

Intersex Social Sciences: Activism, Human Rights, and Citizenship



4-5 June, 2018

**Department of Philosophy and
Communication**

Via Azzo Gardino 23

University of Bologna, Italy

#intersex-HRconf

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Welcome And Introduction

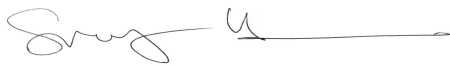
We would like to welcome you to Bologna and to this ground breaking international and interdisciplinary conference about Intersex Activism, Human Rights, and Citizenship.

The field of Intersex-led scholarship and cultural production is growing and there is a need for more space to foster knowledge production, networking, and organising to support the human rights of intersex people and those with variations of sex characteristics. Intersex Studies as an academic field is in its infancy compared to some other areas, with much work to be done in developing understandings of identity, politics, and the social change that is needed if intersex people are to have fundamental human rights. It seems that the barriers to the achievement of Intersex Human Rights are many and strong. At the same time there are heartening developments taking place in many countries and in the international sphere, led by Intersex experts from many different cultural backgrounds, and their allies.

This 2-day conference provides a multi-disciplinary forum for the further development of social science approaches to Intersex and Variations of Sex Characteristics. Sociological, anthropological, political science, philosophical, psychological and other approaches are all crucial for developing knowledge that centres the experiences and insights of Intersex people and those with Variations of Sex Characteristics. A commitment to fostering positive Intersex activist and academic alliances lies at the heart of this conference. The conference forms one of the activities of the Intersex/DSD Human Rights, Citizenship and Democracy project.

We hope that you will have a wonderful time at the conference, that you will come away feeling inspired, that you will gain new activist and scholarly friends and potential collaborators.

On behalf of the conference team, I welcome you to the conference on Intersex Activism, Human Rights, and Citizenship.



Professor Surya Monro (University of Huddersfield, UK)

Please see conference website for information on Bologna and suggestions regarding accommodation and food.

Conference Organizers

- Dr Daniela Crocetti, Senior Research Fellow, University of Huddersfield, UK.
- Professor Surya Monro, Professor of Sociology and Director the Centre for Citizenship, Conflict, Identity, and Diversity (CCID), University of Huddersfield, UK.
- Dr Tray Yeadon-Lee, senior Lecturer of Sociology, University of Huddersfield, UK.
- Professor Roberto Brigati, Professor of Moral Philosophy, University of Bologna, Italy.
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Code of Conduct

In line with good governance arrangements, all attendees, speakers, sponsors and volunteers at the conference are expected to respect with the following code of conduct. We hope for cooperation from all participants to help ensure a safe and enjoyable environment for everybody.

The conference is intended as a friendly environment where everyone should feel welcome, safe and comfortable to share ideas and engage in open discussion without threat of intimidation or public humiliation.

We expect all conference participants to be respectful in person and online towards other delegates, speakers, organisers, staff and volunteers.

We expect all conference participants to behave and to use language that is respectful, non-pathologising and consistent with human rights standards, taking into account its shifting and complex contextual and cultural character. Please respect the pronoun and terminology preferences that people express for themselves.

We expect all conference participants to refrain from identity-policing behaviour, including questioning other participants' identities, self-definitions, personal stories, pronouns and so forth.

Harassment includes offensive verbal comments, and other forms of using disrespectful and pathologising language inconsistent with human rights standards, deliberate intimidation, stalking, following, harassing, photography or recording without explicit consent, sustained disruption of talks or other events, inappropriate physical contact, and unwelcome sexual attention. Conference participants asked to stop any harassing behaviour are expected to comply immediately.

These policies apply in every space at the venue related to conference, and to all participants in every role.

If a participant engages in harassing behaviour, the conference organizers may take any action they deem appropriate, including warning the offender or expulsion from the conference with no refund.

If you are being harassed, notice that someone else is being harassed, or have any other concerns, please contact a member of conference staff immediately.

Conference volunteers can be identified, as they'll be wearing branded clothing and/or badges.

We will be happy to assist those experiencing harassment to feel safe for the duration of the event, and are available to mediate. Contacting police should be the last resource if this is required.

We expect conference participants to follow these rules at all event venues and related social events.

We trust that this code of conduct mirrors the views of our participants.

Program schedule

**Day 1
Monday June 4th**

8:30 - 9:00 registration

9:00 – 9:15 Welcome

9:15 - 11:15 Keynote plenary session

11:15 – 11:30 Coffee

11:30 – 13:00 Paper session 1: Activism / Paper session 2: Open stream

13:00 – 14:00 Lunch

14:00 – 15:30 Panel 1: Intersex and Temporality / Paper session 1: Narrative and identities

15:30 – 15:45 Coffee

15:45 – 17:15 Panel 2: Intersex and Law: Present Problems and Future Directions

17:15 – 18:15 HR – Yogyakarta+10 workshop with Morgan Carpenter

19:30 Conference dinner meet-up

Program schedule

Day 2

Tuesday June 5th

9:00 - 9:30 Presentation EUCIT research project

9:30 – 11:00 Panel 3: Law and Intersex 2: Unequal ‘Treatments’ and New Comparators

11:00 – 11:15 Coffee

11:15 – 12:45 Panel 4: The protection of intersex persons by international law

12:45 – 13:45 Lunch

13:15 – 14:15 Discussion space - academic and activist collaboration; facilitated by Valentino Vecchietti Vecchietti (Intersex human rights activist) and Jantine van Lisdonk (Rutgers).

14:15 – 15:45 Paper session 3: Narrative and identities / Paper session 4: Controversies in medical protocol

15:45 – 16:00 Coffee

16:00 – 17:30 Paper session 5: National experiences / Paper session 6: Controversies in medical protocol 2: Surgery

17:30 – 18:00 Thanks and close

18:00 – 19:00 EuroPSI meeting

UKIA Statement for the conference.

I write as the Director of the UK Intersex Association, the oldest and one of the largest organisations of its kind in the world. My first words should be an apology for our non-attendance at an event we were keen to contribute to. However, recent events have compromised our involvement. These events have reminded all of us as to the continuing pressing need to continue to campaign for the rights of intersex people here in the UK and around the world.

Here in the UK we are campaigning for the protection of intersex people in the UK 'Equalities' Act, a piece of legislation that is still far removed from being equal. In other parts of the world intersex people face even more dangers. A team of UKIA staff lead by UKIA's senior medical consultant Dr James Campbell was to have represented UKIA, However, he and two others from the UK and three staff from Africa have spent the past month supporting the mother of a small child who was murdered by someone who obviously regards intersex people as surplus to humanity's needs. The usual knee jerk from outside Africa has included comments from those who regard anyone with a darker skin as "savages".

The fact is that much of the public's disgust and fear of intersex people has been influenced by how we in the so- called "developed" countries treat intersex people, including infants. Of course it is rare for an intersex child to be battered to death here in the UK as has recently occurred in Africa. However, we do something similar here using surgery to remove signs of intersex, often with negative physical and/or psychological effects and slowly over time, push them even further out into the social reject area by denying them the same human rights enjoyed by others, to be protected from discrimination. As an example of this the UK 2010 "Equalities" Act does not include intersex people. What influences the public view of intersex people is the way in which intersex is seen as a rare deviation from the "norm", but one intersex birth in 700 is NOT rare. The way in which historians have presented classical history as a time before intersex ever appeared leads many to assume that female infants born with a penis and males who develop breasts or are only identified by their chromosomes is a more modern deviation caused by environmental pollution or "faulty" genes. Intersex variation is acknowledged by the medical profession but only as a deviation from what they define as "normal". Their solution is to use surgery as a weapon to eradicate people who contradict the binary stereotype. The combination of the academic denial of intersex as a legitimate part of human ancestry coupled with the surgical child abuse of intersex children adds up to a toxic public, view of who we, as a species, really are and have become.

