# Table of contents

Welcome and Introduction 2  
Conference Code of Conduct 5  
Program Schedule Overview 6  

**Detailed Program schedule**  
Day 1 - Monday Feb 20\textsuperscript{th} 8  
Day 2 - Tuesday Feb 21\textsuperscript{st} 9  
Day 3 - Wednesday Feb 22\textsuperscript{nd} 11  
Day 4 - Thursday Feb 23\textsuperscript{rd} 12  

Keynotes and Activist/Ally Panels 13  

Paper Panel Details 21  

Paper Panel Abstracts 24  

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Centring Intersex Issues: Global and Local Dimensions
Welcome and Introduction

Intersex people have contributed to remarkable changes over the past 30 years, from near silence on the topic of intersex to the current era of intersex activism, advocacy and scholarship. This increase in visibility and recognition of intersex issues globally makes the current conference possible. While we look forward to discussing and celebrating the work of the many intersex people who are part of this conference, we also acknowledge the significant challenges faced by intersex people globally. These ongoing challenges provide the impetus for much of the research, activism and advocacy that are a focus of this conference.

Intersex people face social erasure and discrimination at every stage of their lives, from birth to old age. Babies who are born with noticeable intersex characteristics are usually operated on or subjected to other non-consensual medical treatments in infancy, early childhood or adolescence. There has been limited State implementation of the Council of Europe Resolutions and the United Nation recommendations to stop these harmful non-consensual and unnecessary medical interventions on minors. Other key issues for intersex people and their families include a lack of inclusion in anti-discrimination legislation; bullying and erasure in schools (for example an absence of representation in school curricula); and high levels of direct discrimination and harassment in public places. Greater knowledge is needed as to why there has been such a lack of implementation of international human rights directives. Moreover, there is a real need to better understand intersex people’s needs regarding appropriate healthcare and related policy and practice reform. This conference will provide a forum for knowledge generation and networking in these areas.

Intersex people are sometimes also trans. When an intersex baby is assigned to a gender they then cannot identify with, they may decide later to live in a different gender. While many intersex people identify as male or female, some identify as non-binary. Key issues may be shared, such as the importance of bodily autonomy and legal rights, but the ways these apply to intersex people and non-intersex trans people vary. The conference will facilitate alliance-building and the recognition of diversities amongst intersex people and others.

Whilst a considerable amount of research has taken place about intersex issues, much of this is located in the global north. The conference will take an international approach, foregrounding voices from the global south as well as the north. It will bring in dimensions associated with postcoloniality, both in interrogating the historical construction of intersex and its medicalisation in the global north, and in addressing issues concerning intersex and variations of sex characteristics in the global south. In this way, it aims to shift the field of intersex studies forwards, whilst also complementing
existing activist and scholarly networks that are international and/or based in the global south.

**The conference aims:**

The proposed conference will facilitate the ongoing development of an international network of scholars, students, and stakeholders with an interest in supporting intersex people’s equality, wellbeing, and social and economic success. It will generate original knowledge across a range of fields and academic disciplines. The conference will also generate improved policy advice for key stakeholders especially those in policy and practice positions across sectors such as healthcare, education, and social work. The action will also facilitate greater data collection by bringing scholars and other stakeholders together and showcasing research, both quantitative and qualitative.

Overall, the conference will create an innovative international space for networking and scholarly activities. The conference is funded by the University of Huddersfield and the COST Action LGBTI+ Social and Economic (in)equalities CA19103 and it is sponsored by the journal Social Sciences. Outputs from the conference will include a Special Edition of the international journal *Social Sciences*. The conference also received support from the INIA, Intersex – New Interdisciplinary Approaches’ Innovative Training Network (European Commission’s Marie Skłodowska-Curie Actions program grant number 859869).

The programme is organized so that you can quickly see what is on early in the Programme - but if you want to find a particular paper in a panel its easiest to look it up in the paper panel details section towards the end of the programme.

**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.** We really look forward to working with you during the conference, and hopefully into the future, to foster new knowledge and effective interventions to support the wellbeing and human rights of intersex people. We encourage you to network widely, get support, share ideas, respectfully challenge each other, and consider ways in which the knowledge generated here can be used for positive social change for intersex people, their families, their allies and wider society.

**On behalf of the conference team, I welcome you to the conference.**

Professor Surya Monro (University of Huddersfield, UK).

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1 The views expressed in this conference reflects only the views of each author and, in relation to the INIA project, the funder is not responsible for any use that may be made of the information they contain.
Conference Organizers

Adeline Berry (University of Huddersfield)
Mauro Cabral Grinspan (Global Philanthropy Project)
Morgan Carpenter (Intersex Human Rights Australia)
Daniela Crocetti (Independent scholar)
Rebecca Crowther (Scottish Equality Network)
Limor Danon (Bar-Ilan University)
Fae Garland (University of Manchester)
David Griffiths (University of Surrey)
Morgan Holmes (Wilfrid Laurier University)
Tanya Ni Mhuirthile (Dublin City University)
Surya Monro (University of Huddersfield)
Vasu Reddy (University of Pretoria)
Loé Petit (Université Paris VIII-Saint Denis)
Katrina Roen (University of Waikato)
Amets Suess Schwend (Andalusian School of Public Health)
Prashant Singh (Intersex Asia)
Mitch Travis (University of Leeds)

Contact information
centeringintersexconference@hud.ac.uk
Conference Code of Conduct

This conference is a safe space for people with intersex variations and those with a supportive interest in intersex issues to share their research, advocacy work, and experience. In order to maintain a safe and welcoming environment for all attendees, please adhere to the following code of conduct.

