dedicated to ladan bijani

dear ladan, don’t think that i don’t support your decision
don’t think that i don’t understand your quest for normalcy
because i do
but i refuse to see you as a victim of your own desperation
  i refuse to accept that you chose death
  i refuse to accept that you chose anything less than life
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Being Accountable to the Invisible Community

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Below is a letter sent to Associate Press in response to its article about Pennsylvania Gov. Ed Rendell’s decision to protect transgender state employees from discrimination in state’s own hiring.

July 19, 2003
Hello AP,

My name is Emi Koyama and I am the director of Intersex Initiative, a Portland, Oregon based organization working to end the medical abuse of children born with intersex conditions. I am also a former staffer for Intersex Society of North America, the largest intersex activist group in the world.

I’m writing in response to the article from your Philadelphia bureau titled “Pennsylvania governor makes transgendered a protected class” in which it states: “It generally affects people who are transgendered—a broad term referring to cross-dressers, hermaphrodites, transsexuals or those who have surgically changed their sex.” Several points:

1) The word “hermaphrodite” is both inaccurate and offensive. Literally, it means someone or something that has both male and female reproductive organs (like snails and earthworms), which never happens to people. The appropriate, non-deragatory term to refer to humans with mixed or incomplete reproductive anatomies is “intersex.”

2) Despite what transgender activists have written in the past, intersex activists do not see themselves as part of “transgender.” We are one of the three major intersex activist groups in this country (others being Intersex Society of North America from Seattle and Bodies Like Ours from New Jersey), and I am sure that this view is shared among all of us.

3) Intersex people are not targeted for discrimination in employment, housing, and public accommodation. The violation of civil and human rights for intersex people often takes place in medical and family settings, where medically unnecessary surgeries and other invasive treatments are performed without proper informed consent. The Pennsylvania governor’s executive order will not provide any protection for intersex people, although it is a welcome policy decision for transgender people.

Thank you,

Emi Koyama
Intersex Initiative Portland
http://www.ipdx.org/
Intersex Births: Almost As Bad As Prenatal Death?

ipdxWIRE Intersex News
August 19, 2003
http://www.intersexinitiative.org/news/

There is an article about intersexuality in the new issue of Journal of Paediatrics and Child Health, an Australian medical journal. Written by Low and Hutson of the Centre for Early Sexual Development at Royal Children’s Hospital in Parkville, Australia, the article gives a basic technical overview of understanding and diagnosing several intersex conditions. While the article does not address any particular treatment for these conditions, authors’ biases are obvious in the first line of the article: “Next to perinatal death, genital ambiguity is likely the most devastating condition to face any parent of a newborn.”

But what exactly is it that’s making the birth of a child with “ambiguous genitalia” so devastating, considering the fact that genital ambiguity generally does not itself cause any pain, illness, or death (although it may be a sign that the child might be experiencing some underlying endocrine problem)? Obviously, the author’s illogical insistence that “‘clitromegaly’ in an otherwise phenotypic female is always abnormal,” (p. 409) for example, does not help remove the devastating shame and stigma associated with intersex births, and helps to justify cosmetic surgeries that many intersex adults feel are damaging.

In the review article recently published in *New England Journal of Medicine*, pediatricians Phyllis W. Speiser and Perrin C. White briefly acknowledges the impact of intersex patient advocacy organizing. They state: “Retrospective reviews suggest that both the cosmetic and functional outcomes of genital surgery procedures as formerly practiced were often unsatisfactory. Surgery during adolescence is often fraught with psychological and technical difficulties... Patient-advocacy groups have appealed to physicians to inform families about all the potential surgical pitfalls so that they can carefully consider whether and when surgery should be done. In addition, there is now heightened awareness of the need for psychological support for families with an affected child. Respect for patients’ privacy has led to fewer genital examinations during childhood and adolescence.”

The paper also states that “improvements in the surgical correction of genital anomalies over the past two decades have led to earlier use of single-stage surgery,” while noting that “the long-term outcomes of the newer surgical procedures have yet to be evaluated.” Interestingly, there is no mention of any reason that “ambiguous genitalia” needs to be treated in this paper, leading one to wonder: if the old surgery was so horrible and the new surgery hasn’t been established yet, why are we rushing into it in the first place? Just because we have the surgical techniques to do so?

“IS: Otoko demo onna demo nai sei” is a groundbreaking new comic series by Chiyo Rokuhana, coming from the world capitol of the “manga” (comic) subculture. Based on interviews the author conducted with intersex individuals, each episode of “IS” (which spans about 100 pages) tells a multidimensional human story of an intersex person who lives and breathes in Japan. Our friends in Japan kindly sent us the September 2003 issue of One More Kiss, a romantic comic magazine for twenty-something Japanese women, in which the second episode of Rokuhana’s “IS” is published.

