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Crocetti, Daniela

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Medicalizing the gendered body: Intersex/DSD and Human Rights

Dr Daniela Crocetti
University of Huddersfield; previously University of Bologna
Intersex/DSD Human Rights, Citizenship and Democracy [EUICIT]
Professor Surya Monro, Dr Tracey Yeadon-Lee, Dr Daniela Crocetti,
Zwischengeschlecht/ Stop Intersex Genital Mutilation
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 markers
- Hormones
- **Gonads**
- Gendered behaviour
- Sexual behaviour
The 1800s, Science, Medicine and Citizen bodies

Gender and the body

- Chromosomes
- Gene markers
- 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**

Many physical paths to gendered social categories

**Hierarchy**

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**

**Gender and the body**

**Hierarchy**

**Democracy**

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

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The 1800s, Science, Medicine and Citizen bodies

Gender and the body

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

**Gender and the body**

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

**Hierarchy**

**Democracy**
The 1800s, Science, Medicine and Citizen bodies

Gender and the body

Hierarchy

Democracy

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

Sexuality
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.
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

Hierarchy

Democracy

- Chromosomes
- Genetic markers
- Hormones
- Gonads
- Reproductive organs
- Genital form
- Secondary sexual characteristics (e.g. bodily hair or fat/muscle ratio)
- Clothing and appearance
Science, Medicine and Citizen bodies

Gender and the body

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Gender and the body

- Chromosomes
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- Secondary sexual characteristics (e.g. bodily hair or fat/muscle ratio)
- Clothing and appearance
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
David Reimer Story
(“John-Joan” Case)

John Money, The Hopkins Center, and the Optimal Gender of Rearing Model
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 | Klinefelter’s syndrome (XXY) |
| Genetic markers | - infertility |
| Hormones | - possible cognitive issues |
| Gonads | - 1:700 men |
| Reproductive organs | - Hormone therapy |
| Genital form | - increased fat:muscle ratio |
| Secondary sexual characteristics | -- stigmatization |
| characteristics | - out-dated information |
| | - passive eugenics |
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
Intersex Human Rights Activism

Addressing the suspension of medical rights due to the social “state of emergency” invoked 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)
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
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.

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
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