For all attendees:
1. Be inclusive – support people of all backgrounds, abilities, neuro-divergences, bodies, genders, sexualities and identities;
2. Be respectful to all attendees and speakers. Aggression will not be tolerated;
3. If you are a member of the media/press, please identify yourself to all attendees by wearing the provided lanyards;
4. Avoid using stigmatising and pathologising language and visual imagery;
5. Be respectful of individuals’ self-defined gender identities and pronouns;
6. All events will be chaired. Speakers will be given time to receive questions after the delivery of their paper, please wait for the chair to invite questions – do not interrupt papers in the chat.

For speakers:
1. Please keep your pre-recorded paper within the time allocated and respect the chair of the panel when any guidance is given regarding time;
2. Please be respectful, stay on topic and do not address interpersonal, academic, inter-activist, or any other disputes in your paper;
3. Please be aware that visual imagery may be upsetting to some attendees and seek consent before showing images of people;
4. Please send the pre-recorded presentation to the conference organiser to be reviewed in advance of the conference. Add documentation of consent for your video-recording and consent you have received for showing images of people. Screenshots of emailed consent will be acceptable so long as the names and details are clear in the email.

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

Day 1 Monday Feb 20th

Welcome and Intro
Mauro Cabral Grinspan Keynote: *Justicia Intersex en tiempos anti-género*, Intersex
Justice in Anti-Gender Times (En español with ENG subtitles)
Panel 1: Legal Progress for Intersex People
Online lunch and chat (UK/EU/Africa time zone)
Panel 2: Discursive and Methodological Issues in Research on Intersex Issues
Panel 3: Education and Awareness of Intersex
Panel 4: From Childhood Treatments to the Ageing Experiences of Intersex People
Activist Networking

Day 2 Tuesday Feb 21st

Panel 5: Lived Experiences, Somatic Experiences
Aotearoa New Zealand and Australia Advocacy/Activist Panel
Panel 6: The Struggle to Improve the Health and the Wellbeing of Intersex People
Panel 7: Challenging Medical Practices and Research Biases Towards Intersex Individuals
Online lunch and chat (UK/EU/Africa time zone)
Panel 8: Problematising Medical Interventions
Sharon Preves Keynote: *30 Years of Intersex Activism in the U.S. and Canada*
Intersex - New Interdisciplinary Approaches Panel

Day 3 Wednesday Feb 22nd

Panel 9: Between Preserving and Changing the Medical Practices
Online chat (NZ/AU/Asia time zone)
Activist Networking
Medical Allies Panel
Online lunch and chat (UK/EU/Africa time zone)
Panel 10: Different Theoretical Views for Intersexuality
Panel 11: Intersex Representations
Brújula Intersexual Panel: *A Decade of Activism in México* (En español and English with subtitles; Discusión bilingüe ES/EN)
Fae Garland and Mitch Travis Book Launch: *Intersex Embodiment: Legal Frameworks Beyond Identity and Disorder*

Hiker Chiu Keynote: *Buddhism and Intersex Social Discrimination in Asia*

**Day 4 Thursday Feb 23rd**

**Panel 12:** Between Human Rights, Identity and Self-Determination

Online chat (NZ/AU/Asia time zone)

Final Reflections and Future Projects
Day 1 - Monday Feb 20th
Including Tuesday Feb 21st (NZ time)

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**Day 2 - Tuesday Feb 21st**

Including Wednesday Feb 22nd (NZ time)

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Day 3 - Wednesday Feb 22\textsuperscript{nd}
Including Thursday Feb 23rd (NZ time)

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*Buddhism and Intersex Social Discrimination in Asia*  

8.00pm  Feb 23rd  
Panel 12:  
*Between Human Rights, Identity and Self-Determination*  

3.00am  Feb 23rd  
Online Chat (NZ time)  

11.00am  Feb 23rd  
Final Reflections and Future Projects  
Chair: Kamran Qureshi  

**Day 4 - Thursday Feb 23rd**

*Zoom Link*
Keynotes and Activist/Ally Panels

Welcome and Intro
9.30am–10.15am (UK time) Feb 20th
10.30pm–11.15pm (NZ time) Feb 20th

We will welcome you to the Conference with a series of short speeches. Professor Nick Hardiker, from the University of Huddersfield, will open the conference on behalf of the University of Huddersfield. Evgenia Giakoumopoulou will then provide timely insights into the key issues from a Council of Europe perspective. Professor Surya Monro will then provide an introduction to the Conference on behalf of the team of conference organisers, addressing some of the key intellectual and political issues and providing an overview of the conference programme.

Speaker biographies:
Evgenia Giakoumopoulou is the Head of the Sexual Orientation and Gender Identity (SOGI) Unit of the Council of Europe. She has been working with European Institutions and INGOs for over 10 years, focusing on sexual orientation, gender identity, gender expression and sex characteristics, as well as on anti-trafficking, migration and asylum, and torture prevention. Convinced of the need to bridge the gap between grassroots movements and international organisations, Evgenia has actively engaged with the LGBTIQ+ and feminist movements in France, Greece and at the pan-European level.

Professor Nick Hardiker is the Dean of the School of Human and Health Sciences at the University of Huddersfield, UK. He has nearly 30 years of experience of research in nursing and health informatics, with a particular interest in structured terminologies.

Surya Monro is a Professor in Sociology and Social Policy based at the University of Huddersfield, UK. Surya has published substantially in the fields of gender and sexuality, notably on LGBT and Intersex issues. She leads the Intersex: New Interdisciplinary Approaches project (INIA) in collaboration with intersex activists and academics.
Mauro Cabral Grinspan Keynote:
Justicia Intersex en tiempos anti-género
Intersex Justice in Anti-Gender (En español with ENG subtitles)

10.15am – 11.15am Feb 20th (UK time)
11.15pm – 12.15am Feb 21st (NZ time)
Chair: Mitchell Travis
Monitor: Fae Garland

Abstract:
Around the world, the rise of so-called “anti-gender movements” is imposing extremely challenging social, political and institutional conditions, and intersex communities are particularly exposed to those challenges. While “anti-gender movements” can be internally differentiated as, for example, “conservative/traditional” and “critical/radical”, those movements share a common affirmation of sex as a natural, binary and self-evident truth. In that context, variations of sex characteristics are constantly reproduced as inexistent, insignificant or pathological. Moreover, by reasserting medical authority over all sexed bodies, “anti-gender movements” work against intersex depathologisation, self-determination and justice.