The episode follows the life of Ryoma, who was born with “normal” male appearances, but grew up identifying with girls instead of boys. After rounds of bullying at school, Ryoma learns to suppress his feelings of isolation and alienation and to put on the mask of a “normal” boy who likes to surf in the ocean. At 17, however, Ryoma experiences the sudden development of breast and other feminizing changes in his body, which forced him to abandon surfing (wetsuit reveals his shape too much). He goes to the hospital for an examination, where he learns his chromosomal and endocrine anomalies. Physicians recommend that he receive double mastectomies and testosterone treatment to help him continue to live as a man, but Ryoma decides to live openly as an intersexual whose gender leans more toward female than male.

Deepening the plot are two characters, Ryoma’s younger brother and Tamachan, his ex-girlfriend and neighbor he continues to be close with. The brother gets angry when he finds out Ryoma’s intention to stop living as a male, especially since he had looked up to the tough, surfer side of his older “brother,” but he comes to realize Ryoma’s strength in being true to himself and educating their community about intersex experiences as an “out” intersex individual. Tamachan, who comes from an abusive family background and who have found consolation in her relationship with Ryoma, experiences her own transformation, too, as she becomes pregnant with her current boyfriend and prepares for marriage. She consoles Ryoma back as they struggle with social rejection and doubt, telling him that witnessing Ryoma’s courage and strength made her believe that she could build a family that is supportive, unlike the one she came from.

We welcome the publication of “IS” because it is probably the world’s first serial comics based on the real lives of intersex people, and it’s sympathetic and accessible. The only request we have is that the future episodes of “IS” address issues and struggles beyond gender identity formation, because intersex people’s experiences are diverse and do not always focus on gender identity.
Informed Consent and Clash Over Cultural Values

ipdxWIRE Intersex News
August 30, 2003
http://www.intersexinitiative.org/news/

There is an interesting discussion in the July/August issue of *The Hastings Center Report*, published by The Hastings Center, over a complicated “case” of treating a child with intersex conditions. The child, a thirteen-year old boy, was brought in for treatment for his hypospadias, breast development, and occasional bleeding through the urethra. It turns out that the child was genotypically female (46,XX) with congenital adrenal hyperplasia, and had functioning ovaries and a uterus; the bleeding was in fact menstruation.

To make the situation more complicated, the family was from Middle Eastern background, and could not stay in the United States for much longer. Parents are requesting the removal of all female reproductive organs despite the fact that the child is fertile, as well as the bilateral mastectomy and hypospadias surgery. The boy has not been informed of his complex condition, as parents believe that the father knows what is best for the child, and that it is up to the father to make a decision on his behalf. The boy exhibits stereotypically male behaviors for his culture, and is expressing a desire for mastectomies to avoid teasing. What should physicians do?

Three parties respond to this situation. First, David Diamond considers three possible options: maintaining and enhancing the child’s male appearance and identity by performing the requested surgeries, re-assigning the child to be female in order to preserve fertility, or advising the parents to defer treatment altogether until the child can make the decision himself. Diamond concedes that the lack of the child’s informed consent is problematic, but feels that it is justified to have the father make a decision to have surgeries performed on the boy to remove female reproductive organs because to do otherwise (turning the child into female or delaying treatment) might make it impossible for the family to fit into their culture.

Sharon Sytsma is also troubled by the lack of the child’s informed consent, and argues that physicians should make additional efforts to convince the family to discuss the situation openly with the patient. “Given the cultural bias toward males, the parental attitudes, and the apparently consistent male gender identity and behavior, the child would probably choose not only the mastectomies... but the other surgeries and treatment as well... However, we have learned that withholding information about intersex from children is more likely to be damaging than not.” In addition to discussing further with the parents, Sytsma advocates for educating “our own public—citizens and doctors—about the importance of open communication and informed consent... Doing so could have the effect of dissuading parents from other cultures seeking
surgery for their children without their participation.”

Lastly, intersex allies Alice Dreger and Bruce Wilson challenge how the question is framed in the first place. “The case has been understood primarily as a surgical problem... but that is the wrong way to approach intersex.” Instead of focusing on whether or not to do surgery, they argue for a broader approach to treating the child, which would involve participation of pediatric psychiatry, psychology, and social work professionals. “The case description implies that, if the surgeries are done, the patient might go on in life ‘cured,’ never having been the wiser. But in fact, this patient will need lifelong endocrinological management, regardless of the surgeries.” Thus, it is fundamentally important that the child be allowed to participate in his treatment, they argue. “In the case before us, if even with sensitive team care the parents refuse to allow the child to be consulted about his condition and treatment, the physicians should refuse to cooperate in the deception and should, if they feel the child’s well-being is at serious risk, seek legal help in protecting this child from what might amount to neglect or abuse.”

While I ultimately agree with Dreger and Wilson that physicians should not cooperate with deception of the patient regardless of his parents’ cultural values, I find the closing statement a bit extreme and devoid of cultural sensitivity. While respecting cultural differences does not mean that we set aside our own moral or ethical convictions (such as the fundamental importance of informed consent), it does mean, in Sytsma’s words, that we “try to understand why a culture values what it values, to withhold wholesale condemnation of individuals belonging to that culture for holding such values, to be open-minded to the possibility that the values of another culture may be either equally tenable or morally superior to our own, and to refrain from imposing our own values on a culture whose circumstances are such that doing so would lead to harm.”

