

Feminism & Intersex Movement: This is OUR Vagina Monologue

In *The Vagina Monologues*, Eve Ensler talks about “a wonderful vagina fairy tale” that she heard in Oklahoma City. It goes:

One girl in Oklahoma told how she had been born without a vagina, and only realized it when she was fourteen. She was playing with her girlfriend. They compared their genitals and she realized hers was different, something was wrong. She went to the gynecologist with her father, the parent she was close to, and the doctor discovered that in fact she did not have a vagina or a uterus. Her father was heartbroken, trying to repress his tears and sadness, so his daughter would not feel bad. On the way home from the doctor, in a noble attempt to comfort her, he 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.” [text taken from the V-Day 2002 edition of the script]

Truth About the Missing Vagina

The condition in which vagina is missing or not fully developed is known as Mayer-Rokitansky-Kuster-Hauser Syndrome (MRKH) or vaginal agenesis. Genetic females (XX) with MRKH do not have fully formed vagina, cervix, uterus, and/or fallopian tubes. Causes are not known. MRKH and many other conditions that result in atypical reproductive and sexual bodies are known as **intersex**, and it is estimated that about one in every 2000 child is born with visibly intersex conditions.

Today, the standard treatment for intersex involves surgical and hormonal interventions that are designed to alter the appearance of the body so that they look more “normal,” but do not necessarily address any health issues. These surgeries are often performed when the child is too young to understand or consent to what is being done to them, and they are rarely told the truth about their medical history even after they grow older.

Even though these surgeries have been per-

formed for the last fifty years, there is no long-term studies confirming the effectiveness or safety of these procedures; on the contrary, we have found and recent studies have confirmed that such concealment-centered treatment on genitals often result in physical scars, depression, post-traumatic stress, loss of self-esteem, and, of course, loss of sexual sensation.

In 1993, survivors of these intersex genital mutilations created **Intersex Society of North America** to connect with other intersex people and to take back the control over our own bodies. We believe that intersex is not something so shameful that it has to be concealed medically and socially. We believe that intersex people have the right to know all the information currently available about conditions we experience, and determine for ourselves what is done to our bodies.

Growing up different is always difficult, but it does not have to be as difficult as we have been forced to live. We oppose the idea that eliminating our physical differences is the way to address social issues we may encounter; rather, we believe in addressing social difficulties intersex people may experience through social and psychological interventions. Above all, we believe that honest communication and the patient-centered medical protocol will best serve our needs.

In *The Vagina Monologues*, the portion quoted above is presented comically; the audience is invited to laugh hysterically to the father’s exclamation. We feel that the play not only misrepresents our experiences as intersex people, but also trivializes our pain and confusion due to surgeries done to us. It also suggests that women’s bodies are made solely for their husbands, and that we should alter our bodies to match what is desired by them. The disparities between how the play depicts the African female genital mutilation and the intersex genital mutilation in the West is staggering.

Many intersex people and our friends found this “monologue” - and the roomful of laughter following it - hurtful if not outright offensive. We felt invisible, as it only talked about damages caused

by genital mutilations occurring in Africa, as if we do not experience them here. Many of us went home feeling upset, sick, angry or in tears, walking past the crowd of women telling each other how empowered they felt by the play. We did not feel empowered; we felt invalidated and silenced.

This pamphlet was created to **resist the systemic erasure of our voices, and to ask you to join our movement to end shame, secrecy, and unwanted genital surgeries on intersex children.** What follows below is an excerpt from a first-person narrative written by a woman who has MRKH, as well as practical suggestions as to how you can help us.

The Missing Vagina Monologue by Esther Morris, founder of MRKH.org

[Excerpted from the article published in March 2001 issue of *Sojourner*; for more information about MRKH, visit <http://mrkh.org/>]

My life completely changed when I was 13 and sent home from camp with abdominal pain. When I was examined they discovered an imperforate hymen prohibiting the flow of menstrual fluid. I had my 1st surgery then, to open my hymen so I could bleed. But they found that nothing was there. I had no vagina, just a dimple, and they could detect no uterus. I had secondary sex characteristics, body hair and breasts, so they guessed I had ovaries but no one knew where. The medical profession has known about MRKH since 1838, but I was diagnosed with “congenital absence of vagina” because that’s what they cared about. My abdominal pain was quickly forgotten. I was suddenly and shamefully different. Puberty was over for me. I went from selling Girl Scout Cookies to correcting my sexual dysfunction in one afternoon.

