a reviewer for *The New York Review of Books*.

March 10, 2003

Hello Dr. Hacker,

My name is Emi Koyama and I am the director of Intersex Initiative Portland, a new (since January) intersex activist group in Oregon.

I am writing in response to the review in *The New York Review of Books* (March 27) which you wrote. I'm writing to provide you with a couple of clarifications on the topic you briefly touched, that is intersexuality. Since I haven't actually read "Normal," I'm not sure if these comments are attributable to her or to you, so forgive me if some of them had nothing to do with you...

You wrote: "After about one of every two thousand births, the parents hear a physician saying something like 'Somehow your baby's genitals haven't finished developing, so we don't quite know right now what sex it is.'"

I wish this was true! However, physicians rarely admit to the parents of intersex babies that they *do not know*. In fact, the current medical standard *encourages* physicians to act confident that they *know*, or else parents would not be able to raise the child appropriately to his/her assigned gender.

Medical ethicist Alice Dreger from Michigan State University wrote in 1998: "Since the overarching rule of this system is 'avoid psychological confusion about the patient's gender identity,' doctors often do not tell intersexuals and their parents all that the doctors know, lest information about intersexuality confuse or complicate the family's understanding of gender." She further states, "in no other realm in medicine do doctors regularly argue for active, nearly wholesale deception."

You wrote: "One who is known is John Colapinto, who was made into a Joan shortly after being born, and decided in his teens that he really was a boy."

Actually, John Colapinto is the author of the book *about* the child who has been referred to as "John/Joan," and not the "John/Joan" himself. Colapinto is a freelance writer living in New York.

ALSO, "John/Joan" was **not** intersex; he was born with "normal" male genitals, then was turned into a girl after an accident during the circumcision. Sure, the way he was treated by the medical system was similar to how intersex children are being treated, but if you are talking about intersex, you should probably mention people who are actually intersex.

I hope this information would help with your future projects.

Emi Koyama
Intersex Initiative Portland

About Intersex Initiative

Intersex Initiative (ipdx) 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.

Intersex Initiative is affiliated with **Survivor Project**, which addresses the needs of intersex and trans survivors of domestic and sexual violence.

Emi Koyama has been an intern-turned-staffer at **Intersex Society of North America** before founding Intersex Initiative. Since January 2003, she has been working full-time as the director of ipdx.

For more information or to sign up for **ipdxWIRE Digest**, Intersex Initiative's news and alert list, please visit our web site at **www.ipdx.org**

About Emi Koyama

Emi Koyama is a multi-issue social justice slut who synthesizes feminist, Asian, survivor, dyke, queer, sex worker, intersex, genderqueer and crip politics. Emi is the founding director of **Intersex Initiative Portland** and has presented extensively on intersex activism, working-class sex worker feminisms, and the domestic violence “industry.”

Emi is also the founder of **Confluere**, the alternative “speaker’s bureau without the centralized bureau” and is responsible for putting the “emi” back in feminism via her personal web site, **eminism.org**.

Also available from **Confluere Publications**:

Disloyal to Feminism: Abuse of Survivors within the Domestic Violence Shelter System by Emi Koyama

Instigations from the Whore Revolution by Emi Koyama

Jury Duty by Leslie Bull

I was abducted by white people by Kim So Yung

Kaleidoscope by Leslie + Stacey Bull with the Family

These Nations Forgotten by Lamya Amir el-Chidiac

A Handbook on Discussing Michigan Womyn's Music Festival for Trans Activists and Allies by Emi Koyama

Feel Me by Leslie Bull

Turtle and Gorilla by Leslie + Stacey Bull with the Family

Introduction to Intersex Activism by Emi Koyama

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