In addition to the multidisciplinary team of medical and social work professionals, I would like to see, with the permission of the parents, members of the family’s ethnic and spiritual communities participate in explaining why the child deserves to know about his condition. I would also like physicians to appeal to the leaders of these communities before rushing to the legal system, especially since Middle-Eastern people and immigrants have reasons to fear and distrust American legal system due to its surveillance of Middle-Eastern communities after 9/11. Finally, the medical community needs to make further efforts to increase the number of Middle-Eastern people (and other members of marginalized communities) in the medical profession, including among medical ethicists, which will help us communicate better with patients with Middle-Eastern background and their families in the future.

— Emi Koyama, Director, Intersex Initiative

Intersex People as “Saviours of Humankind”? 

ipdxWIRE Intersex News
September 3, 2003
http://www.intersexinitiative.org/news/

Australian genomics expert Dr. Jenny Graves of Australian National University is visiting New Zealand this week, giving a series of lectures about the “decline of the Y chromosome and the future of humankind.” Among the arguments made by Graves, according to thepress release and the handout prepared for Graves’ talk, is the fantastic claim that “humans might separate into two different species” as the result of the Y chromosome’s shedding of genes over evolutionary timeframe, and “how intersex individuals... could be the saviours of humankind.” Whoa. Wow. Damn.

The story of the diminishing Y chromosome hit the news (or rather, Maureen Dowd’s misleading New York Times column “The Incredible Shrinking Y” on July 10, 2003), when Dr. David Page and his colleagues published a paper about the evolutionary history of Y chromosome (Nature, June 19, 2003). Most chromosomes come in pairs, which enables them to swap corresponding genes with one another and to keep damaged genes from being passed on through the process known as recombination. The Y chromosome however cannot do this because it does not meet up with another Y chromosome. Without recombination, damaged and dysfunctional genes have accumulated on the Y chromosome over the evolutionary time, resulting in the loss of legitimate genes. The human Y chromosome is said to have contained 1,500 genes in the distant past, but now only has about 40. Graves and others speculate that the Y chromosome could lose all of its genes in five to ten million years, a claim that appears scientifically sound.

Adding to this knowledge, Graves states: “As the Y loses its ability to carry traits between generations, other chromosomes have been picking up the slack. It is only a matter of time... until a different gene to cause maleness picks up from the where the Y chromosome leaves off. Some humans already have other mutations that mean their genetic sex does not match their physical characteristics. Such intersex people could be the genetic saviors of mankind once the Y chromosome fails entirely, and take over as a new species. But if several different new sex determination mechanisms evolved, humankind could separate into several different species that are unable to breed with each other.” Are you following this logic? No? Neither are we.

It appears to us that Graves (like Dowd) is mistaking chromosomes for humans. It should be obvious that intersex people, regardless of chromosomal makeup or fertility, are members of the same species as everyone else. Intersex people are known to be born to humans, and mate with (that is, exchange genes with) other humans, when that is possible. Nor is intersexuality caused
by a single gene or solely by the Y chromosome; it includes a wide variety of biological status that may or may not have anything to do with the anomaly of the SRY gene. Besides, we will certainly not see a situation where intersex individuals will only mate with other intersex individuals.

Over all, it seems that Graves’ argument is either oversimplification of many factors that influence human sex differentiation, or a case of poorly executed analogy. We feel that the socially stigmatizing implication of suggesting that intersex people would become a “new species” outweighs any scientific merit this argument might have.

In support of her argument, Graves gives an example of another mammal that have already separated into two species: voles. “The male vole has lost its Y chromosome entirely and become two different species.” We wonder if intersex voles played any heroic role in saving the voledom too. Go intersex voles!

We appreciate Dr. Lisa Weasel, the Assistant Professor of Biology at Portland State University, for her insights and expertise on this topic.
“Sex Life Normal for Women with Rebuilt Vagina” is the headline of the Reuters Healthnews story dated September 12, 2003, but its interpretation of the study the article is based on is inaccurate. The Reuters story states that “an artificial vagina... can lead to a normal sex life for women with an uncommon disorder in which the organ is missing, new research suggests.” However, this is not the conclusion of the research, which is published in the September 2003 issue of Fertility and Sterility.

The study actually states that the constructed vagina “allowed a normal sexual life in patients who had sexual relations” (emphasis mine). More precisely, the study reports that women with surgically constructed vagina who have intercourse at least once a week score similarly to the control group, i.e. women who were born with “normal” vagina. The authors further admit that including those women who are less sexually active “lowered the mean value” (p. 603 in the paper). In short, when all subjects are included, women who had vagina constructed as a group score lower than the control group, contrary to the Reuters report.

We fear that such reporting by a trusted news source as Reuters would mislead MRKH (vaginal agenesis) patients and their family members to underestimate risks of surgical treatment or have unrealistic expectation about it.