My doctors talked to my parents about vaginal reconstruction so I could have a normal sex life with my husband. What husband? And why couldn’t he adjust as he would for any other “birth defect”? My parents did the right thing. They took me down the only path available, the path of “corrective” surgery. But I was staggering from the loss of my fertility, the dream of having children. I received sympathy and even pity about that, but the most pressing concern was to create my vagina ASAP.

I spent the next few years going to specialists,

having tests to confirm my gender, being probed by curious doctors and interns with multiple instruments in multiple holes at multiple times. There were no women doctors involved in any of my treatment. My chromosomes were counted and discussed in front of me. “Got to run that test again just to make sure.” There were not enough other signs to determine gender for these guys. They examined my breasts, labia, clitoris, and dimple with blind eyes.

Not seeing what they wanted, they saw a narrow version of normal, and I wasn’t it. I was too young to know I had the right to ask questions. Or the right to slow the process down to fit my own state of mind. I had major doubts about what was going on, and what was being done to me. But I was not yet capable of wondering who was having the biggest problem with my body. Was it me or the people treating me? Frightened in a cloth hospital gown I did what I was told. And my relationship with my body ended. Suddenly I had no right to have it in the state it was in. Like an android on an assembly line, I had no concept of feeling that this body was mine. There was so much focus on the woman I should be that I lost all knowledge of the girl that I was.

Once I was officially determined female my reconstruction was arranged. Then I could adopt children and life would be just fine. In 1972 I had my 2nd and 3rd surgeries. I was 15 and 1/2. That summer I took a “trip” for three weeks to avoid explaining why I had to go to the hospital. I missed family weddings and graduations for my surgery. “...a slight dimple was present where the vagina was expected to be. A transverse incision was made. By means of sharp and blunt dissection a very adequate vagina was developed... a split thickness skin graft was obtained from the left buttocks and attached to the mold... The Balsa mold was then inserted into the cavity... The skin graft that extended was attached to the vaginal introitus... The vagina was closed... All sponges were accounted for.”

After my surgery I was sent to recover in the maternity ward. For 17 days I shared a room with countless women having babies. I had no visitors since I was on a “trip” and no one knew to come visit me. It was me and my mom, and a lovely nurse named Donna who would wake me in the morning

sitting quietly by my bed holding my hand. I later realized that she was protecting me from nightly visitors wanting to satisfy their curiosity as I slept. My cousin worked in the hospital and visited often, but my reason for being there was never discussed.

Two weeks later I had Phase Two- my 3rd surgery, to have the mold and stitches removed. Then I was told about postoperative therapy to keep my vagina functional. A functional vagina is “a vagina that will be able to accept a normal size penis”. I was given vaginal dilators for postoperative therapy, and brief instruction to insert one and wear it every night. The problem was solved, for everyone but me. I was left out of the experience. The whole shebang was over. I never had a chance to deal with any of it. I had two follow-up visits with my surgeon and never saw him again. I was another surgical success.

Why was my gender challenged, then confirmed like something I didn't already know? Why was my body taken away and rearranged like a sexual Action Figure by men with knives? What was the need to feminize my body, which actually neutered my soul? I wasn't able to see what all the fuss was about. All the excitement just reinforced my despair. I was living within this anomaly and feeling terribly wrong for the fact that I didn't really care that I was born without a vagina.

I was introduced to anger two years later when I started having sex. After all that trouble I discovered that a penis would respond to anything. I felt abused in the most intangible way, a victim of arrogance and assumption. I couldn't identify it then; I became an instant survivor. And I was told that I would never meet another woman like me. Big time isolation. Divide and conquer? Well I don't know, but one in 5000 is NOT that RARE. I just didn't know that then. I denied my depression. Like the Hunchback in the Bell Tower, I found a place to hide when normalcy failed me.

Tidbits of emotion overwhelmed me in very big ways. I was learning that normal was merely a concept for people who couldn't cope with anything different. I alienated myself from peers who would rightfully complain of menstrual cramps and NO I don't have a tampon! I mastered the stoic, intellectual method of coping and strapped myself in. It was going to be a bumpy ride.

As I grew older I realized I was faced with many

questions. How will I experience menopause? How do I monitor the health of my ovaries? How many ovaries do I have and where are they hiding? What about pap smears? I was tracking my cycle with notes on the calendar so I could attempt regular breast exams. I was tired of all this and really pissed that I had to ask all the questions. I was caught in this funky body with no place to go. And I was having other physical problems that needed attention now too.