Paradoxically, many endosex progressive responses to “anti-gender movements” (such as those coming from feminist, queer and/or LGTB voices) are imposing their own -and related- challenges. By recurring once and again to variations of sex characteristics are privileged examples of sex diversity, multiplicity and fluidity, those responses are reenacting the instrumentalization of intersex bodies, experiences and lives. Furthermore, those same responses are implicitly accepting sex as a given and, therefore, rendering invisible the elaborated institutional mechanisms involved in producing it.

Through this presentation, it will be argued that intersex engagement with both “anti-gender movements” and progressive endosex responses must be grounded on a deeply intersectional and human rights-based perspective on bodily integrity, decisional autonomy, reparations and truth.

Speaker biography:
Mauro Cabral Grinspan is an intersex and trans researcher, activist and writer. He serves as Senior Officer for Gender Justice and Equity at the Global Philanthropy Project; before that, he co-founded GATE in 2009, serving as its Executive Director between 2017-2022. He participated in the elaboration of the Yogyakarta Principles (2007) and of the Yogyakarta Principles Plus Ten (2017) and co-authored the Argentinian Bill on the
Mauro edited the book *Interdicciones. Escrituras de la Intersexualidad en Castellano* and has written extensively on intersex issues. He lives in Belgium.

**Aotearoa New Zealand and Australia Advocacy/Activist Panel**

3.00am – 4.30am Feb 21st (UK time)
4.00pm – 5.30pm Feb 21st (NZ time)

Chair: Aileen Kennedy
Monitor: Gabe Filpi / Olympia Balapitos

**Abstract:**

Intersex advocates/activists speak about their leading work in Aotearoa New Zealand, Australia and with intersex youth internationally. This dynamic discussion addresses the importance of psychosocial support, the personal cost of telling personal stories, and the role of community organisations in providing services as well as doing advocacy. The panel address questions about how they remain authentic in their experiences while holding specific expertise, and questions about supporting new activists.

**With:**

Morgan Carpenter (Intersex Human Rights Australia; University of Sydney), Georgia Andrews (YOUth&I), Bonnie Hart (Intersex Peer Support Australia), Aileen Kennedy (University of New England, AU), Stephanie Lum (YOUth&I), Jelly O'Shea (Intersex Aotearoa), and Cody Smith (Intersex Human Rights Australia).

**Sharon Preves Keynote:**

**30 Years of Intersex Activism in the U.S. and Canada**

4.00pm – 5.00pm Feb 21st (UK time)
5.00am – 6.00am Feb 22nd (NZ time)

Chair: Mitchell Travis
Monitor: David Griffiths

**Abstract:**

In the 1990s, Sharon became the first sociologist and the second social scientist to study the quality of life of intersex adults. Between 1997-1998, she interviewed 41 adults born with intersex variations. The people she interviewed then were members of the first generation of intersex activists and support group members. She published findings from this study in her book *Intersex and Identity: The Contested Self* (2003). Her current research is an historical comparative study of approximately twenty of the people that
she first interviewed in the late 1990s and twenty younger, second and third generation intersex activists and support group members. The motivation for this research is threefold: to address the lack of longitudinal research on intersex adults, the lack of research on intersex and aging, and to compare the experiences of different generations of intersex activists and support group members.

Research on gender and sexual minorities reveals stark disparities in health care experiences, which are only magnified as people age. What impact has medicalization had on intersex adults as they age and how has past medical trauma affected their ongoing relationship with healthcare and their overall physical and mental health? Moreover, how do the experiences of older intersex adults compare with those of young adults who have come of age in a social context that is far more accepting of sex, gender, and sexual diversity?

This presentation focuses on methodological highlights and preliminary findings of a research project that is 25 years in the making.

**Speaker Biography:**

Sharon Preves, PhD, is a Professor of Sociology in the Department of Social Justice and Social Change and an affiliate faculty member in Public Health at Hamline University in St. Paul, Minnesota (USA). Preves’ research on intersex has been published in her book *Intersex and Identity: The Contested Self* (Rutgers University Press, 2003), which she is currently updating and expanding for a 2nd edition. Her work has also been published in a number of journals and anthologies, including the Journal of Clinical Ethics, Intersex in the Age of Ethics, Current Sociology, Signs, Research in Political Sociology, The Kaleidoscope of Gender: Prisms, Patterns, and Possibilities, and Contexts. She is a member of the medical advisory group at interACT Advocates for Intersex Youth and historically served on the medical advisory board of the Intersex Society of North America (ISNA). Preves’ is an intersex ally and family member. She lives with her spouse, two cats, and a lone Italian greyhound in the Twin Cities metropolitan area of Minneapolis and St. Paul, Minnesota.

**Anglophone American, European and African activist panel and networking**

6.00pm – 7.30pm Feb 21st (UK time)
7.00am – 8.30am Feb 22nd (NZ time)

Chair: Addy Berry
Monitor: Surya Monro
This panel presents an unmissable opportunity to hear leading activists in the intersex rights movement across the US, the UK, Europe and Africa discuss issues pertinent to their respective countries as well as shared issues and activism goals.

**Speaker Biographies:**

Obioma Chukwuike is a human rights activist and the founder and executive director of Intersex Nigeria.

Paul Dutton is an activist and a Klinefelter Syndrome Association UK trustee.

Irene Kuzemko is an activist from Russia and Ukraine and is currently the community development officer for OII Europe.

Sean Saifa Wall is an intersex and transgender activist, co-founder of Intersex Justice Project and an INIA research fellow at the University of Huddersfield.

**Intersex - New Interdisciplinary Approaches (INIA) Panel**

8.00pm – 9.00pm Feb 21st (UK time)

9.00am – 10.00am Feb 22nd (NZ time)

Chair: Fae Garland
Monitor: Mitch Travis

**Abstract:**

This session will provide an introduction and update on INIA, which is a large training and research programme funded by the European Commission. Running from 2020-2024, this ambitious programme focuses on doing research to support the wellbeing and human rights of intersex people, via ten individual research projects. It also aims to train researchers in this field and to support the development of networks (both academic and stakeholder) that will continue beyond the end of the project. In this panel a number of our INIA members will present key aspects of the programme and will be there to answer questions and take part in discussion.

**With:**

Daria Abrosimova, Audrey Aegerter, Addy Berry, Martin Gramc, Yessica Mestre, Surya Monro, and Amets Suess Schwend.

**Fae Garland and Mitch Travis Book Launch: Intersex Embodiment: Legal Frameworks Beyond Identity and Disorder**

8.00pm – 9.00pm Feb 22nd (UK time)

9.00am – 10.00am Feb 23rd (NZ time)

Chair: Sharon Preves
Monitor: Tanya Ni Mhuirthile
This event will celebrate the launch of the new book Intersex Embodiment: Legal Frameworks Beyond Identity and Disorder by Fae Garland and Mitchell Travis. The book is being published by Bristol University Press. You can order it here: https://bristoluniversitypress.co.uk/intersex-embodiment

Intersex Embodiment examines the divergent medical, political and legal constructions of intersex. The authors use empirical data to explore how intersex people are embodied through these frameworks which in turn influence their lived experiences. Through their analysis, the authors reveal the factors that motivate and influence the way in which policy makers and legislators approach the area of intersex rights. They reflect on the limitations of law as the primary vehicle in challenging healthcare’s framing of intersex as a ‘disorder’ in need of fixing. Finally, they offer a more holistic account of intersex justice which is underpinned by psychosocial support and bodily integrity.

Speaker biographies:

Fae Garland is the Co-Director for the Manchester Centre of Regulation, Governance and Public Law. She is the co-author of Intersex Embodiment: Legal Frameworks Beyond Identity and Disorder (2022, Bristol University Press). Her research examines the impact of legal regulation on the lived experience of intersex people. She has co-authored national and international governmental reports that explore intersex rights and law and has also led several empirical projects in this area. Most recently, she has been awarded funding by the British Academy (with Dr Travis) to examine the operation of Maltese legislation which prohibits deferrable surgeries on minors with variations in sex characteristics.

Mitchell Travis is the Director of the Centre for Law and Social Justice at the University of Leeds. He is the co-author of Intersex Embodiment: Legal Frameworks Beyond Identity and Disorder (2022, Bristol University Press), The co-editor of A Jurisprudence of the Body (2020, Palgrave) and has co-edited special issues of Law, Technology and Humans (2022) and Culture, Health and Sexuality (2021). Mitchell has also published widely in such journals as Legal Studies, Law and Society and Social and Legal Studies.

Medical Allies Panel

11.00am – 12.00am Feb 22nd (UK time)
12.00am – 1.00am Feb 23rd (NZ time)
Chair: Surya Monro
Monitor: Fae Garland
Abstract:
This session provides an important opportunity to hear from medical allies about key issues concerning medical reform, including promising practices and challenges. The allies that are speaking in this session have worked with different intersex activist organisations and a range of other stakeholders.

With:
Dr Marina Elichiry (Instituto de Oncología Angel Roffo, Buenos Aires, Argentina and Hospital Lucio Melendez, Adrogué, Argentina) (En español with ENG subtitles)
Frances Grimstad (Boston Children’s Hospital, Boston, USA)

Brújula Intersexual Panel: A decade of activism in México (En español and English with subtitles; Discusión bilingüe ES/EN)
6.00pm – 7.45pm Feb 22nd (UK time)
7.00am – 8.45am Feb 23rd (NZ time)
Chair: Yessica Mestre
Monitor: Amets Suess Schwend

Abstract:
Brújula Intersexual is a Mexican organization that works with people, activists and intersex communities in our country, in Latin America and Spain. We work to defend human rights and improve the lives of intersex people. We generate informative materials, provide support, and work with government institutions in Mexico to generate public policies. In this panel we will present the work of Brújula Intersexual from 2013 to the present.

With:
Laura Inter, Brújula Intersexual: creating a place in the world
Frida Flores Ruiz (Free IS), Intersexuality from Mexico’s multicultural perspective
Eva Alcántara, Seeking answers to questions: The Guide to CAH
Dr. Carlos Narváez Pichardo, Experiences on medical attention to persons born with intersex bodies with a practice of Person-Centered Medicine

Hiker Chiu Keynote:
Buddhism and Intersex Social Discrimination in Asia
9.00pm – 10.00pm Feb 22nd (UK time)
10.00am – 11.00am Feb 23rd (NZ time)
Chair: Surya Monro
Monitor: Addy Berry
Abstract:
Social discrimination is still the main issue intersex people face in many Asian countries. It impacts hugely to intersex people’s daily life and mental health. One of the main ideas that intersex people are stigmatized in Asia is related to Buddhism discipline and the Karma principle. Motivated by helping intersex people escape this discriminative environment, I tried to understand straight forward and look for a solution. My talk is based on exploring this issue from an intersex activist’s perspective, not duly academic research. Even though there are only around 10% of Buddhists in Asia. However, Buddhism has been pervasive and influenced Asian culture broadly. Removing stigmatized labels and social discrimination are the main challenges in the intersex movement in Asia. Hopefully, my discovery and sharing can inspire people to reframe the old perspective and liberate intersex people from the karma of being discriminated against.

Speaker Biography:
Hiker Chiu is a pioneer of the intersex human rights movement in the Asian region from Taiwan who founded OII-Chinese, the first human rights advocacy organization and information platform for Chinese-speaking intersex people since 2008. Hiker Chiu was the first intersex person to come out in Taiwan publicly, initiating the “Global Free Hugs with Intersex Movement” in 2010. Since 2013, Hiker has devoted themself to building intersex connections in Asia and founded the Intersex Asia community on Facebook, which was the foundation of Intersex Asia. Hiker was also the first intersex person elected as co-chair of ILGA Asia in 2015. In 2018, the intersex community selected Hiker to be the first Co-chair of Intersex Asia – the first and only regional network of intersex organizations in Asia. Currently, Hiker serves as the Chair and Executive Director for Intersex Asia.

Activist Networking Open Sessions
8.00pm – 9.00pm Feb 20th (UK time)
9.00am – 10.00am Feb 21st (NZ time)
and
8.00am – 9.00am Feb 22nd (UK time)
9.00pm – 10.00pm Feb 22nd (NZ time)

These sessions provide opportunities for activists and advocates to share information, news and resources.
## Paper Panel Details

<table>
<thead>
<tr>
<th>Panel Number</th>
<th>Papers</th>
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| Panel 1:     | Legal Progress for Intersex People  
               | *M v France: Towards Binding Human Rights Law*  
               | *The legal ban of intersex genital mutilations (IGM) in Greece: lessons learned and future challenges*  
               | *Intersex Human Rights and their Lived Experience in Malta* |
| Panel 2:     | Discursive and Methodological Issues in Research on Intersex Issues  
               | *Nature, Progress, and Self-Determination: Intersex in Discursive Crossroads of Racialised Sex/Gender Politics*  
               | *Amets Suess Schwend, Intersex epistemologies? Reviewing relevant perspectives in intersex studies*  
               | *Yessica Mestre, The Value of Ethical Research for the Intersex Community* |
| Panel 3:     | Education and awareness of intersexuality  
               | *Education of Intersex Children and Adolescents* (Em portugues with ENG subtitles)  
               | *Educação e sexualidade: Citizenship, sexuality and education* (Em portugues with ENG subtitles)  
               | *Intersex Situation in the Democratic republic of Congo: Taboo or Natural Sexual Variation?* |
| Panel 4:     | From childhood treatments to the ageing experiences of intersex people  
               | Revisiting the Claim of Past Medical Innocence and «Good Intentions»: What a close analysis of Lawson Wilkins’s and the Psychohormonal Research Unit’s early literature reveals on incentives and awareness of objections  
               | *Daniela Crocetti, Adeline Berry and Surya Monro, From Emergencies to a Sense of Abandonment* |
| Panel 5:     | Lived experiences, somatic experiences  
               | *Intersex Lived Experience: Trauma and Posttraumatic Growth in Narratives* |
Childhood-Tamarikitanga Genital (re)assignment Surgery: Respecting a Child’s Right to Embodied Integrity.

Hermstones - A Prosthetic Device of Identity.

Panel 6:
The struggle to improve the health and the wellbeing of intersex people

Obioma Chukwuike, Covid-19: The Situation of Intersex People in Africa

Banning Non-therapeutic, Non-consensual Interventions: The Icelandic Example

Navigating gender, health and labels among Czech individuals with variations of sex characteristics

Panel 7:
Challenging Medical Practices and Research Biases Towards Intersex Individuals

Markus Bauer, Daniela Truffer, Bias in intersex research and the lack of implementation of intersex human rights. Analysis and proposals to ensure good practices

Bodily norms and children’s rights; intersex children have a right to genital integrity, too

An analysis on Scotland’s policy regarding non-therapeutic surgeries on Intersex children

Panel 8:
Problematising Medical Interventions

Saskia Ravesloot, The Universal Periodic Review and the ban on Intersex Genital Mutilation: Is recommending free, prior and informed consent the way forward?

Martin Fafejta, “Disorder of sex development” – medical approach

Limor Meoded Danon, To Imagine and Prevent Future Intersex Bodies

Panel 9:
Between preserving and changing the medical practices

Debilitating to capacitate: Discourses of innate sex characteristics in Hong Kong hospitals
Human rights-based intersex healthcare: Using hospital data to quantify genital and reproductive surgery on children in Aotearoa New Zealand

Creating Connection for Care: Communication and collaboration using a rights-based framework

Morgan Carpenter, Protecting the rights of people with innate VSC in medical settings: progress in Australia

Panel 10:

Different theoretical views for intersexuality

Surya Monro and Daniela Crocetti, Towards a materialist analysis of DSD and Intersex healthcare

What can new materialism offer research with intersex variant people?

Mechanical sex, science, and security: Intersex medical violence and securitisation theory’s underpinnings

Panel 11:

Intersex Representations

Uprisings of an intersex body: self-portraiture and photographic traditions

Kamran Qureshi, American Intersex Television Characters

Stephanie Budwey, Religion and Intersex: Moving Toward a Theology of ‘Both/Neither’

Panel 12:

Between Human Rights, Identity and Self-Determination

Self-determination, Identity and Intersex inclusion: what is the answer?

