IAS Institute of Advanced Studies

UNIVERSITY OF SURREY

After the Recognition of Intersex Human Rights

A MULTIDISCIPLINARY INTERNATIONAL SYMPOSIUM

23-24 September 2016

University of Surrey, UK

Programme

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The Institute of Advanced Studies (IAS) at the University of Surrey hosts small-scale, scientific and scholarly meetings of leading academics from all over the world to discuss specialist topics away from the pressure of everyday work. The events are multidisciplinary, bringing together scholars from different disciplines to share alternative perspectives on common problems.

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The Wellcome Trust is a global charitable foundation dedicated to improving health. They support work in science, the humanities and the social sciences, as well as education, public engagement and the application of research to medicine.

The meeting was additionally supported by a donation from the Foundation for Psychotherapy and Psychoanalysis, Zurich.

AFTER THE RECOGNITION OF INTERSEX HUMAN RIGHTS

Welcome

The conference committee would like to welcome you to this international, multi-disciplinary event around the theme of intersex and human rights. This event is supported by the Institute of Advanced Studies and the Wellcome Trust, and is also the third annual meeting of EuroPSI: The European Network for Psychosocial Studies in Intersex/Diverse Sex Development. We are delighted to showcase such a variety of presentations, drawing on a number of disciplines and using such a wide range of media.

We would like to thank our primary sponsors, the Institute of Advanced Studies at the University of Surrey and the Wellcome Trust, as well as all those who helped in the organisation of the event.

Local organisers:

David Griffiths, Peter Hegarty and Kamila Hawthorne

Conference committee members:

Susannah Cornwall (University of Exeter), Holly Greenberry (IntersexUK), Lih-Mei Liao (UCLH Women's Health Division), Tove Lundberg (University of Oslo), Katrina Roen (University of Oslo), Katinka Schweizer (University Medical Centre Hamburg) and Dawn Vago (IntersexUK).

PROGRAMME

Friday 23 September 2016

Venue: Lecture Theatre M and Upper Concourse

08.30 – 09.00 Registration and Tea/coffee

09.00 – 09.15 Welcome (David Griffiths and Peter Hegarty)

09:15 – 11:15 Interactive Panel Discussion: “Intersex Human Rights: Why we need research supporting an affirmative model of care”

Holly Greenberry (IntersexUK) and Tanya Ní Mhuirthile (Dublin City University)
Kimberly Zieselman, Georgiann Davis (InterACT)
Kitty Anderson (Intersex Iceland)
Miriam van der Have (Nederlands Netwerk Intersekse/DSD)
Morgan Carpenter (Oii Australia)
Lord Wilf Stevenson (House of Lords)

11:15 – 11:30 Tea/coffee break

Session 1

11:30 – 13:00

1. **Natalie Delimata**, Institute of Technology, Sligo
   Intersex without Inter-Gender: Recognising Sex Variance in a Binary Society
2. **Tanya Ní Mhuirthile**, Dublin City University
   Recognising Intersex Human Rights in Ireland: A Reflection on the Introduction and Impact of the Gender Recognition Act 2015
3. **Fae Garland and Mitch Travis**, University of Exeter
   Intersex Embodiment, Vulnerability and Law
4. **Markus Bauer,** StopIGM.org / Zwischengeschlecht.org
   Involuntary Intersex Treatments as a Human Rights Violation

13:00 - 14:00 Lunch break

Session 2

14:00 – 15:30

5. **Roosa Toriseva**, University of Tampere
   Medical Treatment of Intersex in Finland
6. **Irene Kuzemko**, Association Russian-Speaking Intersex
   Intersex in Russia
7. **Keiko Irie**, Kyushu International University
   Identity Politics and Bio-Politics: Intersex/DSD movements in Japan and the US
8. **Daniela Crocetti,** University of Huddersfield & CESD and Claudia Balsalmo (AISIA & CESD)
   Networking between syndrome specific health movements and pan-Intersex social activism, some reflections on our experience in Italy