Every time I get depressed about this I take some little action. Fifteen years ago I got my hospital records and read about my surgery. I have also gotten medical records from every doctor I have ever seen. In the year 2000, I learned about MRKH for the very first time. I got a copy of my latest work-up from eight years before and saw MRKH written there too.

I went to the medical library to research articles on MRKH. I was in my forties and finally had something to call this other than bizarre. That is when I discovered the other symptoms associated with the Syndrome. The connection to years of disability and hearing problems made me numb. If I had known I was predisposed to disabilities I would have made more appropriate decisions about my life. But what a joy to confirm that I hadn't brought them on myself. The most important discovery I made was to learn that there are many variations of gender. This revealed how we are forced into incredibly rigid standards. Those who don't fit the traditional male-female dichotomy may seem few, but maybe not if we allowed ourselves to see them; to respect diversity. A whole new perspective was growing from old emotions.

Reading the articles on MRKH made it painfully clear that this wasn't just about bodies, and that the “corrective” approach to genitals should not immediately be assumed. Emotional and sexual counseling would have provided me with a more permanent and accepting solution. If I wanted surgery later in life then I could work toward that. **I feel abnormal because I had to be fixed, not for the truth about my body. I feel different because of my surgeries, not because of my vaginal dimple. Being born without a vagina was not my problem. Having to get one was the real problem.** It's not that my vagina has shrunk that alarms me now; it's the fact that we

judge genitals at all. People don't fail to meet the definition of normal gender, but the confines of the definitions fail to meet the people. Even with the benefit of normal female chromosomes I feel oppressed by this. Too many people are turned into "freaks" when we refuse to see them as they are. But our genitals are also our privates and they are not to be discussed. Or different. Wishing again to have had choices...

I am an adult now and I DO have choices. I no longer choose to trust without question. I no longer choose to believe without information.

Five months ago I found an online support group for women with MRKH. Having believed that I was the only woman I would ever know with this experience, I was totally overwhelmed. The case studies I had been reading about became real women who finally humanized this experience for me. Some of their stories seemed so traumatic that it challenged me to recognize that their trauma was also mine. What a wealth of information when compared to medical journals. These women taught me more about treatment and courage in a week than any doctor ever could.

I come out about my surgery in carefully selected ways. I have seen the response of too many twisted faces telling me that they have never heard of such a thing. They show me pity. They tell their friends this great gossip and strangers ask intrusive questions on the street corner. One medical practitioner told me I was "just too weird." I have been physically assaulted by women who presumed I was transgender and too active in the women's community. I have been asked if this is what made me a lesbian, by lesbians who were born with vaginas.

Questions have haunted me for too many years because I couldn't find the words. Knowing other MRKH women has finally allowed me a voice. But I don't want it to stop there. My condition seems extreme only because it's unheard of. We exist in a conundrum because our knowledge is powerful but hidden in embarrassment and shame. The approach to our treatment is very extreme but effects all women in subtler ways. Advances in medicine offer men Viagra, but women still get the knife. Scar tissue does not enhance sexual pleasure.

I want people to understand that doing the right thing often does more harm than good.

The standard of normal that we aim for is imaginary. We alter women's bodies when attitudes need adjusting. Correcting our genitals tells us they are wrong. Different is not wrong. Different is different. Women shouldn't have to endure emotional and physical pain to perform one sexual act. I resent it because of the price we pay for society's lack of creative thinking.

Join the Intersex Movement - Help End Shame, Secrecy, and Unwanted Genital Surgeries!

There are many ways you can help end shame, secrecy, and unwanted genital surgeries on intersex children. Here are some suggestions:

1. **Educate yourself.** Visit <http://www.isna.org/> to read more about intersex.
2. **Talk to your friends** and family members. The more people know about intersex, the less it becomes shameful and secretive.
3. **Write letters to Eve Ensler.** Ask her to consider including monologues about genital mutilations that happen in Western societies, and to address what intersex people really experience after the surgeries.
4. If you are part of an organization or a school, **invite us to come and speak** about intersex experiences. Write about intersex in your newsletters. **Educate your members or students** about intersex.
5. **Make a donation to us**, or support us financially by purchasing our educational materials online at <http://www.isna.org/>. Encourage your local production of *The Vagina Monologues* to donate a portion of their proceeds to Intersex Society of North America.

How to Contact Us

Intersex Society of North America
PO Box 301, Petaluma CA 94953
(707) 283-0036 // info@isna.org
<http://www.isna.org/>

Or your local contact:

