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### **Original Citation**

Crocetti, Daniela (2016) Medicalizing the gendered body: Intersex/DSD and Human Rights. In: CRISS seminar series, 6/12/16, University of Huddersfield. (Unpublished)

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# Medicalizing the gendered body: Intersex/DSD and Human Rights

**Dr Daniela Crocetti**

University of Huddersfield; previously University of Bologna

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Inspiring tomorrow's professionals





# Intersex/DSD Human Rights, Citizenship and Democracy [EUICIT]

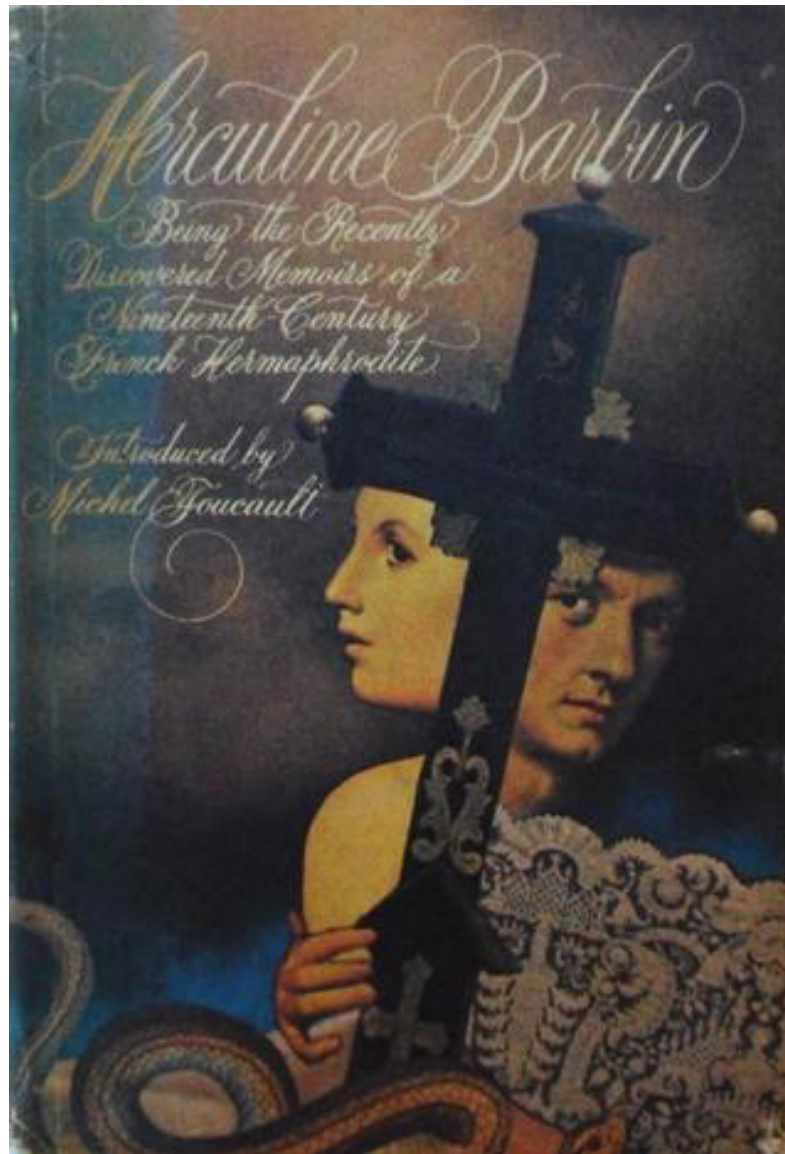
Professor Surya Monro, Dr Tracey Yeadon-Lee,  
Dr Daniela Crocetti,

Zwischengeschlecht/ Stop Intersex Genital Mutilation

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Inspiring tomorrow's professionals





**Intersex  
Awareness Day  
26 October**

I'm intersex  
and I'm beautiful!

