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Intersex activism, bringing the personal to the public

### Original Citation

Crocetti, Daniela, Monro, Surya and Yeadon-Lee, Tracey (2017) Intersex activism, bringing the personal to the public. In: British Sociological Association (BSA) Annual Conference 2017 Recovering the Social: Personal Troubles and Public Issues., 4th - 6th April 2017, University of Manchester. (Unpublished)

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European  
Commission



Intersex activism, bringing the personal to the  
public

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

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

Zwischengeschlecht/ Stop Intersex Genital Mutilation

This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 703352.

Inspiring tomorrow's professionals



## **Background**

**-In the 1990s pan-Intersex activism in the USA and social health activism in the UK**

-Intersex refers to numerous bodily variations of sex 'characteristics'

-Intersex variations have been framed as within medical jurisdiction since the 1800s

-In the 1950s "normalizing" modifications in early childhood became medical protocol

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- 2006 DSD; Consensus Convention guidelines
- Language and terminology, among the many Human Rights issues, are currently contested**



## **EUICIT aims and goals Sept 2016 – Aug 2018**

-Investigate human rights framing and strategies used to address Intersex and DSD in Europe, focusing on Italy, Switzerland and the UK

-Map the agendas, actions and results of the diverse Intersex and DSD activists, and will include the views of clinicians and policy makers working in the Intersex and DSD area

-Zwischengeschlecht; Human Rights activists

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77. Children who are born with atypical sex characteristics are often subject to irreversible sex assignment, involuntary sterilization, involuntary genital normalizing surgery, performed without their informed consent, or that of their parents, "in an attempt to fix their sex", leaving them with permanent, irreversible infertility and causing severe mental suffering...

— *UN Special Rapporteur on Torture, Juan E. Méndez*, 1 February 2013

<https://www.unfe.org/intersex-awareness/>

FREE & EQUAL



Intersex people are born with sex characteristics that don't fit typical definitions of male and female.

In many countries, intersex children are subjected to repeated surgery and treatment to try to change their sex characteristics and appearance, causing terrible physical, psychological and emotional pain – and violating their rights.

Intersex children don't need to be "fixed"; they are perfect just as they are!

The United Nations is calling on governments and parents to protect intersex children from harm.

Help us spread the word!

Facebook

Twitter

## **EUICIT methodologies**

- Multidisciplinary qualitative approach
- In depth interviews with activists, advocates, policy makers and medical practitioners
- Thematic analysis using NVIVO
- Participant action research with collaborators  
Zwischengeschlecht

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### **UK 22 interviews**

### **Swiss fieldwork in May**

### **Italian fieldwork in September**

- Thematic analysis using NVIVO
  - Participant action research with collaborators
- Zwischengeschlecht

# **Policy and current practice**

- UN bodies and Human Rights mechanisms

## **Human rights investigations and statements**

2005 San Francisco Human Rights Investigation,

2006 Yogyakarta Principles

2012 Report of Swiss National Advisory Council on Biomedical Ethics

2013 Report of UN Special Rapporteur on Torture

2013 Resolution by the Council of Europe

2013 Senate Committee inquiry, Australia

2013 Malta declaration

2014 World Health Organization and UN interagency report

2015 Council of Europe Issue Paper

2015 UN Office of the High Commissioner for Human Rights report

2015 WHO report, "Sexual health, human rights and the law"

2016 Asia Pacific Forum of NHRIs manual

2016 UN and regional experts statement

### **+ Support from**

EU FRA; UNHCHR; CAT; CEDAW; UNCRC

## **Human rights investigations and statements regarding:**

1. Harmful practices
2. Prohibition of torture and inhuman or degrading treatment
3. Integrity of the person
4. Access to justice
5. Involuntary medical experimentation
6. Violence against children
7. Right to life
8. Coercive sterilization
9. Right to health
10. Rights of the Child
11. Anti-discrimination laws that include sex characteristics



# Policy and current practice

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- Lack of EU national policies besides Malta 2015  
*Gender Identity Gender Expression and Sex Characteristics Act*

which recognizes a right to bodily integrity and physical autonomy

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lack of capacity and clarity also regarding jurisdiction  
lack of data regarding practice and outcomes

# Activist framing and strategies

- Pan-Intersex social activism
- Social health activism/advocacy

“Well let’s keep it simple, the one we do never, never, never use is DSD, because one of the problems that Intersex people have faced, for generations, is that pathologisation of Intersex.” **Dr. Jay Hayes-Light from UKIA**

“I will never choose to use Intersex...I respect that people don’t want to be called having a DSD...I have never used the term disorder, because I don’t think that my child is disordered and I think that’s the same for many parents.” **Ellie from DSD Families speaking as an individual**

# Activist framing and strategies

-Pan-Intersex social activism

Intersex UK

UKIA

OII-UK

“So the prevention of irreversible surgeries on children and young people, without their fully informed, fully autonomous, free and understood consent.” **Holly Greenberry co-founder IntersexUK**

**Ending unnecessary medical treatment**

**+ secrecy and shame**

**International Human Rights**

-Social health activism/advocacy

# Activist framing and strategies

-Pan-Intersex social activism  
Intersex UK; UKIA; OII-UK

-Social health activism/advocacy

LivingwithCAH

AISSG

Klinefelter Syndrome Association

The Turner Syndrome Support Society

The Hypospadias UK Trust

DSDFamilies

# Activist framing and strategies

-Pan-Intersex social activism  
Intersex UK; UKIA; OII-UK

-Social health activism/advocacy  
LivingwithCAH; AISSG; KSA; TSSS;  
Hypospadias UK Trust; DSDFamilies

Contested collaboration with Medics for  
better treatment – **Right to Health**



# Conclusions

- International Human Rights documents
- Rights included in UK policy and NHS documents
- Continued state of exception for Intersex

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Needed:

- National enquiry
- Joined up approach
- Intersex activist and advocate inclusion