Prenatal Diagnosis of Mixed Gonadal Dysgenesis

ipdxWIRE Intersex News
October 3, 2003
http://www.intersexinitiative.org/news/

A group of physicians from Modena, Italy published a case report about the early prenatal diagnosis of 46XY partial gonadal dysgenesis in the recent issue of *Prenatal Diagnosis*. The case involves a pregnant woman whose first son had partial mixed gonadal dysgenesis, who came in to test her fetus for the recurrence of the same condition. Combining sonography and karyotype testing, doctors determined the female genital structure, 46XY karyotype, and disturbed functioning of testes indicating that the fetus, like his/her brother, has partial mixed gonadal dysgenesis. Doctors proposed the parents that the child be raised as a girl, explaining that “it is possible to treat with appropriate means and to enable a good quality of life,” but the parents chose to terminate the pregnancy.

We do not know for certain why the parents chose to have an abortion, but it may have to do with the traumatic process their older child had to go through. According to the article, the child went through laparotomy (to examine the intra-abdominal gonads) at age three, bilateral gonadectomy at age four, and masculinizing genitoplasty at age six—all before he was old enough to understand the procedure. In addition, he was repeatedly brought into hospital to measure levels of various hormones, to look for possible mutations of SRY and the androgen receptor gene, and to analyze DNA sequences for any abnormality. There is no mention of any counseling or psychological support provided to the child or the parents—which explains why the parents may have felt that it was unbearable to raise another child with partial mixed gonadal dysgenesis.

Doctors are absolutely correct in insisting that it is possible for a person with mixed gonadal dysgenesis to have a good quality of life, but that needs to be enabled by social and psychological support for parents and children dealing with the medical condition, not by giving the false promise that surgical treatment will solve all of the problems. In the absence of appropriate social and psychological support, early prenatal diagnosis will only coerce women to “choose” socially imposed devaluation of the fetus with stigmatized but livable conditions.

There is a strange article in the September 19 edition of The Washington Times, in which the paper brings up the recent criticisms of unwanted genital surgeries on intersex children as an example of the “intense criticism” that the National Institute for Child Health and Human Development (NICHD) is supposedly facing for funding sex researches, as if cutting funds to NICHD would magically stop surgeries.

The reality, of course, is the opposite: researches that investigate the long-term consequences of surgical treatments or that explores alternative treatment models can only help our cause. The only connection that the reporter seems to draw is that the surgical treatment was pioneered by John Money from Johns Hopkins University, who also happened to be a major recipient of NICHD grants.

We wrote a letter to the Washington Times defending the NICHD and its sex research funding, but we aren’t completely happy either with the comments made by NICHD president Dr. Duane Alexander in the article. Asked about Money’s failure in the David Reimer case, which is detailed in the book As Nature Made Him, Alexander responds that this case was “one that did not turn out well,” then blames parents for not making “the switch in their minds” and not being “consistent in raising him as a female instead of a male.” Such explanation, of course, is purely speculative, and does not give the public the impression that NICHD knows what it’s doing.

Of course, that may be how the reporter intended to present it. Counted among the “lying liars” in Al Franken’s recent bestseller about the conservative media, the Washington Times is an ultra-conservative newspaper owned by a right-wing religious group, so its biases for a “small government” and against researches on sexuality are obvious. In part because of that, we chose to leave Dr. Alexander alone and focus on the main topic in the letter we wrote to the editors of the Washington Times:

Dear Editor,

In your story about the National Institute for Child Health and Human Development’s funding of sex research projects (“Sex and child health,” September 19), you refer to the controversy surrounding the
surgical sex-reassignment of children born with “ambiguous (intersex) genitalia” as an example of how NICHD “has been the subject of intense criticism.” However, the fact that this “treatment” was initially promoted by a physician who happened to be a major NICHD grant recipient does not make this ongoing medical practice a NICHD-funded project. Nor are the critics of this particular “treatment” necessarily the critics of NICHD’s funding of sex researches.

In fact, it is precisely these researches that, in recent years, provided evidences indicating that these surgeries performed without the child’s knowledge or consent did indeed cause physical, psychological, and sexual damages. Cutting NICHD’s research funds will not stop these surgeries; more researches that evaluate their long-term effects and explore less invasive alternatives will. As a patient advocate, I support NIH/NICHD’s continued funding of researches of intersex conditions, which will help doctors provide better medical treatment for children born with intersex conditions.

Emi Koyama
Director, Intersex Initiative
www.intersexinitiative.org
Transgender Medicine Experts Show Some Interest in Intersex

ipdxWIRE Intersex News
September 20, 2003
http://www.intersexinitiative.org/news/

Over 300 transsexual and transgender people and the professionals who work with them gathered in Ghent, Belgium for four days last week for the 18th International Symposium of the Harry Benjamin International Gender Dysphoria Association (HBIGDA). HBIGDA is particularly influential in transsexual medicine, as it produces the treatment guideline known as the “standard of care” that majority of physicians use in determining who can receive hormone and surgical interventions designed to help transsexual people “transition” to their preferred gender/sex. Over the last couple of years, there have been an increased interest in intersexuality within HBIGDA, although to this date HBIGDA seem to have made miniscule effort to dialogue with intersex activist groups.