15:30 – 15:45 Tea/coffee break

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Session 3

15:45 – 16:45 **9.** **Elena Bennecke,** Charité, Universitätsmedizin Berlin, and **Annelou de Vries**, VU University Medical Centre, Amsterdam
European research project "dsd-LIFE"

10. **Ute Lampalzer**, Institute for Sex Research & Forensic Psychiatry, Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf
Questions and controversies in intersex management. Creating an online information and counseling platform for parents, persons concerned and students within the HOOU (Hamburg Open Online University)

16:45 – 18:00 **Keynote Presentation: Georgiann Davis**, University of Nevada, Las Vegas

18:00 – 19:00 Wine reception with informal visual presentation – Del LaGrace Volcano, Intersex Scandinavia: *Visibly Intersex 2016*

There will be an opportunity to engage with the poster and other visual presentations

19:30 Conference dinner in Guildford

A free bus will leave the bus stop at the piazza at 19:10

Saturday 24 September
Venue: Lecture Theatre M and Upper Concourse

09.00 – 09.30 Tea/coffee

Session 4

9:30 – 10:45 **11.** **Marion Hulverscheidt**, Childrens Hospital Zurich and University Kassel
Historical substantiation of the medical treatment and accompaniment of children with intersex conditions in the 1950s – insights of an interdisciplinary, patient record based project in Zurich

12. **Charlotte Jones**, University of Sheffield
Imagined futures: Intersex women's experiences of infertility and reproductive choice

13. **Celeste Orr**, University of Ottawa
The (temporarily) non-intersex body and the colonial cultural imaginary

10:45 – 11:00 Tea/coffee break

11:00 – 12:15 **Keynote Presentation: Kitty Anderson,** Intersex Iceland & Oii Europe

12:15 – 12:30 Introduction to sculptures on display

Fabian Vogler, Fine Art
Sculpture and presentation: Liquid Gender - Sneak Preview Exhibition

12:30 – 13:30 Lunch break
There will be an opportunity to engage with the poster and other visual presentations

PROGRAMME

Session 5

13:30 – 15:00	**14. Katrina Roen,** University of Oslo *Medical disclosure dilemmas and children's rights*
	15. Julie Alderson, University Hospitals Bristol NHS Foundation Trust *Negotiating children's involvement in health service based research*
	16. Marta Prandelli, University of Padova *Parents, social sciences and human rights: is there a common agenda?*
	17. Tove Lundberg, University of Oslo *Moving forward with intersex/dsd rights and care: Focusing on principles or engaging with dilemmas?*
15:00 – 15:15	Tea/coffee break

Session 6

15:15 – 16:15	**18. Suzanne van Rossenberg,** Middlesex University *Visualising intersectionality in intersex and LGBTI activism and human rights advocacy*
	19: Del LaGrace Volcano, Intersex Scandinavia and Erika Alm, Göteborg University *Intersex interventions in early childhood education*
16:15 – 17:30	**Keynote Presentation: Ruth Baldacchino,** International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA)
17:30 – 18:00	**Closing comments**

KEYNOTE AND PANEL CONVENOR BIOGRAPHIES

Holly Greenberry, IntersexUK

http://www.intersexuk.org/

My name is Holly Greenberry and I'm a co-founder and co-director of IntersexUK (iUK). Along with Dawn Vago, and Kim Zieselman it's been a privilege to bring this highly regarded panel to Surrey.

I'm a post graduate of Cardiff university. To date I've had a successful career in the television and film industry and latterly as a business woman. I've had the benefit of an amazing family and in recent years the absolute pleasure of being a mother to an incredible daughter.

As a younger person I'd lived some of the most horrific nightmares imaginable; my silent isolation and shame began to diminish through attending support groups and meeting some incredible peers and friends. I went on to co-develop the UK's first intersex human rights NGO in 2011.

I took part in a BBC documentary with the support of US friends. Since then my work's taken me to many countries educating, supporting, consulting and training within a variety of differing events.