Intersex Awareness Day  
October 26

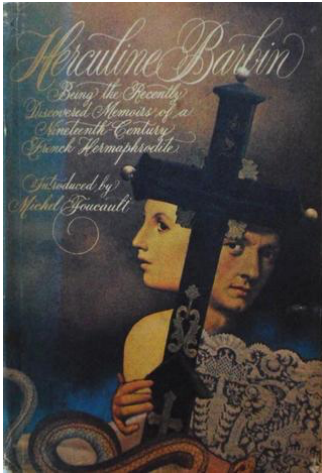
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## The 1800s, Science, Medicine and Citizen bodies

- Gender and the body
- Sexual orientation
- Legal gender categories



The 1800s,  
Science, Medicine and Citizen bodies

-Gender and the body

*Variations of sex characteristics,  
Intersex traits,  
DSD (Disorder/Difference of Sex development)*

-Legal gender categories

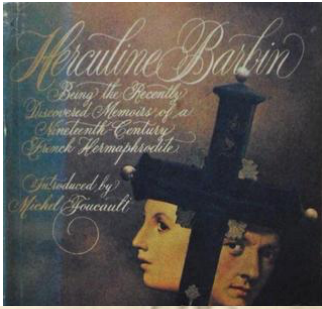


# The 1800s, Science, Medicine and Citizen bodies

*Variations of sex characteristics, Intersex traits,  
DSD (Disorder/Difference of Sex development)*

- Chromosomes
- Genetic markers
- Hormones
- Gonads
- Reproductive organs
- Genital form
- Secondary sexual characteristics (e.g. bodily hair or fat/muscle ratio)





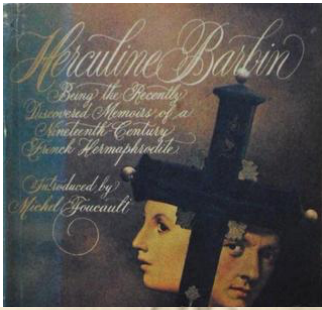
# The 1800s, Science, Medicine and Citizen bodies

## Gender and the body



- Chromosomes
- Genetic markers
- Hormones
- **Gonads – gendering the body**
- Reproductive organs
- Genital form
- Secondary sexual characteristics (e.g. bodily hair or fat/muscle ratio)

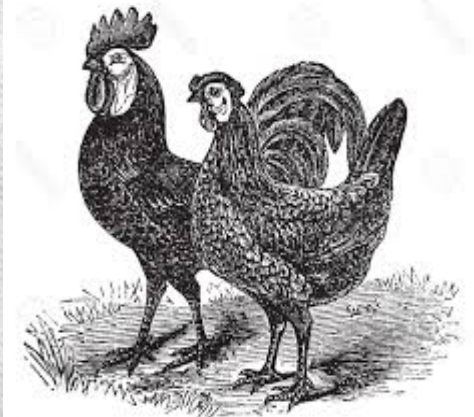


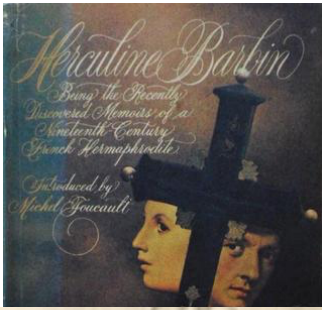


# The 1800s, Science, Medicine and Citizen bodies

## Gender and the body

- Chromosomes
- Genetic material
- Hormones
- **Gonads**
- Gendered behaviour
- Sexual behaviour

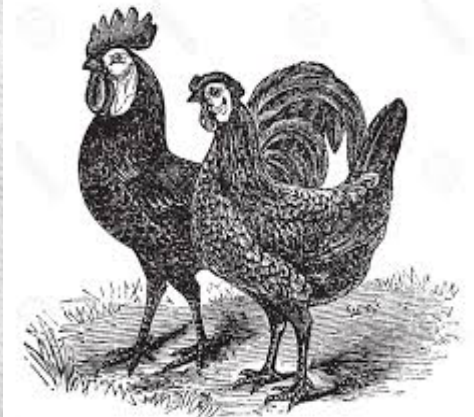




# The 1800s, Science, Medicine and Citizen bodies

## Gender and the body

- Chromosomes
- Genetic medicine
- Hormones
- **Gonads**
- Gendered behaviour
- Sexual behaviour
- Gender hierarchy