It is no surprise therefore that other countries take their cue from all this and choose to eradicate those who challenge the concept of 'Normal'.

Now we find that the attitudes towards and treatment of intersex people in the UK, Europe and other developed nations (described by the United Nations inspection teams as "torture" and "child abuse") is being exported to countries where they do not have the resources of modern hospitals in rural areas and nothing to combat the long- standing tribal fear of the unfamiliar whipped up by fear of ancient spirits. Therefore, things MUST change and change NOW and this change then be exported around a world to ensure that children and adults never need to fear retribution for being different from the majority.

Poster Presentation

Poster: Educating Therapists to Better Support Intersex Clients in Therapy; Valentino Vecchiotti (Intersex human rights activist and campaigner) and Jane Czyzselska (Psychotherapist)

Jane Czyzselska, a psychotherapist, and the former editor of Diva Magazine, and Valentino Vecchiotti, an intersex human rights campaigner and independent academic, have collaborated on a project to provide workshops to educate therapists so that they are better able to support intersex clients in therapy. 1.7% of the UK population are born with intersex variations, but this is not reflected in the therapy available in the UK. In contrast to the current existent literature, which is written from the clinician's perspective, Czyzselska's masters degree data provides material sourced directly from clients, and identified key ways in which therapists can support this group. The main conclusions drawn are that the bodily integrity and autonomy of this client group has been severely and repeatedly compromised through institutional treatment practices and through the imposition of normative sex and gender categories, and it is therefore vital that adequate therapy is provided.

THERE WILL ALSO BE LARGE PAPER PROVIDED NEAR THE REGISTRATION TABLE FOR PEOPLE TO WRITE THEIR IDEAS FOR FURTHER RESEARCH NEEDS AS WELL AS BEST PRACTICES FOR COLLABORATION BETWEEN ACTIVISTS, ACADEMICS AND INSITUTIONS.

Day 1 Monday June 4th

Keynote plenary session

9:15 - 11:15

Daniela Truffer and Markus Bauer founding members of the Swiss Intersex Human Rights organization Zwischengeschlecht.org and StopIGM.org.

Daniela and Markus are part of a growing trend in intersex activism that not only frame intersex rights claims as human rights abuses but that also systematically seek International Human Rights Mechanism's acknowledgement and action on these issues. In 2014 they began to strategically address Treaty bodies, addressing IGM as a harmful practice to the CRC. The NGO reports include detailed evidence of on-going practice, lifelong physical and mental pain and suffering, the inaction and awareness of the State, a HR bibliography and a historical overview. In 2015 this led the CRC to recognize IGM as constituting a harmful practice like FGM for the first time, referring to the CRC-CEDAW Joint General Comment 18/31 "on harmful practices". Building on this CRC verdict, in 2015, recommendations were also obtained from CAT, who recognized IGM as constituting 'Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment', and recommended that Switzerland take legislative measures, guarantee appropriate services as well as provide protection and redress.

They began to collaborate with international intersex advocates and organisations (some of whom conduct separate IHRM lobbying as well) to write reports for other countries. This collaborative and strategic approach has enabled the international intersex movement to produce a relatively high number of strong reports to UN treaty bodies, resulting in over two dozen UN Treaty body verdicts explicitly recognizing IGM as a serious human rights violation. This part of the plenary will address intersex international human rights strategies in detail, as framed by StopIGM.org.

Holly Greenbury co-founder of Intersex UK. Holly is a consultant specialising in Intersex Human Rights work and has collaborated internationally with many other NGOs.

Holly Greenberry will talk about the human rights abuses that are taking place in the UK against Intersex people and those with variations of sex characteristics. She will outline the key areas where change is needed, and discuss the different actions that are taking place. Holly will provide an overview of the way that Intersex UK has developed, its UK-based and international work, and directions for future activism.

Holly data researched and co authored the report regarding the UK and intersex human rights abuses which led to condemnations of the UK from the UNCRC and UNCEDAW. She spoke at the UN plenary and since then worked on international media projects and consulted in the UK on the amendments to the Gender Recognition Act, and also provided consultation to the Home Office on their new LGBTI asylum policy. She was listed in 2015 as number 5 on the Rainbow List as one of the most influential LGBTI people in the UK.

Alessandro Comeni, steering board member of Associazione Radicale Certi Diritti, co-founder and steering board member of OII-Europe and OII-Italia.

The struggle for intersex rights in Italy started in the early 2000s in the form of 'patient' associations with various relationships with parents and medical institutions. A few years later Italian intersex social activism began, and rapidly connected, to international groups such as OII; drawing on human rights and public awareness strategies.

Italian intersex activism has some very specific issues to address due to the cultural-political presence of the Vatican and the catholic church, the regional nature of the national health system as well as the state's disconnect from international human rights mandates. Obviously some of these issues resonate in other national contexts.

Alessandro will address some of the specificities of intersex in the Italian context as well as elaborating on current rights claims and actions of OII-Italia.

He will also bring his experience as project creator and promoter of the first (in Europe) media informative campaign on intersex issues, as well as the very first effects of this campaign.

Irene Kuzemko is a co-founder of Intersex Russia, secretary of OII Europe and a member of InterACT Youth. She has been involved in intersex activism since 2015. Irene is one of the very few publicly out intersex people in Russia.

If you're born intersex in Russia, your human rights magically disappear. Doctors in Russia proudly say that they perform intersex genital mutilation. The Russian Ministry of Health recently posted an article on their website that presented IGM as a good thing. Most Russian intersex people keep the truth about their bodies a secret. So how do you build a community in such circumstances? How do you fight for intersex human rights? Irene Kuzemko will cover all of this in her talk about the situation with intersex human rights in Russia, reflecting on how different intersex activism is in her country.

Paper session 1: Activism

11:30 – 13:00 Monday

Chair: Tanya Ní Mhuirthile (Dublin City University)

1. **100% Human**; Georgia Andrews (Intersex Youth Aotearoa) and Denise Steers (University of Otago, New Zealand)

This qualitative research has been conducted in collaboration with Intersex Trust Aotearoa New Zealand. Ten young people with IVSC were recruited via health professionals, intersex advocates, support groups and social media platforms throughout Aotearoa/New Zealand. Interviews were in-depth and semi-structured, digitally recorded and transcribed. Braun and Clarke's (2006) Thematic Analysis was used to identify key themes regarding their experiences. A variety of experiences were reported in relation to their health care: Communication, perceived bias, and understanding and inclusivity of diversity in relation to interactions with health professionals had a direct impact on young people's decision making. The complexities of identity, gender, bodily autonomy, acceptance of difference and challenging the concept of "the Norm" was a major theme for young people.

Implications include better support systems (especially peer support and the development of caring communities); training, and collaboration with healthcare providers.