In the UK it's typical with an intersex baby or child to operate first and think later! A unique paradox in the face of contradictory evidence to such 'treatments'. I hear and see a huge amount of youth, teen and adolescent trauma, pain and tears based on harrowing medical experiences in childhood and stigma and shame based on these lived abuses. This is repeated again and again from young people and older people alike - people who needed acceptance, care and autonomy. I've spoken to numerous parents still harbouring unanswered questions, often suffering understandable but unnecessary feelings of isolation and fear. I've watched many cry tears through angst, worry and the humbling honesty of fearing they'd made incorrect and coerced decisions without support, when in essence they wanted the best for their children. The inequality and lives of intersex people sadly does not compare to the life equality experienced by non-intersex-bodied people.

IntersexUK (iUK) was born through the pain of lived traumas and huge life experience and a large skill set; it has not developed to be shamed or silenced, but to fill a gaping void, to create a discussion, to educate, to profile, to make changes socially, legally, and medically.

My work often examines lived testimony, medicine, ethics, law, and ultimately why it's so unethical that the first port of call for a healthy intersex bodied baby or child is still typically that of a 'willing' paediatric surgeon with ideals of irreversible anatomical culturally 'normalising' experimental surgeries. Bodily autonomy with appropriate emotional care, reassurance, education and peer support is lacking yet essential if the person is to have a long term improved quality of life. Families additionally need to be afforded non-clinical only opinions and this balanced factual truths, and need greater support to dispel angst. The typical surgical approach knowingly conflates medical advice with lived reality. Our focus is to continue educating positively and accessibly to change this and afford appropriate depathologised care for healthy intersex bodied people.

My work also focuses on dispelling the many myths around intersex which is vital; as is ensuring the conflation is ended between people's intersex biology and their genders. I and Dawn Vago continue to ensure we as an NGO engage with the media educationally and with cross party parliamentarians. We highlight the need for a psycho-social care model which must regard the whole person, the family, and the persons 'lived' needs, environment and future, which is also in line with international human rights laws. Current surgical and hormonal approaches on healthy intersex children are considered by many to be an abomination of appropriate ethical care. Yet irreversible and damaging surgical and hormonal practices continue without any autonomous consent in the face of 'limited leaky data', notable lived testimony and in breach of international human rights laws.

We engaged as the first intersex human rights organisation in the UK, we work nationally and with colleagues in a international capacity, at numerous forums, conferences, symposiums and more. I've co-authored and we co-signed the Maltese Declaration. In unity we have additionally attended and supported numerous UN interventions. I was personally humbled to have been asked to speak as the first intersex woman at the UN plenary in Geneva in March 2014, and sat with my respected intersex colleagues at the first UN intersex panelled side event.

Both myself and iUK deliver at parliamentary engagements. Dawn Vago, myself and iUK became the first intersex voices and NGO to develop intersex forums supported by our Scottish advocates; we delivered the first ever intersex address and welcome at the Scottish parliament, we have also delivered the first intersex lectures in the UK initially to Scottish and English medical students and, on occasion, to law students. Additionally, we have become the first intersex NGO to deliver and train both the human and Scottish human rights commissioners and commissions, and the children's and youth commissioner of Scotland. It's been a privilege to also present ground breaking intersex human rights work in Ireland this year alongside our Irish advocates and one of iUK's co-founders Dr Tanya Ni Mhuirthile.

Within England we have ongoing engagements with various advocates within the Lords and human rights commissions plus advocate NGOs.

I developed the concept behind the intersex video blog project (Interface) which our US colleagues took on board and developed brilliantly into the Interface Project. Amongst other outputs, I've co-authored some of the first UK intersex comments independently and with academics for various cross party equalities committees, co-developed the report with Swiss colleagues which was delivered to the CRC in the spring of 2016. We've additionally developed the first UK academic lectures examining and discussing intersex within law, sociology, medicine and bioethics. We've also delivered the first UK wide training to in excess of 40 public sector organisations and NGOs within the UK. We were proactive in delivering the first UK wide intersex media campaigns. We've delivered consultancy to journalists, co-developed and appeared in front page features, and spoken openly in ground breaking features within the national broad sheet press and weekend supplements, high end magazines and worked in all other mediums with the BBC, and other media companies. Dawn Vago and I were positioned 5th through open nominations, in the UK's most influential top 100 LGBT and intersex people. Our work is unsalaried and the demand often outstrips our availability.

I sit on the Westminster parliamentary forum for gender identity, to ensure intersex is defined and represented clearly and accurately and certain rights focused upon.

A child's right to bodily integrity, autonomy, and gender should be locally protected. Biology and gender should never be conflated; and surgery should never be used as tool to ease social discomfort or practice outdated hypothesis around future wellbeing.

It's a pleasure to bring the reality of intersex life, human rights, and education to you.

Kimberley Zieselman, InterACT

http://interactadvocates.org/

Kimberly is an intersex woman and nonprofit professional with more than twenty years of experience in advocacy and nonprofit management. After graduating from Suffolk University Law School, she served as a policy analyst for the Massachusetts Joint House and Senate Committee on Health Care, and then worked in Government Relations and Advocacy for a variety healthcare related nonprofits, including Boston Children's Hospital. From 2009 through 2015. Kimberly served on the board of the largest intersex support group in the US, the AIS-DSD Support Group and was the annual conference host and organizer in Boston 2013.

In March of 2013, Kimberly joined interACT, a national non profit advocacy group dedicated to protecting the legal and human rights of intersex children. Kimberly is also a 2015-2016 Arcus Foundation Leadership Fellow. Kimberly works from Massachusetts where she lives with her husband, two daughters and two cats.

Georgiann Davis, University of Nevada, Las Vegas

Georgiann Davis is an intersex scholar and activist originally from Chicago, Illinois. She joined the University of Nevada, Las Vegas' Sociology Department in the fall of 2014 after spending close to ten years studying the intersection of the sociology of diagnosis and feminist theories. Among other scholarly contributions including co-editing a special issue on intersex for the journal Narrative Inquiry in Bioethics, she has written numerous articles on intersex in various venues ranging from Ms. Magazine to Gender & Society to the American Journal of Bioethics. In her book, Contesting Intersex: The Dubious Diagnosis (2015, NYU Press), Davis explores how intersex is defined, experienced, and contested in contemporary U.S. society. She is also the former president of the AIS-DSD Support Group (2014-2015) (www.aisdsd.org), and a current board member for interACT: Advocates for Intersex Youth (www.interactadvocates.org). You can read more about her work at www.georgianndavis.com.

KEYNOTE AND PANEL CONVENOR BIOGRAPHIES

Kitty Anderson, Intersex Iceland & Oii Europe

Kitty Anderson is an Intersex activist based in Iceland. In 2014, she was one of the founders of Intersex Iceland and has served as the organisations Chairperson since. She has also served on the board of Samtökin 78 - The National Queer Organisation of Iceland, in 2015 as a board member and from 2016 as the Organisations International Secretariat. Since the fall of 2015, she has served as the Secretary of OII Europe and has had a place on the board of the Icelandic Human Rights Center since 2015, taking the position of the chairperson in May 2016. She has also served on Iceland's Ministry of Welfares Queer Committee since 2014.

Ruth Baldacchino, International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA)

Ruth Baldacchino is ILGA World's Co-Secretary General. They have been involved in activism and advocacy work in Malta, Europe and globally for the past 15 years, and served on a number of boards including ILGA, ILGA-Europe, IGLYO and MGRM (Malta LGBTIQ Rights Movement). Ruth is also Program Officer for the Intersex Human Rights Fund at the Astraea Lesbian Foundation for Justice. They are responsible to lead the Fund's grantmaking, capacity building and philanthropic advocacy to support and strengthen intersex activism globally. Prior to joining Astraea they worked at the Maltese Ministry for Civil Liberties in the areas of human rights and integration, where they were actively part of the process towards the passing of the groundbreaking *Gender Identity, Gender Expression and Sex Characteristics* Act. Ruth holds an M.A. in Women's Studies from University College Dublin and a B.A. (Hons.) in Sociology from the University of Malta. They are a PhD candidate in Sociology / Gender Studies and lecture Queer Studies at the University of Malta.

Julie Alderson, University Hospitals Bristol NHS Foundation Trust: “Negotiating children’s involvement in health service based research”

Collaborators: Alderson J, Cole S, Nichol N, Skae, M, Nicholls J. Jones, J. Crowne E

It is well acknowledged that parents of children with atypical genitals are careful about how they and others talk to their child about genital difference (Sanders et al 2012). Also frequently expressed worry amongst parents of young children with genital difference concern risk that the child may be subject to judgement, prejudice, bullying or ‘nosey-ness’ as a result of their atypical genitals being known about outside of very close and enduring relationships (Gough et al 2006; Lundberg et al 2016).

In 2012 Schober noted that studies investigating DSD/ Intersex tended to report retrospective views of parents only. Sanders has since gained some useful views from young people, particularly about services (Sanders 2014).

In this study we speak to parents of girls with Congenital Adrenal Hyperplasia (CAH) about how they face certain parenting challenges ‘now’, and note the presence or absence of concern about atypical external genitalia.

We introduce the prospect of talking to girls with CAH about common childhood leisure activities as a possible research method for gaining information directly from young children.

This presentation describes the process and early findings of these aims.

Markus Bauer, StopIGM.org / Zwischengeschlecht.org: “Involuntary Intersex Treatments as a Human Rights Violation”

For over two decades, intersex persons and their organisations have denounced involuntary non-urgent treatments as a form of genital mutilation, torture and sexual abuse, and as a serious breach of international law. In 2008, they started reporting to UN and other human rights mechanisms, resulting in treaty bodies issuing over a dozen reprimands to complicit states in Europe, South America and Asia. Most notably the Committee against Torture (CAT) considers involuntary intersex treatments as constituting at least inhuman treatment in breach of the Convention against Torture, while the Committee on the Rights of the Child (CRC) recognises them as violence against children and as a harmful practice like FGM.

Typically, treaty bodies oblige complicit states to:

(a) take effective legislative, administrative, judicial or other measures to prevent non-urgent treatment without informed consent of the person concerned

(a) adopt legal provisions to ensure access to redress and adequate compensation for victims

(a) provide families with intersex children with adequate counselling and support

While intersex human rights are increasingly referenced in public and academic discourse, typically they’re only mentioned as a catch phrase, with the non-binding statement by the

Special Rapporteur on Torture as the only reference given. I'll analyse the most relevant human rights frameworks, their implications and the history of their application by human rights bodies.

Elena Bennecke, Charité, Universitätsmedizin Berlin: "European research project 'dsd-LIFE'"

In 2012 the four-year multicenter European research project "dsd-LIFE" was granted European Union Seventh Framework Program (FP7) funding to investigate clinical care and long-term effects of hormone therapies, experiences with surgery and psychological support in individuals with different congenital conditions in which the development of chromosomal, gonadal, or anatomical sex was atypical. Areas that are of high importance for life quality were focus of study: general quality of life and psychological well-being, psychosexual development, quality of treatment and satisfaction on treatment, and metabolism. In particular the project aimed to focus on patients' views, ethics and cultural context.

Method:

The study was a collaboration between 15 European centers in France, Germany, the Netherlands, Poland, Sweden and the United Kingdom. Study recruitment took place at each participating site as well as through DSD (differences of sex development) patient support organizations. In total over 1100 individuals with various DSD conditions (chromosomal DSD, XY DSD and XX DSD) participated. They completed a survey on their general and psychological well-being, their previous and current everyday experiences with their conditions, potential sexual complaints and their experiences and satisfaction with previous and actual health care and treatment. Moreover, participants were asked about their views on the terminology and ethical issues. The study centres further offered physical examination and laboratory investigations to evaluate long-term effects of hormone therapy. Data on medical history were gathered.

Expected outcomes:

Data collection ended in the fall of 2015 and data analyses are presently conducted. Until date dsd-LIFE is the largest clinical outcome study with individuals with different DSD's. Preliminary results on Quality of Life, psychological well-being, psychiatric comorbidity, psychosexual outcome and participants' views on terminology and ethical issues results will be presented.

Daniela Crocetti, University of Huddersfield & CESD and Claudia Balsamo, AISIA & CESD: "Networking between syndrome specific health movements and pan-Intersex social activism, some reflections on our experience in Italy"

This joint presentation from Claudia Balsamo (teacher; activist AISIA; CESD) and Daniela Crocetti (social scientist; activist CESD) intends to provoke discussion regarding overlapping and/or differing requests, issues and strategies posed by syndrome specific health movements and pan-Intersex social activism groups. Addressing our overlapping experience interacting or working with these various realities (AISIA; Nascere Klinefelter; Intersexioni;

Zwischengeschlecht) as a case study, we will reflect on the discord and solutions that arise to address medical treatment of DSD/Intersex in Italy based on these different perspectives and strategies. We intend to focus on the positive results of the differing strategies as well as areas that continue to require further attention. We hope that this presentation will stimulate a discussion on how these often diverging strategies (collaboration with medical teams, versus a strong anti-medicalization approach) impact medical practice and the social perception of Intersex/DSD, and how future research can work to incorporate all of these voices.

Natalie Delimata, Institute of Technology, Sligo: "Intersex without Inter-Gender: Recognising Sex Variance in a Binary Society"

Many intersex human rights organisations have argued that the primary issue concerning intersex is non-consensual genital surgery and not gender recognition (ILGA-Europe, OII Australia, OII Europe; stop.genitalmutilation.org, Zwishengeschlect.org). On the contrary intersex people are described as being as content with their binary gender assignment as the general population, thus seeking non-binary gender recognition is not a priority (OII Australia, 2014). Imbedded in this argument is the implicit assumption that intersex genitals can be socially recognised and accepted within a binary gender system. For this strategy to be effective in removing the desire for normative surgical interventions, intersex genitals must be integrated into what it means to be a boy/man and girl/woman. However, this constitutes a major ontological shift in the presumed mimetic relationship between sex and gender. Drawing on the work of Kittay (2006), Butler (1990) and Kessler and McKenna (1978) this presentation will explore the necessary conditions for this shift, and what it might mean, particularly in light of emerging concerns in relation to gender deception and sexual consent.

Fae Garland and Mitch Travis, University of Exeter: "Intersex Embodiment, Vulnerability and Law"

This paper draws upon empirical research with members of the intersex community and intersex advocacy groups. It considers intersex embodiment and the ways in which these bodies are structured by discourse and institutions. The research takes place during a global paradigm shift in the management of intersex bodies from medicalised models to increasingly juridified responses. This paper questions this shift in jurisdiction and highlights how institutions such as law contribute to the precarious situations in which intersex embodied people find themselves. The option of a 'third gender' in Germany, as well as 'X' markers on passports and anti-discrimination law in Australia are discussed as failing to increase the resilience of intersex individuals and highlight a lack of responsiveness to the needs and claims of particular groups. The paper draws upon interviews with intersex people to consider the ways in which legal institutions should manage intersex bodies. Malta's recent move to protect the bodily integrity of intersex children from non-therapeutic surgical interventions is contrasted as an institutional intervention that has drawn praise from the intersex community.

This project draws upon research that was aided by a grant from the Socio-Legal Studies Association.

Marion Hulverscheidt, Childrens Hospital Zurich and University Kassel: "Historical substantiation of the medical treatment and accompaniment of children with intersex conditions in the 1950s – insights of an interdisciplinary, patient record based project in Zurich"

During the 1950s, the term "intersexual" became commonly accepted. This was used to describe both mal-developments as well as discrepancies between the inner resp. outer sexual organs and/or the chromosomes. New diagnostic methods (hormone levels in the urine and serum, smears from the oral mucosa and drum sticks in the nucleus of leucocytes) and new therapeutic options (particularly cortisone for congenital adrenal hyperplasia (CAH) as well as markedly improved surgical and anaesthetic methods) opened up a whole new range of interventions during the 1950s, initiating a substantial increase of interventions in cases of intersexuality ie. variations or deviations of the biological sexual development. The Zurich Kinderspital (Kispi) with its leading director Guido Fanconi, endocrinologist Andrea Prader and the pediatric surgeon Max Grob was on the cutting edge of this development.

The main sources of this project are patient files from the archive of the Kispi from the time period between 1945 and 1970. A KEK (kantonale Ethikkommission, cantonal ethic committee) request is provided. With this approach it is possible to open up new perspectives and in the course new questions for the concealed time period of the 1950ies. Some of the patient records cover a period of more than twenty years and show the development of a continuing, reliable relation between doctor, parents and patient.

This paper will outline the sources and the scope of the project and will provide examples which illustrate different ways of care and treatment. By now it can be demonstrated that there was no strict time frame for treatment and medical procedures, but recommendation for the right time for surgical intervention tends to be given earlier in the life of a child. Connected to the theoretical framework of endocrinological psychopathia by Manfred Bleuler, Zurich, there were psychopathological expertises performed on the children, which reveal a distinct insight of the understanding of society and gender roles in the 1950s.

Keiko Irie, Kyushu International University: "Identity Politics and Bio-Politics: Intersex/DSD movement in Japan and the U.S."

This paper analyzes the process and the construction of discourse of social movement on intersex/ Disorders of Sex Development (DSD). Specially focusing on the movement in Japan and United States, this paper reveals the dynamics of medicalization and its process of creating the social deviance, and how people with condition would cope with such a situation by declaring, identifying themselves, and protesting against labeling. For this purpose, this paper deals with the narratives of people with condition and the articles and personal blog posts.

By focusing on medicalization process and nomenclature change, this paper proposes intersex/ DSD interdisciplinary; as medical intervention into body in terms of medical sociology, and as identity politics in terms of social movement theory. This paper follows the discussion about intersex as medical intervention to body (Dreger, 1999). In addition to Dreger's discussion, this paper explores the comparative study of intersex/DSD movement in Japan and the U.S. As a result, it was found the difference in the attitudes toward new nomenclature between in each country, which was based on its historical backgrounds. Especially in Japan, it was based on the history of LGBT movements which has negative feedback from society.

In conclusion, it was found that the different attitude toward the new nomenclature was based on the social background which deprives from identity politics and/or bio-politics. In Japan, the "mainstream" discourse emphasize on biological body: bio-politics. In the U.S., since the Intersex/DSD movements were empowered by LGBT movements, the identity politics motivates the whole community.

Charlotte Jones, University of Sheffield: "Imagined futures: Intersex women's experiences of infertility and reproductive choice Proposal"

'The life that I planned, the children that I wanted, were taken away from me' – Pandora

For some people with intersex variations, a medical identification of 'infertility' is acquired at the same time as their intersex diagnosis. This often takes place within a medical context prior to any of their own concerns about fertility and parenthood or any attempts to conceive: for some in infancy, others in childhood or adolescence. Imagined futures and identities are sometimes mapped out or re-drawn according to this discovery.

This paper explores the significance of this timing, and the extent to which infertility can be experienced as a 'biographical disruption' (Bury, 1982) in various intersex life narratives; some where the potential for biological reproduction has always been a basic expectation, and others where infertility was known and understood from the earliest possible stage. I consider how social, relational and material barriers related to an intersex diagnosis may interact with a status of infertility in the biomedical context of treatment options, and in alternative life paths available outside of parenthood.

Drawing on the stories shared in my doctoral research with people based in UK who have intersex variations or diagnoses of atypical sex development, I argue that the language we use to talk about 'infertility' does not accurately characterise the full range of experiences of people to whom it is ascribed. An 'infertile' status is not understood by all of those affected at all stages of their life course to be pathological or prohibitive. These experiences are complex and diverse; some participants in my research felt disempowered or constrained by their infertility, but there were also examples of ways in which participants challenged dominant narratives of parenthood, searched for alternative directions, and constructed, and re-constructed, different visions of the future.