In summer of 2001, intersex activists first became aware of HBIGDA’s interest in creating an internal “intersex committee,” not directly from them, but from professionals who were invited to take part in the committee (as far as we know, no intersex individuals have been invited). We got in touch with some members of HBIGDA we are friends with and asked them to keep us updated on HBIGDA’s activities in this area. We are already in conversation with various medical societies and experts, and did not want to have to deal with yet another medical body unless they are working in collaboration with us. HBIGDA went on to survey its members regarding their interest in intersex medicine in order to determine whether or not the intersex committee was needed.

Which brings us to this year’s symposium: In a morning plenary on September 12, Tom Mazur of the Children’s Hospital of Buffalo, the tentative “intersex committee” chair, reported the outcome of the membership survey. According to several sources who attended the conference, Dr. Mazur reported that many HBIGDA members are indeed interested in learning about intersexuality and treatment for intersex patients, but there did not seem to be a mandate for HBIGDA to take active role in defining or redefining intersex treatment protocol. For example, HBIGDA members do not see themselves to be in the position to create a version of “standard of care” for intersex individuals. Needless to say, we were relieved to hear this. The board of HBIGDA approved the intersex committee as a formal committee of the organization to continue to explore how HBIGDA will be involved in the intersex medicine.
We at Intersex Initiative urge the intersex committee of HBIGDA to focus its energy on improving the medical care for those intersex people who are also transgender/transsexual (e.g. someone who was born intersex, and wishes to “transition” gender as an adolescent or adulthood). We know of several cases where physicians who are otherwise experienced in treating transgender/transsexual clients refused to prescribe hormones when they found out the patient’s intersex status (they typically claim that they don’t know the appropriate dosage or what it would do to someone’s endocrine system when it’s already atypical—folks, what about starting with a low dosage and monitoring carefully?). We frankly do not want HBIGDA to get in the middle of the discussions over intersex medicine in general; at the very least, we urge HBIGDA to work in close alliance with intersex activists should they choose to get involved there.

Other intersex-related highlights of HBIGDA symposium:

* Dr. Ken Zucker gave a presentation about the research on gender role and identity acquisition in people with intersex conditions. It is questionable if such a research has any use, as studying “intersex” as a group does not give us any meaningful information about the experiences of people with any particular intersex condition. We expect gender role and identity acquisition to be vastly different across various diagnostic groups, and grouping various conditions into “intersex” would simply average them out. No wonder Zucker found intersex people’s gender roles and identities to be somewhat intermediate.

* A.B. Dessens and F.M.E. Slijper of the Netherlands reported that the most 46XX individuals born with classical CAH (congenital adrenal hyperplasia) continue to live as women into their adulthood. Duh.

* Contrary to the oft-cited report by Dr. Julianne Imperato-McGinley, Dr. P.T. Cohen-Kettenis from the Netherlands reported that many individuals born with 5-alpha reductase deficiency syndrome or 17-beta hydroxysteroid dehydrogenase and raised as girls often continue to identify as female after puberty.

* Among small the group of participants Tom Mazur came across, no women born with complete androgen insensitivity syndrome transitioned to live as men; among partial AIS population, Mazur found one case each of people transitioning from male to female and female to male.

* Dr. Heino F.L. Meyer-Bahlburg of Columbia University surveyed many cases in which young non-intersex boys were re-assigned as female after their penis is damaged in one way or another. Meyer-Bahlburg reports that while some of these individuals—like David Reimer from the famous “John/Joan” case--revert back to male when they grow up, many actually continue to live and identify as women.

* At the last minute, Miriam from the AIS Support Group in the Netherland was given the podium to present about how intersex issues are different from transgender ones. One of the PowerPoint slide stated: “don’t just talk about us—talk with us.” That sums up our message to HBIGDA as well.
In the latest (August 2003) issue of *Journal of Sex Research*, Vern Bullough of the State University of New York profiles the life and work of John Money, calling him “one of the great pioneers of American sexology in the last part of the 20th century” who should “be included in the pantheon of pioneer researchers.”

In his glowing praise of Money’s contribution to sexology, Bullough blames the masculine gender identity development in the famous “John/Joan” case (in which Money made parents change their son’s gender to female after a circumcision accident) on parents’ non-compliance with the treatment, and also on the doctor who performed botched circumcision in the first place (“He undoubtedly suffered from the attempts to change him, but the real suffering was caused by the physician who botched the circumcision, not by Money who was later sought out by the parents”).

Further, Bullough responds to intersex activists’ criticism of the surgery-centered protocol of intersex medical treatment as follows:

*The issue of intersex children has been further complicated by the fact that the whole question of treatment has been politicized. [...] In short, [ISNA] changed the playing field, and though the Society brought hemaphroditism out of the closet, it also at its extreme became rather shrill. The ISNA tends to ignore the fact that the gender in which an intersex child is brought up will undoubtedly influence the child’s ultimate decision, since in our world it is always impossible to be a neuter. The real need in my mind is in helping parents decide what to do with their infants, since society has not yet accepted the fact that there are males, females, and others, and both the medical community and the parents need some guidelines. Undoubtedly, major reconstructive surgery should be postponed until puberty if possible, but chromosomal sex alone cannot be a guide. [...] The problem is to communicate the options to the parents more effectively without influencing them and then to support them in their decision. Quite frankly, some parents of intersex children seem to be almost incapable of dealing with an intersexed child unless a gender is assigned and some surgery done.*

This is an oversimplification of ISNA’s position regarding the treatment of intersex children. As far as intersex activists are concerned, it is not just whether to perform surgery or to delay it; we believe in replacing medically unnecessary cosmetic surgeries with social and psychological support.
(counseling, peer support, etc.) and information, which will address parents’ understandable anxiety about raising the child with atypical genitalia without all the damages surgeries would incur. Surgery coerces silence on both parents and the intersex child, which breeds shame and isolation. We could end up being “wrong” about the gender of rearing with or without surgeries, but under ISNA’s protocol we preserve the widest range of options when the child is old enough to decide for herself or himself.

There is no denying that John Money made some important contribution to the field of sexology, such as his adoption of the word “gender” to refer to socially constructed masculine or feminine characteristics apart from the biological “sex.” But in his eagerness to praise Money’s achievements, Bullough made the same mistake he attributes to some of his critics, that is, he oversimplified the opponent’s position in order to make the alternative seem more reasonable.

In the article titled “Sexual Identity Hard-Wired by Genetics,” Reuters reported on October 20 that one’s sexual or gender identity is “wired into the genes,” citing the new research by UCLA geneticist Eric Vilain and colleagues. According to Vilain, the findings would suggest that “sexual identity is rooted in every person’s biology before birth” and that this knowledge may be used to ensure that intersex babies are assigned the correct gender. “If physicians could predict the gender of newborns with ambiguous genitalia at birth, we would make less mistakes in gender assignment,” Vilain said. However, none of this is actually established or discussed in the actual research paper this news report is based on.

The actual research published in *Molecular Brain Research* (Vol. 118, pgs. 82-90) is titled “Sexually dimorphic gene expression in mouse brain precedes gonadal differentiation,” and this title summarizes the entire paper accurately: this study shows that female and male mice develop different brain structure even before their gonads are formed. The significance of this study is that sex differences in the brain have been traditionally said to be caused by the different levels of hormones produced by the gonads—testes for males, ovaries for females. Vilain et al. observed sex differences in the brain prior to the formation of sexually specific gonads, which suggests that there are other mechanisms that cause brain sex differences than hormones.

Interesting discovery, but how does that show that gender identity is “hard-wired”? Paper does not address this question at all, but it would be ridiculous to claim to have discovered the nature of gender identity in a study using mices, because mices do not report their gender identity to researchers like human subjects do. And besides, is findings from the mice sexuality really generalizable to the human population?

Vilain’s application of his “findings” to the intersex controversy is also ethically questionable. If there was really a way to predict a child’s gender accurately, will that justify surgically mutilating the child to fit into her or his “true gender”? Intersex activists are seeking to end shame, secrecy, and traumatic medical treatments that are not necessary, safe, nor effective—not an end to “mistakes” of assigning the “wrong” gender.

Besides, the methodology Vilain used for studying the brain structure of a mice involves cracking its head and grinding brain—not an ideal method if our goal is to “predict the gender of newborns with ambiguous genitalia.” Clearly, the Reuters story is way, way off at many levels.
How did a reputable news agency such as Reuters make such horrible reporting errors? We found a press release issued by UCLA on October 15 which apparently provided the basis for the Reuters story. Titled “Is sexuality hard-wired by the brain?”, the UCLA release states, among other things:

“Our findings may explain why we feel male or female, regardless of our actual anatomy... These discoveries lend credence to the idea that being transgender—feeling that one has been born into the body of the wrong sex—is a state of mind... Their gender identity likely will be explained by some of the genes we discovered.”

Vilain’s findings on the brain’s sex genes may also ease the plight of parents of intersex infants, and help their physicians to assign gender with greater accuracy... “If physicians could predict the gender of newborns with ambiguous genitalia at birth, we would make less mistakes in gender assignment,” said Vilain.

Lastly, Vilain proposes that the UCLA findings may help to explain the origin of homosexuality. “It’s quite possible that sexual identity and physical attraction is ‘hard-wired’ by the brain,” he noted. “If we accept this concept, we must dismiss the myth that homosexuality is a ‘choice’ and examine our civil legal system accordingly.”

These are wild claims, and none of them is warranted from the actual study. And Vilain knows it: which is why he and his colleagues didn’t mention any of this in the actual paper, which must be peer-reviewed by other scientists, but chose to wildly speculate in the press release, which is only read by science novices. I suspect that Reuters reporter did not even read the actual paper, relying solely on the press release to write the article.