2. **The normalisation of intersex bodies and othering of intersex identities in Australia**; Morgan Carpenter (OII Australia/Intersex Day Project)

Individuals born with intersex variations are routinely subject to 'normalising' medical interventions, often in childhood. Opposition to such interventions has been met by attempts to discredit critics, and reasserted clinical authority over the bodies of women and men with 'disorders of sex development'. At the same time, the construction of intersex as a third legal identity category has been accompanied by pious hopes and instrumentalisation. The creation of gender categories associated with intersex bodies has created profound risks, including a paradoxically narrowed and normative gender binary, and maintenance of medical authority over the bodies of disordered females and males. The combined effect of these medical and socio-legal approaches is that medicine constructs intersex bodies as either female or male, while law and regulation construct intersex identities as neither female nor male. An emerging human rights approach focuses on the right to bodily integrity, and principles of self-determination.

3. **Dismantling forms of structural violence: Opportunities for future alliances between intersex and trans depathologization movements?**; Amets Sues Schwend (Andalusian School of Public Health)

The paper aims at analysing the discourses, strategies and developments of international intersex and trans depathologization movements over the last decade, in order to identify differentiated priorities, as well as opportunities for future alliances. Over the last decade, the emergence of an international intersex movement can be observed that demands, among other claims, the cessation of genital surgeries and other non-consensual treatments performed on intersex newborns, children and adolescents. At the same time, an international trans depathologization activism raised, demanding, among other claims, the removal of the diagnostic classification of gender transition as a mental disorder. After achieving an international development on their own over the last decade, currently opportunities for future alliances between the international intersex and trans depathologization movements can be identified. For establishing these alliances, it is relevant to recognize differentiated experiences, priorities and strategies, as well as to build up collaboration structures aimed at dismantling forms of structural violence and denouncing human rights violations.

4. **Activism of Intersex in Nepal**; Parbati Kumari Regmi (Esan) (BDS/CFC)

The authors cannot be presented but have prepared a statement that will be read regarding Human Rights abuses of Intersex people in Nepal. The Joint statement for the PSWG briefing in collaboration with StopIGM.org will be highlighted.

Paper session 2: Open stream

11:30 – 13:00 Tuesday

Chair: Eva De Clercq (University of Basel)

1. **Intersex Advocacy and Policy from a Social Work Perspective;** Michelle Anklan (Minnesota State University, Mankato)

As an ethics-driven profession, the United States' National Association of Social Workers (NASW) implores social workers to "help people in need and to address social problems" (2017). The NASW has 62 policy statements on a multitude of issues, but does not address working with individuals and families affected by intersex conditions. Social workers are key providers of mental health care in medical settings in the United States. Establishing a policy statement on the wellbeing of intersex people would provide ethical guidelines to follow in helping families make decisions regarding medical intervention and provide leadership to other professional organizations as an example of policy development promoting best practice in the care of intersex infants and children. This project demonstrates the intersection of research, advocacy, and policy development by calling upon the NASW to develop a policy statement to discourage the practice of medically unnecessary surgical intervention on intersex infants and children.

2. **Intersexuality. A historical artifact of epistemic emancipation;** Sara Lugo-Márquez (Universitat Autònoma de Barcelona)

This dissertation expects to trace how the "social emergency" has become a key concept to guard the traditional social order of gender classification into the historical construction of intersexuality as a disease, promoting the consolidation of a corrective medicine practice in the 20th century. The protocols for surgical procedures intersex newborns, disseminated in the fifties by John Money (1921-2006) et al. does not take into account patients' health and self-determination, and promote hierarchized public health with power practices over our bodies led by normative structures of women or men definitions. Motivated by the recent intersexual social movements that promote the right to be intersexual, and the Colombian Constitutional Court decisions of the last twenty years, we would like to propose that intersexuality is an example of how our biological representations of body are becoming, just as they should be, anarchist, transcending the boundaries that have been tried to be imposed.

3. **Introducing a Third Gender in Germany- pros and cons;** Katinka Schweizer and Hertha Richter-Appelt (Institute for Sex Research University clinic Hamburg-Eppendorf)

In 2017 the German Supreme Court decided to introduce a third Gender option in German law. There is also discussion regarding totally abolishing the judicial sex/gender category. The intention is to provide justice for individuals born with ambiguous sex or diverse sex characteristics and experience themselves neither as women nor as man. In the Hamburg Intersex Study we had asked participants more than 10 years ago as to whether they would prefer the introduction of a third gender. The results were meaningful: Half were in favour, half were opposed. Nevertheless, the line of argument was similar in both cases: There were worries amongst the opponents whether new discrimination would begin due to an obligatory choice of a third gender if one had diverse sex characteristics. We address the new situation from both aspects, looking at the pros and cons of both options, taking into account the main themes of psychological intersex care of the past years.

4. **Intersex Citizenship;** Surya Monro, Daniela Crocetti and Tray Yeadon-Lee (Uni. Huddersfield)

Citizenship studies is a large and growing field, with bodies of scholarship available in the areas of gender, sexuality, children's rights and health. However, there is a deficit regarding citizenship of intersex people and those with variations of sex characteristics. Citizenship theory, which concerns people's rights over their bodies, identities, and self determination, as well as social and political rights more broadly, could be a very useful tool for thinking about intersex human

rights. This paper presents initial ideas about intersex citizenship, drawing on a number of areas of citizenship theory. It is based on original research (Lead Researcher Daniela Crocetti, collaborators Zwischengeschlecht and other Intersex colleagues) conducted in Italy, Switzerland and the UK. Key issues for intersex citizenship include the right to bodily autonomy and self-determination, freedom from non-consensual medical interventions as well as legal protection.

Panel 1: Intersex and Temporality

14:00 – 15:30 Monday

Narratives of temporality are common in discussions of intersex. Justifications for non-consensual and medically unnecessary surgeries on intersex infants often involve the consideration of the adult that the child will be, and what their genitals should look like and be able to do, at some point in the future. However, individuals with variations of sex characteristics and human rights activists and advocates often speak of early medical interventions as having created temporal disconnections, “severing futures” (intersexuk.org) and dragging individuals back to the past.

In this panel we bring together sociology, phenomenology, bioethics, art and queer theory in order to open up a conversation about the relation between time, temporality and intersex or variations of sex characteristics considering such questions as:

What kind of time is embodied in medical policies and decision-making regarding variations of sex characteristics and how?

How do intersex people experience and narrate their lived experience of time?

How does this relate to more general notions of time, the body, sex, gender and sexuality?

How can creative and cultural expressions shift our understanding of time?

Chair: Michelle Anklan (Minnesota State University, Mankato)

1. **Time Matters for Intersexed Bodies: Between Socio-medical Time and Somatic Time**; Limor Meoded Danon (Hebrew University of Jerusalem)
2. **Harms to the Child, in their ‘Being’ and ‘Becoming’, arising from ‘Normalising’ Genital Surgeries**; Sorcha Uí Chonnachtaigh (Keele University)
3. **Queer Temporalities and the Futureless Moment of Hypospadias ‘Repair’**; David Andrew Griffiths (University of Surrey)
4. **Liquid Gender | Sculpting for a Multipolar Gender Image**; Fabian Vogler (Independent Artist)

1. **Time Matters for Intersexed Bodies: Between Socio-medical Time and Somatic Time**; Limor Meoded Danon (Hebrew University of Jerusalem)

Common medical practice regarding intersexed bodies assumes that the more rapidly intersexed patients are (surgically) normalized, the less they will suffer from future social alienation, psychosexual pathologies, and gender dysphoria. This paper focuses on the relationships between time, intersexed bodies, and gender in medical policy on intersexed bodies and in intersexed people’s subjective experiences. From a sociological perspective, I demonstrate that time is a crucial socio-medical factor that influences diagnostic practices, regulations, and treatment policy regarding intersexed bodies. I explain how biomedical professionals establish time frames that are oriented to normalize intersexed bodies according to the ‘dimorphic soma-gender order,’ the imaginable, coherent, polar normative relationship of female bodies to femininity and male bodies to masculinity. From a phenomenological perspective, I describe the concept of somatic time, intersexed people’s experience of medical time, and the relationship between time, somatic experiences, and gender identities. This qualitative comparative study is based on narrative interviews with biomedical professionals, parents of intersexed children, and intersexed adults from Israel and Germany.