Developing law reform for individuals with variations in sex characteristics in the Australian Capital Territory

Informed Consent and the Human Rights of Intersex Children in Aotearoa New Zealand

Morgan Carpenter, Constructions of intersex and DSD in Australian data
Religion and Intersex: Moving Toward a Theology of ‘Both/Neither’

Stephanie Budwey

1Vanderbilt University Divinity School, Nashville, USA

Abstract

While much has been written about the erasure of intersex people in the areas of science, law, and culture, there has not been much attention paid to the theological and liturgical erasure of intersex people. As an endosex ally, I conducted interviews with six German intersex Christians to learn about their religious experiences for my book Religion and Intersex: Perspectives from Science, Law, Culture, and Theology. To conform with ethical guidelines, each interview partner signed a consent form and was asked if they wished to remain anonymous. As most did, all interview quotations in the book are anonymous and no pseudonyms are used.

Due to theologies based in sexual dimorphism, intersex people have been wrongly told they are sinful, flawed, not human, and not made in God’s image. Drawing from the work of authors such as Susannah Cornwall, Leah DeVun, Sally Gross, and Laurel Schneider, I argue for a move toward sexual polymorphism and what I name a theology of ‘both/neither.’ This theology (1) recognizes that intersex people exist; (2) teaches that intersex people are made in God’s image due to a sexually polymorphic reading of Genesis 1:27; and (3) celebrates difference, the truth and reality of the diversity of God’s creation, and the multiplicity of human embodiment. Additionally, my interview partners shared stories of how they were made to feel unwelcome, invisible, and excluded in worship, and so I discuss the need to employ a theology of ‘both/neither’ in worship.

Constructions of intersex and DSD in Australian data

Morgan Carpenter

1Intersex Human Rights Australia, Altona, Australia. The University of Sydney, Sydney, Australia
Abstract

As yet, there is no coherent understanding of intersex people in Australian law, policy and data, but different understandings are each represented in data.

A dominant clinical model regards people with intersex variations as female or male with ‘disorders of sex development’ (DSD) that need to be ‘fixed’ to ensure familial and social integration. Data frameworks associated with this model include disease and procedure classifications. Diagnoses are enumerated in the International Classification of Diseases.

A dominant socio-legal model regards people with intersex variations as ‘sex diverse’, ‘indeterminate sex’, neither female nor male, and needing to be represented through legal frameworks and data models recognising a third sex. Further, public policies and statements frequently imply that actions on grounds of sexual orientation or gender identity address matters of concern to people with intersex variations. Data frameworks associated with this model include categories of sex and gender.

This paper, based on a paper invited by the Australian Institute of Health and Welfare, finds that neither the clinical model nor the socio-legal model respect the diversity of the population nor human rights to health and bodily integrity. Both models primarily reflect the dominance of non-intersex interests, with little account taken of community perspectives. The needs and circumstances of people with intersex variations are frequently misrepresented and poorly reflected in available data, with implications for policy development and implementation.

Protecting the rights of people with innate variations of sex characteristics in medical settings: Progress in Australia

Morgan Carpenter1,2

1Intersex Human Rights Australia, Altona, Australia
2The University of Sydney, Sydney, Australia

Abstract

Evidence shows that, in Australia, people with intersex variations undergo or risk medical interventions, including surgeries and hormonal interventions to “normalise” sex characteristics, from time of diagnosis. In 2021 the Australian Human Rights Commission reported on an inquiry finding significant human rights and ethical concerns
with current and historical medical practices. The report recommended legislative protections to ensure that medical treatment conforms to human rights norms, accompanied by independent oversight; resourcing for peer and family support; development of resources by community organisations; development of national guidelines and access to multidisciplinary care; and improved research practices. These recommendations substantively coincide with community demands expressed in a 2017 ‘Darlington Statement’. The Australian Medical Association and Public Health Association of Australia have also supported calls for recognition of the right of the affected population to bodily integrity. The Australian Capital Territory government has become the first to publish draft legislation to give effect to this demand.

This presentation will outline available evidence on current medical practices in Australia, the human rights and legislative response, and progress towards enactment of legal protections.

The author was a member of the Australian Human Rights Commission’s expert reference group and has been contracted to the Australian Capital Territory government.

Covid-19: The Situation of Intersex People in Africa

Obioma Chukwuike

Intersex Nigeria, Lagos, Nigeria

Abstract

The unprecedented crisis of the COVID-19 pandemic is creating havoc in human lives. It has created unimaginable changes of tremendous scale on personal and public levels. An exploratory study on the situation of intersex people in Africa was examined, questionnaire consisting of a set of 46 questions, covering the impact of Covid-19 in the following areas of life; physical, mental health and wellbeing; access to healthcare related to a possible Covid-19 infection; access to support (peer and financial support, another kind of support); personal safety (at home during lockdowns, when seeking access to health services); Intersex activism and more where covered in the question structure. Dissemination of questionnaire was done with intersex organizations and networks (social media and in-person) of intersex individuals and their families (snowball sampling). 29 African intersex people, including 2 family members of intersex people responding on behalf of those intersex persons from 9 countries in Africa: West Africa (15 intersex respondents): Nigeria, Ghana, Burkina Faso, and Liberia. Southern
Africa (11 intersex respondents and 2 family members responding on behalf of intersex persons): Zambia, Zimbabwe, Malawi and Botswana. East Africa (1 intersex respondent): Kenya. The quantitative and qualitative data together strongly point towards intersex people being a highly vulnerable part of the population in the context of the Covid-19 pandemic. One of the most critical findings in this respect is the highly increased risk of intersex people not being able to access financial support with a history of discrimination at workplaces and an inability to gain employment.