Reuters is irresponsible for uncritically relaying the message, but we find UCLA’s press release much more unethical, because it appears that the release is intentionally written to be misleading and sensationalistic. Perhaps the UCLA researchers thought that the press release would help make the society more accepting of gays and transsexuals, but they overstepped the ethical line when they made these wild predictions and suppositions about the biological roots of transsexuality or homosexuality when their study actually had nothing to do with gender identity or sexual orientation (or even human sexuality).

— Emi Koyama, Director, Intersex Initiative

Thanks to Dr. Lisa Weasel for her knowledge and insight that contributed to this commentary.
Hello Dr. Paechter,

My name is Emi Koyama and I have just come across your paper, “Learning masculinities and femininities: power/knowledge and legitimate peripheral participation.” I’m glad to see that you took notice of the “writing guidelines” on intersex that I wrote, which addresses the ethical issue of scholars using intersex merely as a theoretical device to support their point, rather than using their theories to support people who live that experiences. I do hope that you would identify my name correctly next time.

A comment about the content. In page 547, you wrote:

Three things seem to be involved here. The first seems to be a sense that part of establishing a shared history within the local community of practice of masculinity or femininity is physical conformity to some kind of norm. [...] Second, and in the context of these reified markers being seen as all important, is the issue of shared history and continuity of memory. [...] Third, community boundaries are being reinforced through a constructed illusion of clear anatomical differences between men and women; the considerable variations in genital appearance and chromosomal configuration are masked through surgery that makes as many people as possible conform to a standard model.

While all of these are true when you only consider the *gendered* aspect of how medical community deals with intersex conditions, they are incomplete as the answer to the question you raised, which was “why such invasive and risky surgery is thought, by doctors working in the field, and some parents, to be necessary for these very young babies who have nothing surgically wrong with them.”

The treatment of intersex children under the current medical protocol needs to be understood in the context of other ways in which natural human variations are diagnosed as “abnormal” in need of “correction,” whether they have to do with gender or sexuality at all. Here, I’m talking about surgeries
intended to lengthen naturally short limbs, separation surgery on otherwise healthy conjoined twins, the “rehabilitation” program that prohibits children whose hands are impaired and cannot use spoon or fork easily from using their hands to eat, the use of human growth hormone on children who are healthy but short, pathologization of homosexuality until 1973 and of “gender identity disorder” since, and many other ways in which natural human variations are pathologized and irrationally targeted for eradication.

There are certain things that are unique about intersex, such as the devastating secrecy and shame that are imposed on children born with intersex conditions. But for the most part, the experiences of children with intersex conditions (and others’ reactions to them) are remarkably similar to the experiences of children born with other socially stigmatized disabilities and deformities. Of course, gender affects the treatment of other conditions too (e.g. the established guidelines for prescribing human growth hormone sets the standard for boys’ height higher than the girls’), but I am certain that even in the absence of the society’s preoccupation with enforcing gender boundaries, intersex bodies would continue to be pathologized and treated with invasive and harmful procedures. In fact, in most cases, doctors do not consciously see a “gender” problem when they see an intersex child; they see a girl (or a boy) who is “abnormal.”

I can also add that I’ve traveled across the country to present about intersex everywhere, and even the most religious or conservative audience who have never questioned the existing binary and hierarchy of genders “get” that whatever is being done to intersex children today is morally, ethically wrong, even though they might disagree with me about everything else. The only audience in which this does not happen is the medical community. Does that mean that the medical community is more invested in maintaining the current gender system than, say, conservative Christians in the Midwest? I don’t think so. But they are more invested than anyone else in maintaining the current biomedical paradigm that gives them the authority to define what is normal or abnormal—which explains their reluctance to question the existing treatment protocol.

Thanks for your work and I hope this feedback is useful.

Emi K.
Director, Intersex Initiative
http://www.ipdx.org/

“Boys will be boys” and “nature trumps nurture” were two of the cliché expressions echoed throughout the media as they reported the latest findings by Johns Hopkins researchers (and intersex allies) William G. Reiner and John P. Gearhart on genetic males assigned as females at birth due to cloacal exstrophy. “Cloacal exstrophy” is a rare medical condition in which the development of lower abdominal wall structures is incomplete, causing a portion of the child’s intestines to be exposed outside of the body. It can occur in both genetic males as well as females, but gender assignment becomes a concern in the case of genetic males with cloacal exstrophy, where the penis is short, absent, or split in half. Over the past 25 years, it was standard practice for these genetic males to be assigned female sex, with corresponding genital “reconstructive” surgeries.

In the paper published in the January 22, 2004 issue of *The New England Journal of Medicine*, Reiner and Gearhart studied sixteen genetic males who had gone through Johns Hopkins’ cloacal exstrophy clinic in the past, fourteen of whom have been assigned female; the remaining two were assigned male. Among the fourteen female-assigned patients, Reiner and Gearhart report, eight have made the switch to live as males despite their gender assignment and two more expressed identifying as males, while the two male-assigned patients remained male-identified. In addition, all sixteen patients have been found to have “moderate-to-marked interests and attitudes that were considered typical of males.” Reiner and Gearhart thus conclude that reassignment of genetic and hormonal males to the female sex should be reconsidered because it may “complicate already complex neonatal conditions.”