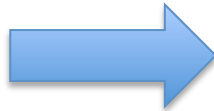


# The 1800s, Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Many  
physical  
paths to  
gendered  
social  
categories



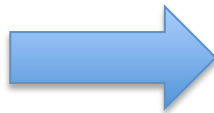
Two legal gender  
categories

# The 1800s, Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Many  
physical  
paths to  
gendered  
social  
categories



Two legal gender  
categories +

Punitive state regulation  
of legal gender  
(and consequentially sexual  
orientation)

# The 1800s, Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

Excluded from democratic participation  
and/or accumulation of wealth in different periods

- Women,
- Young people,
- Non-white ethnicities,
- Poor (without property),
- The mentally infirm,
- Certain disabilities (e.g. the blind)

The 1800s, Science, Medicine and Citizen bodies

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The 1800s, Science, Medicine and Citizen bodies

Gender and the body

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- Genital form
- Secondary sexual characteristics  
(e.g. bodily hair or fat/muscle ratio)
- Clothing and appearance

The 1800s, Science, Medicine and Citizen bodies

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The 1800s, Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### Intersex Human Rights Issues (1800s)

- Legal gender decided by doctors
- Social discrimination due to perceived sexual orientation and/or gender status.

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex Human Rights Issues (1900-2000s)

- Legal gender regulated by doctors
- Bodily integrity and autonomy (childhood surgeries)
- Full informed consent to medical treatment
- Medical stripping and examination
- Medical stigmatization (communication)
- Children's rights to medical communication
- Experimentation on children
- The right to medical treatment informed by documented research
- Social discrimination

# Science, Medicine and Citizen bodies

Gender and the body

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# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## **John Money, The Hopkins Center, and the Optimal Gender of Rearing Model**

- Congenital Adrenal Hyperplasia
- Adrenal androgens
- Salt-wasting

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## **John Money, The Hopkins Center, and the Optimal Gender of Rearing Model**

- Congenital Adrenal Hyperplasia
- Adrenal androgens
- Salt-wasting
- Genital “ambiguity”
- Social determinism

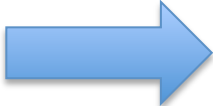
## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **John Money, The Hopkins Center, and the Optimal Gender of Rearing Model**

- Congenital Adrenal Hyperplasia
- Adrenal androgens
- Salt-wasting
- Genital “ambiguity”
- Social determinism  Genital Surgery

## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **John Money, The Hopkins Center, and the Optimal Gender of Rearing Model**

- Cosmetic Genital Surgery before age three
- False or coercive diagnosis and treatment communication
- Gonadectomy (Sterilization)
- Hormone Therapy
- Vigilance regarding gendered behaviour and sexual orientation



G

J

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# David Reimer Story ("John-Joan" Case)



Joan with her twin baby boys, Brian and Bruce. The catastrophic accident that would lead to Bruce's sex change was still some months in the future. (Photo courtesy of the Reimer family)



Brenda, around age 12, shortly before her assignment. (Photo courtesy of the Reimer family)



Brenda at age twelve, shortly after she started estrogen therapy to promote the feminization of her figure. (Photo courtesy of the Reimer family)

David and Brian in May 1980 at their uncle's wedding, where David made his public debut as a boy. David still carries the evidence of the binge-eating he had done, as Brenda, to disguise his breasts. They would be surgically removed five months later, and testosterone injections would soon make David catch up in height to his twin. (Photo courtesy of the Reimer family)



David at age eighteen. (Photo courtesy of the Reimer family)



Brian and Brenda at age fourteen, shortly before they were told the truth of Brenda's birth. (Photo courtesy of the Reimer family)