**From Emergencies to a Sense of Abandonment**

Daniela Crocetti¹, Adeline Berry², Surya Monro²

¹Independent researcher, Bologna, Italy
²University of Huddersfield, Huddersfield, United Kingdom

**Abstract**

Medical treatment for individuals with Variations of Sex Characteristics (VSC) has been recognized as a disputed ethical terrain since the first public protests in the US in the 1990s. Irreversible bodily modification on subjects that cannot give direct consent, such as genital surgery in childhood, has been the first line point of critique across the evolving forms of public activisms. The struggle over childhood medical treatment clearly implies the future adult, yet adult care has been either absent or in the background of medical and social science literature. Studies in nursing identify transition from pediatric to adult care as a delicate to difficult process in chronic disease in general. Variations of Sex Characteristics are not chronic diseases because they are not in themselves diseases, but they are congenital (one is born with them) and can require life-long medical care that can be provoked by childhood medical treatment itself. This presentation explores how adult intersex healthcare is addressed by ‘experts of experience’, by exploring interview data and recent co-produced health projects. Two interconnected significant themes appear in these narratives: the long-term impact of childhood medical treatment; and difficulties accessing quality adult care. Our discussion will focus on quality adult care, as there is extensive research that details the impact of childhood VSC medical treatment.
“Disorder of sex development” – medical approach

Martin Fafejta

1Faculty of Arts, Palacky University, Olomouc, Czech Republic

Abstract

The paper is based on first research (anonymised qualitative interviews and questionnaires) ever among Czech physicians who treat intersex people. It identifies three main problematic issues:

1) Terminology. The term “disorder of sex development” is preferred by the Czech physicians. They see it as descriptive, non-stigmatising term even if it implies that disorder must be corrected. They refuse other terms, specifically intersex or third sex. They understand intersex as "between the sexes" and consider it stigmatising. They reject the term third sex because they consider it to be contrary to human biology.

2) Surgical interventions. Although physicians stress that all procedures must respect patients’ right to a fulfilling sexual life, some still consider acceptable to shorten a “longer” clitoris even if they are not medically urgent. During interviews, they did not mention any other types of treatment in detail.

3) Psychosocial support to the patients and their parents provided by self-help organisations. Articles in medical journals often state that it is the duty of medical staff to contact parents with such organisations. However, this form of cooperation is not sufficiently supported in Czechia, and patient organisations of intersex people are non-existent in Czechia. It is important to have support organisations that are not official part of health care institutions. However, physicians prefer organisations and groups which are “cooperating”, that is which are not dissenting to predominant medical views.

Funder: TAČR (Technology Agency of the Czech Republic)

To Imagine and Prevent Future Intersex Bodies

Limor Meoded Danon

1Azrieli Faculty of Medicine, Bar-Ilan university, Zefat, Israel

Abstract
Aims: This paper focuses on the meanings and practices exist in prenatal diagnosis settings in Israel, especially in the context of pre-implantation genetic testing (PGT) of ‘intersex’ embryos/ or embryos with variations of sex characteristics (VSC).

Background: Israel promotes and subsidizes the use of assisted reproductive technologies including IVF cycles and PGT for early diagnosis of genetic diseases and carriers of genetic diseases. Many Israeli parents with a background of various genetic diseases often use PGT, that include IVF cycles and taking cells from the pre-embryos for genetic testing. Recently, ‘DSD panels’ have been developed and are being used for genetic testing of VSC.

Conceptual framework: I use a critical sociological perspective which focuses on the biopolitical context in relation to the role of medical professionals in neoliberal societies, as well as undermines the socio-medical discourse on normative, healthy human bodies. From this perspective I will analyze the ways Israeli medical professionals perceive VSC and the use of PGT for VSC.

Methods: Between 2019-2022 I conducted 27 in-depth interviews with different medical professionals from different hospitals in Israel.

Ethics: I have IRB and Helsinki approval.

Findings: The meanings given to VSC changes according to cultural-religious and temporal context in doctor-parents/patients interactions.

Parents of children with CAH and patients with CAH are the common users of PGT in the context of VSC. During any PGT cycles, pre-embryos with karyotype other than 46XX or 46XY will not be implanted or preserved.

The value of ethical research for the intersex community

Yessica Mestre\textsuperscript{1,2}
\textsuperscript{1}Andalusian School of Public Health, Granada, Spain
\textsuperscript{2}University of Granada, Granada, Spain

Abstract

Researching communities that have been subjected to human rights abuses is a practice that requires some ethical understanding to conduct research in the most respectful way and address possible challenges such as realizing results out of context, over-
researching, or stigmatization. For the case of the intersex community, the context of research comes with a history of medicalization, imposition of gender roles, pathologizing language, epistemological injustice, and misrepresentation. These features have jointly created the development of harmful practices during research. The aim of this presentation is to introduce the findings made in the project fieldwork “Research ethics in intersex studies – Exploring ethical principles for a human rights-based research practice” that is part of the research network INIA, which has received funding from the European Union’s Horizon 2020.

The project gathered twenty participants through snowball sampling recruitment methods. The participants were intersex people who had taken part in research, researchers, and experts on research ethics who answered semi-structured questions according to their experiences in qualitative research on intersex issues. The data were examined using thematic analysis to determine common gaps highlighted for the participants, such as the Ethics Boards’ lack of knowledge about the population, reflections around the involvement of intersex research within LGBTQ research, considerations for doing research with intersex children, and the challenges researching the intersex population. The research findings imply that researcher awareness of possible problems with research in this field is important in the production of ethical knowledge.

Towards a materialist analysis of DSD and Intersex healthcare

Surya Monro¹, Daniela Crocetti²

¹University of Huddersfield, Huddersfield, United Kingdom
²Independent Researcher, Bologna, Italy

Abstract

Whilst critical intersex scholars have produced crucially important critiques of the medical management of intersex from constructionist, queer, and poststructuralist positions, there has been a lack of attention to the materialist aspects. This presentation aims to start to develop a materialist critique of historical and current medical practices, framing these in relation to capitalist accumulation and the power relations that underpin it. We explore the financial aspects of the development of medical specialisms such as urology, individual career trajectories, and the related pharmaceutical industry. The presentation also indicates some of the strategies that may be used to protect the interests of the medical and related industries.
This presentation is primarily based on literature work, using theoretical tools and intersex-related literatures, as well as a range of sources about the medical professions and web materials. However, it also draws on empirical material from a European Commission funded study carried out between 2016-7 with intersex activists, patient groups, medics, and others in Italy, the UK and Switzerland. This study was carried out in collaboration with activist organisation Zwischengeschlecht and it passed University Ethical approval. The data are anonymised.

The key finding from the materialist analysis of the dynamics taking place in medical institutions are that power and money are both highly relevant to understanding the persistence of harmful medical practices. Luke’s 3 faces of power can be used to deepen understanding of why this is the case.

American Intersex Television Characters
Kamran Qureshi¹
¹Solent University, Southampton, United Kingdom

Abstract

This research provides a critical analysis of North American television dramas and investigates how they have represented intersex characters and their issues. American television has previously portrayed humans in two conventional genders, male and female. Anything other than that is whether taken as a freak or a monstrous creature from an alien world. Intersex characters have either been misrepresented or mocked in these dramas.

Having directorial experience of a feature film and a TV series on intersex, I am using the practising academic’s lens and conducting a close textual analysis of randomly selected fifteen television series with at least one intersex character, aired in the last 30 years, between 1992 till 2022 in the United States.

This study explores major themes used in these dramas and investigates how American television directors have approached the intersex subject and used their directorial vision and techniques to represent intersex characters as a mirror of society. In conclusion, this study sheds new light on the little-recognised issues of intersex citizens in American society.
The Universal Periodic Review and the ban on Intersex Genital Mutilation: Is recommending free, prior and informed consent the way forward?

Saskia Ravesloot¹

¹Sciences Po (PSIA), Paris, France

Abstract

The Universal Periodic Review (UPR) assesses the human rights records of all 193 UN Member States against the benchmark of the Universal Declaration of Human Rights and its core human rights treaties. The UPR has resulted in more than 93,250 recommendations received by States under Review from their peers. Less than 1% explicitly emphasises the rights of intersex children and adults. Intersexuality is identified against the framework of a binary understanding of sexuality, whereas intersex persons are considered somewhere in between the two categories of women and men. Although human rights are universal, intersex persons experience one of the worst forms of human rights violations: Intersex Genital Mutilation (IGM). This is a medical intervention imposed on individuals with perfectly healthy bodies, with only one goal: conforming to the prevailing medical and socio-cultural norms. While significant research is conducted on the rights of persons of diverse sexual orientation and gender identity in relation to the UPR, the rights of intersex persons have scarcely been discussed. This article broadens the scope and integrates the ban on IGM into the discussion of UPR recommendations. The findings of the discourse analysis of 750 UPR recommendations reflect that only a few address IGM and that this is most often done in a conditional way: medical interventions are only allowed if there is free, prior and informed consent of the person involved. The article argues that IGM is torture and since there is no such thing as ‘consent to torture’, banning IGM should rather be unconditional.

Intersex epistemologies? Reviewing relevant perspectives in intersex studies

Amets Suess Schwend¹, ²

¹ Andalusian School of Public Health, Granada, Spain
Abstract

Over the last decades, intersex studies achieved an increasing development as a field of knowledge, in tight collaboration with intersex activism. Intersex authors and allies from different academic disciplines and world regions are contributing, among other topics, critical reflections on clinical practices, legal frameworks, social inequities and forms of knowledge production. Within the process of establishing intersex studies as a field of knowledge, I propose a self-reflexive view on their epistemological foundations.

This presentation is based on a narrative literature review of epistemological, methodological and ethical reflections in intersex and trans studies I conducted over more than ten years as a work-in-progress project, including my PhD thesis, other publications and discussions shared in the INIA: Intersex – New Interdisciplinary Approaches project (European Commission, MSC-ITN 859869), completed by a scoping review of recent knowledge production in intersex studies.

In this presentation, I will review relevant epistemological perspectives in intersex studies, including human rights frameworks, discourses on citizenship, reflections on epistemic injustice and epistemology of ignorance, a critical review of medicalisation using approaches such as biopolitics, sociology of diagnosis, bioethics, depathologisation perspectives and contributions from disability/crip studies, reflections on gender and bodily diversity, and analyses of social inequities, including the intersectionality perspective and social determinants of health approach.

Within an emerging field of metatheoretical reflections in intersex studies, the review focuses on a less explored aspect, the analysis of theoretical perspectives. The awareness of epistemological frameworks aims at contributing to the development of strategies for supporting the human rights of intersex people in academic and activist contexts.

Bias in intersex research and the lack of implementation of intersex human rights. Analysis and proposals to ensure good practices

Markus Bauer¹, Daniela Truffer¹
Abstract

Since the 1990s intersex advocates have been criticising medical research on intersex and the consequences of “corrective” surgery as biased, followed by similar criticism of social research. Documented criticism of medical publications includes sampling bias, directive questionnaires, lack of evidence as an argument to continue with non-consensual surgery, and the recurring fallacy of “surgery is better now, and in 20 years we will be able to prove it”, as well as discrediting critical intersex voices as “zealots” and “a (small) group of activists standing on the barricades for sexual diversity”. Criticism of social sciences includes misrepresentation of intersex as a gender issue, erasure of human rights criticism, and academic complicity. In recent years, medical and social research on intersex has increased and a new type of research has emerged with an explicit focus on human rights.

We will analyse some recent salient examples and demonstrate that despite positive developments and examples of good practice, in many cases the aforementioned biases and fallacies persist and new ones are being added, while positive examples often only have limited reach. We will argue that these shortcomings and deficiencies in often not genuinely disinterested academic papers are a contributing factor to the lack of implementation of human rights, policy and legal directives, and propose measures to ensure good practices in intersex research.