2. Harms to the Child, in their 'Being' and 'Becoming', arising from 'Normalising' Genital Surgeries;
Sorcha Uí Chonnachtaigh (Keele University)

'Normalising' genital surgeries (NGS) on intersex infants are typically justified on two main grounds: relational requirements and psycho-social welfare. The former justification is concerned with either or both the child in their 'being' and the adult they are 'becoming': 'atypical' genitalia are viewed as an obstacle to bonding and relationship-building between the child and their parents in the current moment, and these same genitalia will be cause physical and psycho-sexual difficulties for the adult they will become. The latter justification is concerned with social relations between the older child/teen who has a 'different' body to their peers, and the difficulties of romantic and sexual relationships for the young/adult who does not fit with binary sex-gender norms. The intersex infant, it seems, faces a precarious present and catastrophic future. If benefits of NGS to the adult could be proven and evaluated, and if it could also be shown that the benefits could only accrue through early intervention, there might be a (theoretical) justification for NGS. With neither of these and counter evidence (from intersex adults who have experienced NGS), it is morally impossible to justify such risky, irreversible interventions on the intersex infant.

3. Queer Temporalities and the Futureless Moment of Hypospadias 'Repair'; David Andrew Griffiths (University of Surrey)

Justifications for early surgeries to 'normalise' variations of sex characteristics often stress the importance of timing. Surgeries must be performed early on the child for the supposed benefit of the future adult; genitals must be 'normalised' early, so that future adult genitals will supposedly look and function 'normally'. Activists and advocates have for decades argued that these surgeries are unnecessary, unethical, a breach of human rights, and fail on their own terms, leading to physical and psychological damage. Intersex narratives often invert the claims of medical professionals: instead of surgeries allowing a 'normal' future, they deny this future. Taking the example of the most common genital surgery in infants, hypospadias 'repair', I will argue that before thinking about the future, we need to think about the 'moment'. Using queer theories of temporality and analysing urological texts I will demonstrate that these surgeries, despite the future-oriented justifications, are utterly without a future. They are stuck in a present of inevitable surgery and lack any responsibility (for the past or the future). I will argue for the expansion of the moment, slowing down, and for the critique of infant genital surgeries on their own terms.

4. Liquid Gender | Sculpting for a Multipolar Gender Image; Fabian Vogler (Independent Artist)

Individuation primarily results from orientation towards suitable role models. Fine Art has always had a superior capacity in reflecting a contemporary vision of the prevailing conception of the human being. Can Intersex people find their place in today's dichotomizing world, where hardly any depictions of in-between paragons can be found in our museums? How can "allegedly unaffected" cisgender people build up an understanding for alternative concepts of gender classification system, if predominant gender representations of the human being throughout the centuries are binary? Therefore I have explicitly included a multipolar gender image in my sculpting – an ongoing search for a contemporary conception of the human being. In my view Intersex is physical proof for the falsehood of the binary gender construct. It is proof of the grace of gender variety – a diversity that must be seen as a gift. By showing exemplary works of my latest sculptural artistry, created specifically for the transdisciplinary publication *Die Schönheiten des Geschlechts* (The Beauties of Sexes) edited with Dr Katinka Schweizer, expected early 2018, I will give a short introduction into this book|art|project.

Panel 2: Intersex and Law: Present Problems and Future Directions

15:45 – 17:15 Monday

This session on law and intersex considers some of the most pertinent legal issues in regards to intersex variance and embodiment. This covers traditional considerations of autonomy and consent and how these may be introduced at both national and international levels. This panel also seeks engages with new critiques of ‘informed consent’ and their role in individualizing systemic failure. As a consequence some of the papers consider the role of state responsibility in the context of intersex.

Chair: Dr Susannah Cornwall (University of Exeter)

1. The Right to Personal Autonomy of Persons with Variations of Sex Characteristics; Pieter Cannoot (Ghent University)

2. Mapping the Transition to “Informed Consent” Models for Medical Interventions on Persons with Intersex Conditions (or other Differences in Sex Development); Dr Jameson Garland (Uppsala University)

3. Why are Intersex Surgeries still happening? Jurisdiction, Scale and Temporality; Dr Mitchell Travis (University of Leeds) and Dr Fae Garland (University of Manchester)

4. Legislating for Intersex Rights: Opportunities and Limitations Dr Tanya Ní Mhuirthile (School of Law and Government, Dublin City University)

1. The right to personal autonomy of persons with variations of sex characteristics; Pieter Cannoot (Ghent University)

The legal system devotes very little attention to the situation of persons with variations of sex characteristics. Although variations of sex characteristics is a common phenomenon, data about the prevalence of medical treatment regarding persons with variations of sex characteristics and their living conditions are rare. Persons with variations of sex characteristics are currently put under particular pressure by the legal system because of its binary normativity. The connected conceptualization of “sex” according to the binary maintains the pathologization of variations of sex characteristics and reinforces the focus on sex normalizing treatment on children who are too young to provide their informed consent. This contribution specifically deals with the legal challenges of sex assigning/normalising medical treatment, sex registration by the government and discrimination of persons with variations of sex characteristics, from a human rights approach. It will focus on the right to personal autonomy of persons with variations of sex characteristics and will make use of the Belgian legal order as a case study. First, with regard to sex assigning/normalising treatment of persons (in particular: children) with variations of sex characteristics, the paper argues that by de facto substituting the child’s informed consent with the view of the legal representative, Belgian law fails to respect the former’s right to autonomy. It therefore calls for the adoption of a legal ban on non-consensual, medically unnecessary treatment on a person’s sex characteristics. Secondly, the paper argues that the Belgian legal system needs to end its structural conflation between the legal meaning of sex and gender (identity) in order to effectively protect bodily autonomy of persons with variations of sex characteristics. Moreover, in order to ensure legal inclusiveness of persons with variations of sex characteristics (a) non-binary option for sex registration should be available. Lastly, the paper examines whether the law should include a specific ground for non-discrimination of persons with variations of sex characteristics.

2. Mapping the Transition to “Informed Consent” Models for Medical Interventions on Persons with Intersex Conditions (or other Differences in Sex Development); Dr. Jameson Garland (Uppsala University)

In October 2017, the Parliamentary Assembly for the Council of Europe (CoE) passed a joint resolution and a recommendation regarding protection of the rights of intersex persons. Resolution 2191 called on Member States to enact laws to prohibit non-consensual gender-conforming medical procedures without the informed consent of the children with intersex conditions, as well as to ensure that non-emergency procedures are delayed until the children can participate in care decisions, ‘based on the right to self-determination and on the principle of free and informed consent’. In addition to a number of civil law reforms, the resolution called on Member States to ensure access to patient-centered health care for persons with intersex conditions. In support of the Resolution, Recommendation 2116 directed the CoE’s Committee on Bioethics (DH-BIO) to develop guidelines for informed consent. These developments, in fact, followed the initiative of DH-BIO to map all of the rights of children that may be affected by scientific risk and uncertainty in biomedicine, including clinical, medical practices. Indeed, two reports commissioned by DH-BIO as part of this initiative have warned that current clinical practices involving children with intersex conditions affect a broad spectrum of rights that intersect with and go beyond rights in biomedicine.