While the media went frenzy over the findings in this study, loudly proclaiming the supremacy of nature over nurture, what left untold were the severity of the condition and what children with cloacal exstrophy go through in addition to being made into a genea pig to experiment the latest, most fashionable gender theory (last I heard, biological determinism is back in style). No wonder: Johns Hopkins University’s own press release describe cloacal exstrophy only as: “Cloacal exstrophy is a severe birth defect that occurs in approximately 1 in 400,000 live births. One of the most pronounced characteristics is severe phallic inadequacy, or the complete absence of a penis in genetic males.” But when the child has portions of her or his intestines and bladder exposed outside of the body, which is a serious medical condition that must be treated, the “absence of a penis”—which does not pose any health risk
by itself—is far from “the most pronounced” concern for the patient.

This mirrors how all intersex conditions are automatically viewed as primarily an issue of gender, often overlooking other issues that are more important to the patient. When doctors see a child with an intersex condition, or any other conditions that involve atypically formed genitalia, they see a crisis of gender: the focus of the medical intervention thus becomes making sure that the child has a stable gender identity that is consistent with the genitalia; a successful case is defined as the combination of a visually acceptable genitalia and the gender identity that matches it. What’s left out are concerns for other medical impacts of the underlying hormonal or anatomical conditions that cause genitals to be formed differently, and for the patients’ subjective quality of life, which is often harmed by humiliating or traumatizing medical experiences.

While we welcome the findings of Reiner and Gearhart as it will make it less likely for children to receive involuntary “sex change surgeries” in the future, how we as the society approach biological differences of the genitalia leaves a room for improvement.

Refer to Children’s Hospital of Boston for more detailed information about cloacal extrophy.

<http://web1.tch.harvard.edu/cfapps/A2ZtopicDisplay.cfm?Topic=Cloacal%20Exstrophy>
Pro-Surgery Doctors Continue to Ignore Patients, Refuse Discussion

ipdxWIRE Intersex News
January 30, 2004
http://www.intersexinitiative.org/news/

Harvard Medical School physicians David MacLaughlin and Patricia Donahoe published review article in the January 22, 2004 issue of New England Journal of Medicine—the same issue in which a paper questioning sex change surgery for genetically and hormonally male intersex children was also published. MacLaughlin and Donahoe are ardent supporters of the surgery-centered medical approach to intersexuality and frequent contributor to medical journals; Donahoe has co-authored one of the most influential textbook chapters on intersex treatment, which endorsed the surgical quick-fix.

Titled “Sex determination and differentiation,” the NEJM paper focuses mostly on the genetic and cellular mechanisms for the “problems” of sex differentiation—i.e. causes of intersex conditions. Authors’ pro-surgery bias shows up toward the end of the paper, where they discuss the cause and treatment of congenital adrenal hyperplasia (CAH) in genetic females: “The diagnosis can be made in utero, and early maternal dexamethasone therapy can ameliorate the masculinized phenotypes. Surgical reconstruction can be performed in infancy to restore the female phenotype.” In conclusion, the paper state: “Our knowledge is expanding regarding the molecular events necessary to initiate the development of the urogenital ridge and to select and sustain further sex differentiation and development of gonads, reproductive ducts, and external genitalia... This knowledge must be incorporated into treatment strategies in order to increase and sustain the function, happiness, and emotional fulfillment of patients with abnormalities of sex differentiation.”

The paper is flawless as a summary of molecular mechanisms that contribute to sex differentiation, but it is not clear how such “knowledge” is improving the patients’ subjective sense of quality of life. For the statement about feminizing surgical reconstruction in infancy, the paper cites another article Donahoe herself co-authored to support its recommendation, while neglecting recent evidences that show clear risks of performing such surgeries and the controversy surrounding this practice. And while MacLaughlin and Donahoe seem to hold patients’ happiness and emotional fulfillment as important goals for any medical intervention, they do not seem to be interested in how patients themselves feel about the treatment or in giving patients the ability to make an informed decision on their own behalf. Instead, they insist that the scientific knowledge about the molecular basis of sex differentiation is enough to determine the best course of treatment for these patients.
What is perhaps most deceptive about MacLaughlin’s and Donahoe’s stance in this and many other papers they write is that they completely ignore the fact that there is an increasingly heated controversy over the cosmetic genital surgeries on intersex children, with experts arguing from both sides. Regardless of what they happen to believe about the treatment, it would be dishonest medically or academically to not acknowledge that it is controversial. Further, physicians who endorse and promote surgery-based treatment for intersex have the ethical obligation to respond to criticisms from adults who went through the procedure and to explain why intersex children should continue to be treated the same way despite these criticisms.

Failure to do so is a sign of weakness of their position.

Source:
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 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.
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