David and Joan on their wedding day, 22 September 1993. It was Joan's reaction to the truth about David's past that convinced him of his "true birth." (Photo courtesy of the Reimer family)



## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

**Intersex is an umbrella term for 30+ variations**

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex is an umbrella term for 30+ variations

Chromosomes

Genetic markers

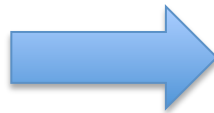
Hormones

Gonads

Reproductive organs

Genital form

Secondary sexual  
characteristics



**Klinefelter's syndrome (XXY)**

-infertility

-possible cognitive issues

-1:700 men

-Hormone therapy

-increased fat:muscle ratio

--stigmatization

-out-dated information

-passive eugenics

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex is an umbrella term for 30+ variations

Chromosomes

Genetic markers

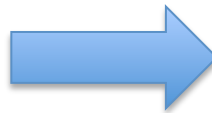
Hormones

Gonads

Reproductive organs

Genital form

Secondary sexual  
characteristics



**Androgen Insensitivity**

**Syndrome (possible outcomes)**

-gonadectomy (social ratio)

-hormonal therapy

-vaginal track lengthening

-stigmatization

-medical stripping

-lack of communication

-lack of informed consent

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## **Intersex Human Rights Activism**

Addressing the suspension of medical rights due to the social “state of emergency” evoked by bodies that don’t enter neatly into the gender binary

## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **Intersex Human Rights Activism**

Medical “state of emergency” focused on:

- Gender assignment/classification
- Surgical “normalization” of genital form



## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **Intersex Human Rights Activism**

**Medical “state of emergency” focused on**  
Gender and genital form

**Some research on**

Developmental pathways and hormone therapy

**Little research on**

Patient satisfaction and long-term health

## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **Intersex Human Rights Activism**

- Health activism and “syndrome” specific patient associations (AISSG UK 1988)
- Pan-Intersex social activism (ISNA 1993-2008)

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex Human Rights Activism

- Health activism and “syndrome” specific patient associations (AISSG UK 1988)
- Pan-Intersex social activism (ISNA 1993-2008)  
**devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for people born with an anatomy that someone decided is not standard for male or female.**

## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **Intersex Human Rights Activism**

2006 Consensus Statement (CS)  
and DSD (Disorders of Sex Development)

#### **The changes advocated in the CS include:**

- Patient-centred care (psychosocial support)
- More cautious approach to surgery
- Language and communication changes

## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### Intersex Human Rights Activism

2006 Consensus Statement (CS)

- Patient-centred care/psychosocial support; **not always present**
- More cautious approach to surgery; **unclear if this is happening**
- Language and communication changes; **more communication is happening yet options are still presented coercively and children are often still excluded**

## Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

### **Intersex Human Rights Activism and Visibility has globally multiplied**

- internet presence
- visibility campaigns
- human rights lobbying
- patient associations
- pan-Intersex social activism

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex Human Rights Issues

**In places without accessible medical systems,** if an intersex trait is obvious

- abandonment,
- infanticide,
- mutilation,
- stigmatisation of the child and mother.

Carpenter (2016) The human rights of intersex people: addressing harmful practices and rhetoric of change. Reproductive Health Matters 24:74.

# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex Human Rights Issues

**In places w/o accessible medical systems,** if an intersex trait is obvious

- abandonment,
- infanticide,
- mutilation,
- stigmatisation of the child and mother.

**In places with accessible medical systems,**

“normalising” interventions violate “rights to health and physical integrity, to be free from torture and ill-treatment, and to equality and non-discrimination”.



# Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

## Intersex Human Rights Issues

abandonment; infanticide;  
mutilation; stigmatisation; health;  
physical integrity; torture; equality  
+

**Bodily integrity and Autonomy**

**Lack of research**

The landmark **2015 Maltese Act** on Gender Identity, Gender Expression and Sex Characteristics, **specifically prohibits social, cultural and other unnecessary interventions on the sex characteristics of minors**