This paper maps the challenges likely to be faced by persons with intersex conditions and other differences in sex development, as well as the Member States of the Council of Europe, in any transition to “informed consent” models regarding gender-conforming medical procedures in childhood. Many of these challenges, in fact, have been indirectly identified by those who have invoked systemic legal problems as justification for resistance to law reform. The paper problematizes the model of “informed consent”, with examples from the Nordic region, where several medical and bioethics authorities have criticized current practice but have left many questions unresolved in how to transition to an informed consent model of care. The paper proposes essential criteria for such a model with cautions as to why informed consent alone, as traditionally conceived, will leave children in vulnerable positions in health care and in Europe, and why the breadth of the Council of Europe’s recommendations require full consideration.

3. Why are intersex surgeries still happening? Jurisdiction, Scale and Temporality; Dr Mitchell Travis (University of Leeds) and Dr Fae Garland (University of Manchester)

Despite a number of high profile human rights interventions from the Council of Europe, The UN Special Rapporteur on Torture, the UN Committee on the Rights of Children amongst others, pressure from human rights and intersex activists and growing numbers of academic support for the notion of bodily integrity non-therapeutic medical interventions on the bodies of intersex children continue to be routine. This paper attempts to unravel how and why, despite growing opposition, such interventions can take place without legal constraint. In order to do so this paper analyses the issue through a lens of governance asking questions of jurisdiction, scale and temporality. In terms of jurisdiction the paper questions rigid notions of medical authority in this area and considers the importance of state responsibility for its citizens. Questions of scale allow the disjunctions between human rights organisations and day to day medical practice to be revealed. Such analysis points towards the importance of dialogue between these institutions but notes how such dialogues have been prevented through both jurisdiction and scale. Finally, the paper considers temporality as a problem in this area. Conceptualising intersex as a ‘medical emergency’ prevents the appropriate level of scrutiny of healthcare professionals. This paper highlights law as a space where different understandings of temporality can be considered with appropriate weight given to the concept of

‘deferability’. Overall, this paper attempts to reorient discussions around intersex away from the reliance on ‘rights’ towards placing obligations on the state and its institutions.

4. Legislating for Intersex Rights: Opportunities and Limitations Dr Tanya Ní Mhuirthile (School of Law and Government, Dublin City University)

Language is the means through which legal rights are mediated. Yet language in the context of intersex issues is highly contentious. This creates a tension for legislative drafters: how best to enshrine rights using language that has legal meaning and yet guarantees these rights employing language that respects the dignity of people with intersex variations.

Over the past few decades discourse about intersex has been divided into two types of discussions: deliberations aimed at achieving recognition of intersex identity which may differ from that recorded at birth and debates about medical management. While these may seem to be two disparate aims at their core, they concern questions of dignity, respect and the realisation of human rights. This paper will examine whether the Irish response to this challenge has adequately achieved this aim.

Yogyakarta+10 workshop with Morgan Carpenter

(OII Australia/Intersex Day Project)

17:15 – 18:15 Monday

In 2017, the Yogyakarta Principles were updated to include (amongst other additions) a new attribute of "sex characteristics" in the "Yogyakarta Principles plus 10". New principles recognise rights to bodily integrity and truth. These, together with new State Obligations, have direct relevance to the human rights situation of intersex people.

Morgan Carpenter was a signatory of the Yogyakarta Principles plus 10, and a member of the drafting committee. Morgan will discuss the goals of the update process, the new attribute, principles and obligations, and the relevance to intersex populations.

In the following workshop, intersex human rights strategies and goals will be discussed in smaller groups. The main concepts developed by each small group will then be brought back to the larger group for further discussion and reflection.

We hope this workshop will further tactical and collaborative discussion between activists and allies on current, on-going, and future intersex human rights demands.

Day 2 Tuesday June 5th

Presentation EUICIT research project

9:00 - 9:30

About the Intersex/DSD Human Rights, Citizenship and Democracy project

This project investigates human rights framing and strategies used to address Intersex and DSD in Europe (specifically focusing on Italy, Switzerland and the UK). It maps 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. In order to be as inclusive as possible, the terms 'Intersex', 'DSD', 'variations of sex characteristics' or other terms have been used based on the choice of the research participant. The project has four basic aims:

- Map the strategies, agendas, actions and results of Intersex and DSD activists in Italy, Switzerland and the UK.
- Map policy and medical perspectives and actions regarding Intersex Human Rights and Social Health Activist claims.
- Generate knowledge about Intersex and DSD human rights, citizenship and democracy issues.
- Facilitate Intersex led public engagement.

Methodologies:

The project has utilized a qualitative approach in order to gain an in-depth understanding of activist and policy perspectives. It is interdisciplinary in its use of concepts and tools adopted from sociology, gender and sexuality studies, social study of science, politics, social policy and socio-legal studies.

Outcomes of the project:

The project draws out issues that have been addressed (or not) at their associated policy levels, from local hospitals to national legislation to UN and EU policy documents. Outputs include journal papers, a report, and conference papers. These outputs and activities are taking place in collaboration with Intersex activists.

Conducted by:

Dr Daniela Crocetti University of Huddersfield (Principal researcher), Professor Surya Monro, University of Huddersfield (Coordinator), Dr Tray Yeadon-Lee, University of Huddersfield (Co-Investigator). Collaborators: Zwischengeschlecht/ Stop Intersex Genital Mutilation, Switzerland.

Dates: 05/09/2016 – 17/11/2019.

Panel 3: Law and Intersex 2 Unequal ‘Treatments’ and New Comparators **9:30 – 11:00 Tuesday**

This session on law and intersex seeks to consider comparative perspectives of intersex issues. Primarily these focus on the different standards of care that have been applied to trans and intersex children in both law and healthcare. The third paper in this session seeks to introduce new comparators through an understanding of ‘bodily gifts’ constructed through religion.

Chair: Dr Mitchell Travis (University of Leeds)

- 1. Comparing the Legitimacy of Genital Surgery in Transgender and Intersex Minors: An Alternative Ethical Perspective;** Edmund Horowicz (Edge Hill University)
- 2. Sex and Gender in the Family Court;** Aileen Kennedy (University of New England, Australia)
- 3. Bodily Rights and Gifts: Intersex, Religion, and Human Rights;** Dr Susannah Cornwall (University of Exeter)
- 4. “Inform and guide”: the role of activism in shaping the legal protection of intersex rights;** Stefano Osella (European University Institute)

1. Comparing the Legitimacy of Genital Surgery in Transgender and Intersex Minors: An Alternative Ethical Perspective; Edmund Horowicz (Edge Hill University)

Genital surgery on intersex infants is well recognised as being controversial, with increased international condemnation arguing that the practice breaches the rights of intersex minors and subjects them to unnecessary and inhumane treatment. Whereas the ethical problems with intersex surgery are widely debated, this surgery is still performed, which is by itself morally questionable. However, when the comparator of genital reassignment in minors with gender dysphoria is analysed, a stark difference between accepted clinical practice in both cases is highlighted. This paper seeks to explore why the medical acceptance of genital surgery in intersex infants as legitimate medical treatment is not mirrored for minors with a diagnosis of gender dysphoria. The paper will identify that the diagnostic classification is a key influence and that subsequently this impacts upon how genital surgery is considered by doctors. My main argument is that the predominant consideration for not performing genital surgery in minors with gender dysphoria, which is potential psychological harm through dissatisfaction and regret, appears to contradict the medical justification for genital surgery in infants with a DSD, which uses a paternalistic approach to addressing these issues. The paper argues that exploring these contrasting positions demonstrates the moral legitimacy of surgery provision in adolescents with gender dysphoria and provides an alternative perspective to the argument that genital surgery in infants with a DSD should be prohibited. Furthermore, that any decision by a minor to undergo genital surgery must hold legal authority from the minor themselves, rather than being based on a medical presumption of best interests.

2. Sex and Gender in the Family Court; Aileen Kennedy, (University of New England, Australia)

This paper will examine the role of the Australian Family Court, exercising its ‘special medical jurisdiction’ in regulating medical treatment protocols for intersex and trans children. In Australia, the Family Court has been tasked with authorising special medical treatment. The definition and scope of jurisdiction comes from Marion’s Case, heard by the High Court in 1992, identifying some non-therapeutic medical procedures as being outside the scope of parental authority. Initially the jurisdiction was concerned with sterilisation procedures performed on intellectually disabled women and girls.

Since 2004, the jurisdiction has largely been invoked to authorise treatment for children with gender dysphoria. Over 70 cases involving minors wishing to transition have been reported. By contrast, the medical normalisation of children with intersex variations has rarely been seen as requiring court authorisation. Only 8 cases involving intersex children have been brought to Court. The likely explanation for this disparity is that medical interventions on intersex children is constructed as therapeutic, even where the aim of the surgical procedure is to normalise ambiguous genitals.

This paper will argue that the therapeutic/non-therapeutic dichotomy adopted in Marion's case as the threshold consideration has resulted in egregious medical breaches of human rights, in relation to both trans and intersex children.

3. Bodily Rights and Gifts: Intersex, Religion, and Human Rights; Dr Susannah Cornwall (University of Exeter)

Intersex has recently begun to be recognized legally in jurisdictions including Malta, Australia and Germany. Even where legislation has not yet been passed, recommendations and human rights discourses (such as the recent discussion of intersex by the UN Special Rapporteur on Torture, and the Council of Europe's resolution on intersex children's rights to physical integrity) seem increasingly to be acknowledging that the lack of specific protections for intersex people to date has been a problem. Religious communities, especially those which teach that binary sex is intended by God, may be particularly challenged by intersex, particularly in the areas of birth and naming ceremonies; ethical responses to corrective surgery (especially given constructions of medical intervention as religious duty); and anthropological accounts of the cosmic significance of maleness and femaleness. However, they also contain resources for constructing rich and robust accounts of personhood. In this paper I note some ambiguities around human rights language in this area, and ask - drawing on Ethna Regan's discussion of human rights as "boundary discourse" - whether Christian and Muslim constructions of life as gift from God may present a different way to promote intersex people's physical and spiritual integrity and wellbeing.

4. "Inform and guide": the role of activism in shaping the legal protection of intersex rights; Stefano Osella (European University Institute)

Italy and Colombia constitute two paradigmatic cases of the legal attitude towards normalizing medical treatments on intersex children. Italian administrative and judiciary bodies have insisted on the legal obligation of doctors to carry out normalizations. The Constitutional Court of Colombia, on the other hand, has offered a strong constitutional protection to intersex people's rights. How can we explain this difference? The paper focuses on the attitude of the courts and administrative bodies vis-à-vis intersex activism and scholarship, as expressed in the legal narrative. While in Italy critical voices have been ignored, the Constitutional Court of Colombia has listened closely to them, and has produced an informed legal outcome. The paper concludes with a normative discussion of the alliances to build between lawyers and intersex activism, to show how a close collaboration is vital to improve the protection of intersex rights.

Panel 4: The protection of intersex persons by international law

11:15 – 12:45 Tuesday

Since 2009, international organizations have started to pay attention to intersex issues. Indeed in 2009 the UN, the Council of Europe and the European Union were the first to publish legal documents in which intersex issues were addressed or at least mentioned. Since then those organizations, also joined by others (e. g. the African Commission on Human and People's Rights or the Inter-American Commission on Human Rights), have continuously produced normative documents where this issue is addressed.

This panel aims at giving a better understanding of the international norms, which can be linked to intersex issues. Therefore we will present the current state of international law regarding the protection of intersex people. Also we will look at on the impact that international norms have on national law and, more generally on the day-to-day situation of intersex people.

Chair: Benjamin Moron-Puech (University Panthéon-Assas).

- 1. Prohibition of Non Consented Sex Assignment Surgeries in Public International Law;** Benjamin Pitcho (Member of the Paris Bar and of the Bar Council)
- 2. Recognition of Third Gender and its Consequence for Sexed or Gendered Rules;** Mila Petkova (Member of the Paris Bar)
- 3. Deletion of Sex Markers on Identity Documents;** Benjamin Moron-Puech (University Panthéon-Assas).
- 4. Open discussion on 'What can International Law do for Intersex';** Facilitated by panel members as well as Daniela Truffer and Markus Bauer (StopIGM.org)

- 1. Prohibition of Non Consented Sex Assignment Surgeries in Public International Law;** Benjamin Pitcho (University Panthéon-Assas)

Intersex people are safe and healthy people. Yet, since intersex is not recognized in France, doctors consider they are granted the right to practice sex assignments surgeries and other "medical treatments". These operations however consist in important and permanent body injuries and harm. They should be considered as illegal since they do not present the mandatory requirements for their authorisation. First, they are not supported by any therapeutic motivation. They are moreover realised without any regular, prior and informed consent, contrary to international norms.

In this communication we will present the work made by French lawyers and intersex in order to make a tribunal recognize that such global treatment consists of important infringements to intersex people's rights. Two cases have been introduced in France before criminal courts and decisions are pending. Besides the useless condemnation of doctors and hospitals, victims together with their lawyers have decided, using public international law, to raise the cases only so that the Tribunals forbid any further sex assignment surgery.

Also, using public international law, French lawyers and intersex are trying to facilitate the compensation of damages by opening compensation funds to victims of intersex genital mutilations. Therefore, in this communication, we will look how public international can be used to obtain an explicit prohibition of surgeries and and a better compensation of the damages that our societies have caused in the past to intersex persons.

- 2. Recognition of Third Gender and its Consequence for Sexed or Gendered Rules;** Mila Petkova (Member of the Paris Bar)

In this communication we will present the legal work made by lawyers and scholars in order to obtain in France, on the basis of public international law, a recognition of a third sex marker on register and civil status for an intersex persons.

Currently French regulation (a circular of 28 October 2011) states that children whom are born with an ambiguous sex can be registered as « sex undetermined » during a limited period, 1 or 2 years. This regulation is applied. For instance between January 2013 and February 2017 the French National statistics Office had registered at least 53 persons as « sex undetermined ». However, this regulation does not provide anything about the period after 2 years, could a sex marker “other” could be inscribed?

Following the recent evolution of French and international law, and the French legal tradition, lawyers have tried to demonstrate that French law could be interpreted as allowing permanently a third sex marker on the register of civil status. In this communication we will present their work, mainly based on international law. We will present the reasoning of the French courts on the case and talk about the application that was made in November 2017 before the ECHR and based on many international norms.

Therefore the main focus of our communication will be to look on which basis France and other members of the Council of Europe should recognize officially a third gender for intersex who wants to be identified neither as man or woman.

3. Deletion of Sex Markers on Identity Documents; Benjamin Moron-Puech (Member of the Paris Bar and of the Bar Council).

For some times now, intersex association have asked that sex or gender marker be removed from their identity documents, arguing that the presence of such marker was exposing them to some discrimination.

In this communication we aim to investigate whether or not this claim can be supported by public international law. Even if very few international norms recommend to abolish sex or gender marker, we will try to demonstrate that right to privacy — a right recognized in particular by article 8 of the European convention of human rights — could compels States to ban compulsory sex or gender registration, even on international travelling documents such as passports. We will show also that this international right to privacy should lead States to forbid firm to ask information related to the sex or the gender identity of their customers. To make this demonstration we will use national and international texts related to sex or other elements of once privacy, especially markers concerning once religion.

4. Open discussion on ‘What can International Law do for Intersex’; Facilitated by panel members as well as Daniela Truffer and Markus Bauer (StopIGM.org).

The panel members and StopIGM.org will facilitate an open discussion on applying International Law to Intersex rights. International Human Rights Mechanism’s attention to Intersex medical treatment is due to extensive lobbying by International networks of Intersex activists. Human Rights (HR) framings were present quite early in the Intersex movement, particularly mutilation and torture claims, but it took over 20 years for institutions to replicate these framings. Currently, specific aspects of Intersex medical treatment are increasingly being addressed as serious HR abuses, with verdicts from numerous UN Committees, regional HR bodies, UN agencies, the Council of Europe, the Australian parliament, and the Italian, German, and Swiss national ethics committees, the Palm Center report by three ex-US Surgeon Generals, and the US Human Right’s Watch. In addition, the Malta Gender Identity, Gender Expression and Sex Characteristics Act in 2015, and the Yogyakarta Principles plus 10 in 2017 specifically included ‘sex characteristics’ as a protected category.

Discussion space on academic and activist collaboration

13:15 – 14:15 Tuesday

Facilitated by Valentino Vecchietti Vecchietti (Intersex human rights activist) and Jantine van Lisdonk (Rutgers).

We have created this brief networking and discussion moment to add to the on-going conversation on how activists and academic allies can further collaborate to promote intersex rights claims. This facilitated space will provide an opportunity to informally exchange experiences as well as discuss examples of good (and bad) collaborative practices.

Paper session 3: Narrative and identities

13:45 – 15:15 Tuesday

Chair TBA

- 1. The long journey towards intersex identity;** Loé Petit (Université Paris 8 Vincennes-Saint Denis)
Based on intersex life stories in the contemporary western world, this paper will explore the patterns we can see in the paths from a person's singular experience of their intersex variation to their access to the intersex community and their self-identification as a part of it. The obstacles they face can be of various forms and sources, from the medical community, from the psychological and often social shift the person needs to endure to leave the pathologizing approach, but also from some strategic choices of the intersex movement. How do intersex people overcome these obstacles? The implications for the field are diverse: the questions raised are about identity building, about relationships of power, especially in health care, and about social movements strategies.
- 2. Using expertise by experience to inform health care, education, and advocacy in the Netherlands;** Jantine van Lisdonk (Rutgers)
In addition to medical and human rights perspectives, a social science perspective that focuses on experts by experience offers new insights that can promote to bridge gaps needed to realize further change in society, policy and care provision. In the Netherlands, the representation and mobilization of experts of experience has grown. I describe these developments and in addition present on preliminary findings from a study on parents' perspectives using storytelling. What are their experiences and needs in everyday life and health care settings? Preliminary key issues are lack of information, narrow focus by care providers, need for contact with other parents, fragmentation in support groups, and variation in use of language, the view on health care, openness and gender. I will discuss the implications for health care, educational programs, advocacy, and social change.
- 3. "You ought to be a girl" The biography of Congenital Adrenal Hyperplasia in contemporary France (1950-2010);** Michal RAZ (EHESS, Paris, France)
This paper will present the history of medical knowledge and interventions on intersex individuals in contemporary France after WWII. It will question, through the emblematic example of Congenital Adrenal Hyperplasia, the social construction of the pathologisation of all intersex bodies. The talk will focus on three questions: how did CAH with XX chromosomes became unquestionable girls?; in which ways gender norms play a prominent role in quality-of-life studies and the evaluation of long-term health of CAH adults?; finally, I will discuss parents' positions about their CAH child and the medical path s/he had to undergo. My study follows one of the Guidelines for allies, instead of taking intersex as an object of study. This paper will therefore engage in a more large exchange on ethical and methodological aspects of sociological research on intersex issues.

Paper session 4: Controversies in medical protocol

13:45 – 15:15 Tuesday

Chair TBA

1. **Inside the doctor's office: talking about intersex with Italian health professionals;** Marta Prandelli and Ines Testoni (Università degli Studi di Padova)

The moment of the identification of a variation of sex characteristics is often concomitant or prior to the birth of the individual. Usually, the sociocultural setting doesn't prepare individuals to the possibility of this occurrence, leaving unaware parents unprepared in a critical moment. In the Italian context, there is a lack of knowledge towards the psychosocial aspects and social implications that such diagnoses entail. The present research aims to explore the opinions and representations on the matter of various health professions working for the everyday care of the family in Italy. Brief interviews have been conducted with 24 GPs, 23 general paediatricians and 18 family counselling psychologists around the country, using a dialogic approach. The content analysis focused on six categories related to previous knowledge, professional reactions, interventions, professional roles, gender biases and family role. The results underlined lack of knowledge, cultural biases and difficulties in approaching the matter.

2. **The bio-medicalisation of intersex variations in Italy;** Michela Balocchi (University of Verona)

I'll present a part of the results of a 3 years research project on the sociological aspects of the medicalization of intersex variations. Genetics and biological sciences have widely demonstrated the variety of congenital differences in human sex characteristics. Paradoxically, the more we know about intersex variations, the more the 'Western' medical system tries to counteract and conduct those differences into an apparent conformity with the sex/gender dichotomy. I will focus here on the bio-medicalisation in the Italian context, where the current medical practices and biotechnology are still focused on a wide range of unnecessary, non life-saving, irreversible surgeries. If the aim is to protect human rights of people with intersex traits and the full free development of their capabilities, a paradigm shift is urgent. The research methodology is both qualitative and quantitative, including 60 in-depth narrative interviews with intersex individuals, parents, and key professionals, and quantitative data regarding people with intersex traits hospitalized over the last 20 years in Tuscany.

3. **Intersex Existence and Patient Autonomy;** Valentino Vecchiotti (Intersex human rights activist and campaigner)

With an initial focus on current medical practice in the UK of Dexamethasone use in female foetus's considered to be 'at risk' of virilization in the womb, and the subsequent practice of 'corrective' genital surgery, this paper considers ways in which lack of option to give consent situates the intersex individual as object and not subject in their own health care, which subsequently precludes the possibility of patient autonomy. The argument that social stigma and parental discomfort must be soothed by surgical interventions is debunked by increasing support given to trans and queer children so that they can exist in schools. Through a comparison of current medical practice in the UK for trans children with that of intersex children, this paper argues that rather than seeking to 'restore' intersex children to a hetero-normative/bio-normative model, it is time to support intersex children, and acknowledge their right to exist.

4. **Rethinking Medical Discourse through Intersex Experiences;** Ceren Aydın (Sabancı University)

By bringing together experiences of intersex individuals and dominant medical narratives in contemporary Turkey, this paper raises questions regarding how the human rights of individuals with intersex conditions can be improved. Based on the data collected through in-depth interviews with intersex individuals and with clinicians who take part in their treatment procedures, the paper first provides an analysis of implications of medicalization of intersex both

on discursive and practical levels; it looks at the kinds of the discourses medicalization enables or suppresses and how the dominant medical discourses around intersex intersect with broader cultural and political discourses, especially in relation to body, gender and sexuality, justifying medical practices that violate the rights of patients to informed consent and bodily integrity. Secondly, it expands upon medical experiences of intersex individuals and shows how these experiences can provide insight into the ways in which intersexuality and health can be rethought.

Paper session 5: National experiences

15:30 – 17:00 Tuesday

Chair: Amets Seuss Schwend (Andalusian School of Public Health)

- 1. Social and medical approaches toward intersex people in the Soviet Union;** Aleksander Berezkin (Founder of The Association of Russian Speaking Intersex people)
Attitudes towards intersex people have not always the same in the Soviet Union. First time, Intersex people get an opportunity to express themselves (personal communication with doctors) and their right to self-determination of the gender identity. Based on critical discourse analysis of secondary sources, the author asserts that perception of intersex people in Russia has own unique sociocultural features. These characteristics continue to influence the Russian State bio policy about the intersex people. Moreover, it has consequences for the current intersex activism. For example, there is bio-naturalistic approach regarding intersex people in Soviet and post-Soviet medicine. According to this approach, the priorities for "treating" intersex people are hormone therapy, surgical operations (as the highest act of humanity) and psychosexual adaptation. This bio-naturalistic approach was based on Early Soviet' ideology when there was a discussion about the methods for the construction a new Soviet man.
- 2. The "everyday discrimination" IVSC are facing in Japan and what is behind;** Ulrike Nennstiel (Hokusei Gakuen University)
In Japan, as in many other countries, only very few persons with IVSC speak out in public; most of them rather prefer to remain silent and to (try to) find their individual way of life without being bothered by intruding others. According to the limited data publicly available, many IVSC people have had traumatic experiences in their childhood, being treated like rare animals in the zoo by physicians and medical students when they were in hospitals for medical treatment. Methodologically, I will analyze reports and interview data from persons concerned, and use the theoretical analyses of sociologists, psychologists and philosophers. I will point to the barriers which prevent people from easily accepting differences and from accepting taking others just as the individual persons they are without categorizing into "us" and "them".
- 3. Intersex in Serbia;** Kristian Randelović
There is very little information about intersex people living in Serbia. Large ignorance exists among representatives of institutions, including doctors and health workers, resulting in significant violations of human rights. There are no active intersex communities and services in Serbia where intersex people and parents of intersex children can look for support. There is no official term for intersex in Serbian language, and the English term is used without proper understanding. The Serbian public and media equate intersex with the term "hermaphrodite" thereby strengthening the social stigma relating to being intersex. For a long time intersex people in Serbia are living in isolation and circles of silence. Silence is promoted by medical professionals to parents, from parents to child, between intersex people and from intersex person with no medical intervention/s (often that can be genital surgery) to intersex person to another intersex person with experience of medical intervention.
- 4. Position of Intersex People in Pakistan: Socio-Cultural, Religious and Legal Perspectives;** Muhammad Ali Awan (Goethe University Frankfurt am Main, Germany)
This presentation reveals the politics of manipulation and negotiation among various social actors - hijra community and State. They have been suppressing socio-cultural representation of intersex people in Pakistani Society. This research study based on constructivist grounded theory and data gathered through biographic and in-depth interviews. The mainstream society idealizes a hijra -intersex- body with ambiguous genitals, sexual impotency and spiritual status. However, other hijra identities manipulate this image of intersex people through a performance of intersex

identity. The same strategy of manipulation is performed by the State party. It reflects by the categorization of intersex people in three different identities. This categorization serves the purpose of United Nation Human Right treaties and response to the social activism of the transgender community. Hence, the State of Pakistan presents the traditional concept of intersex people as modern day transgender people. As to suppress distinct identity of intersex people and create social vulnerability for them.

Paper session 6: Controversies in medical protocol 2: Surgery
15:30 – 17:00 Tuesday

Chair Katinka Schweizer (Institute for Sex Research University clinic Hamburg-Eppendorf)

1. **Cuts into children's future: a comparative analysis between female genital mutilation, male circumcision and intersex treatments;** Ino Kehrer (University of Padova, Human Rights Centre) and Els Leye (International Centre for Reproductive Health, Ghent University, Belgium)
It is possible to find, in many countries, forms of genital alteration practices that vary in extent, circumstances and legal approach. Starting from the analysis of the short- and long-term consequences and the harm produced with the removal of healthy tissue from sexual organs, the intent is to consider whether there are any analogies between the male circumcision perceived as a private, religiously acceptable practice; the female genital mutilation declared as a culturally unacceptable practice that must be brought under public discussion; and the intersex surgical treatment understood as a private, medically acceptable practice. With this contribution, the aim is to problematize the non-necessary genitalia-altering practices on infants and examine their implications within the child's rights framework, taking into account the child's best interest, the child's right to develop freely their identity and the 'do no harm' principle.
2. **A principled ethical approach to intersex paediatric surgeries in South Africa;** KG Behrens (University of the Witwatersrand)
South Africa has one of the highest incidences of intersex births globally. In certain communities, such infants are sometimes killed at birth by nurses or midwives. Beliefs that being born intersex is a curse, or a sign of punishment, combine with an intolerance of difference to render intersex children exceptionally vulnerable to social stigma, rejection and even physical violence. In this paper I develop and defend five fundamental principles to guide medical teams and parents to make ethically justified decisions about possible surgery for intersex children in the South African context. Many South African intersex infants are subjected to surgery. I develop five principles for making ethically justified decisions about such surgeries in the South African context.
3. **Intersex surgeries: Framing bias & parental decision-making;** Eva De Clercq (University of Basel) and Jürg Streuli (University of Zurich)
The aim of the present study was to gain insight in how early treatment choices regarding DSD/intersexuality are framed and to evaluate how this framing bias might affect parents' decision-making process. The presented data come from 25 semi-structured interviews with healthcare professionals and parents in Switzerland and Germany. The interviews were analyzed using interpretative phenomenological analysis to identify relevant themes regarding choice and decision-making. Framing treatment decisions as choices of medical necessity and parental responsibility was a way to deal with the medical, social, personal and psychological uncertainties involved in DSD. Increasing emphasis needs to be placed on care and holistic support for parents and children with DSD throughout the life-cycle. The availability and accessibility of these services might be more important for the future well-being of the child than the decision to operate or not.

4. **Controversies in intersex care: Surgery to the external genitalia;** Ute Lampalzer and Katinka Schweizer (Institute for Sex Research and Forensic Psychiatry, University Clinic Hamburg-Eppendorf)

A paradigm shift in intersex care has been described in different countries within the past 15 years. Nonetheless, there are still a variety of controversies around intersex care, e.g. around surgery of the external genitalia that are not medically necessary. The aim of the study which is part of the project “intersex-kontrovers” within the Hamburg Open Online University (HOOU) is to outline key points of the controversy around surgery of the external genitalia and to point out various perspectives included in intersex care. Eight structured interviews with persons concerned, parents of children with an intersex/dsd condition, medical doctors and psychologists were carried out and analyzed according to the principles of Mayring’s (1990) qualitative content analysis. The findings show how questions of medical indications, timing, normality, stigmatization, and risks are seen differently. Knowing about these differences can help to improve communication between the groups of persons involved in intersex care.