Irene Kuzemko, Association Russian-Speaking Intersex: "Intersex in Russia"

Is Russia as interphobic as it is homophobic? The first ever research about lives of intersex people in Russia and post-soviet countries. Statistics and information about their experiences with medical institutions, their life experiences of discrimination, violations of their human rights, "treatment" performed on them without their consent, their mental state, information about their views on the "I" inclusion in LGBTQIA, their views about the future of the intersex movement in the post-soviet countries, and other unique statistics about their life will be represented in our research. Our Intersex community is small and young, and our research project truly will be the first one - the topic of intersex have never been researched here before, and our Ministry of Health doesn't provide any official public statistics on the topic of Intersex. The research project will be done in a form of an anonymous online survey, and it is already being worked on. The research will be held by me together with other members of our organization, including Aleksander Beryozkin. The results of the survey along with our conclusions will be presented.

Ute Lampalzer, Institute for Sex Research & Forensic Psychiatry, Center for Psychosocial Medicine, University Medical Center Hamburg-Eppendorf: "Questions and controversies in intersex management. Creating an online information and counseling platform for parents, persons concerned and students within the HOOU (Hamburg Open Online University)"

Collaborators: Ute Lampalzer, Peer Briken, Katinka Schweizer

The birth of a child with an intersex condition or diverse sex development (dsd) still confronts parents – but also experts in the field – with a variety of challenges. Many questions come up for which there are no easy answers. As gender development and later gender identity are not predictable in most dsd, one of the most difficult decisions concerns the child's gender in which it shall initially grow up. Moreover, there are scientific controversies concerning irreversible medical interventions, like gonadectomies and genital surgeries, as well as hormone administration. So far there is no (interactive) German online platform for students, parents, persons concerned and experts in the field (e.g. medical doctors and psychologists) that imparts knowledge around these topics from different perspectives and disciplines – and also addresses gaps in knowledge.

The aim of the project is to conceive an online platform for the above-named target groups that at the same time provides information in an understandable manner, but also emphasizes complexity, uncertainty and ambiguity.

In this presentation, the concept for the online platform will be outlined. Apart from bringing together the perspectives from different medical disciplines (e.g. endocrinology, pediatrics, urology) as well as psychology, medical ethics, law, sex research and other scientific fields, it incorporates the expertise of support groups and artistic points of view. Moreover, methods and procedures of the accompanying research will be described, as one of the main ideas is a user- and need-oriented, participative development of the platform's content. Subsequently, challenges (e.g. copyrights and licenses) that go along with creating open educational resources dealing with dsd are open to discussion – also in the light of experiences from other countries than Germany.

Tove Lundberg, University of Oslo: "Moving forward with intersex/dsd rights and care: Focusing on principles or engaging with dilemmas?"

Collaborators: Lundberg, T., Dønåsen, I., Hegarty, P., & Roen, K.

A recent global update on dsd has noted that "unresolved questions and dilemmas" are still evident in relation to health care (Lee et al., 2016, p. 16). Almost all agree that promoting physical and psychological wellbeing for people with personal experience of intersex or diverse sex development (dsd) is a high priority, but perspectives differ on what should count as wellbeing, how wellbeing is achieved, and how to deal with inherent uncertainties and dilemmas. Medical perspectives focus on developing treatment guidelines with principles building on evidence-based medicine to promote patient-centred care and quality of life. Legal advocates focus on changes in legislation to limit medical intervention. Recently articulated principles position people with experiences of intersex/dsd as a group denied human rights, and entitled to protection against discrimination akin to LGBT people or to protection under existing sex discrimination acts.

We inform these debates by drawing on political psychology to analyze how lay people, without specific knowledge or experience of intersex/dsd, made sense of dilemmas currently managed by medical care. We presented vignettes of two situations that young people and parents might face, to 10 focus groups with 41 participants, and we asked what they would have done in these situations, or what they would have wanted their parents to do. Participants used principles to resolve these dilemmas, but this only addressed them at a superficial level. Substantial engagement required also a direct engagement with the dilemmas themselves. We conclude that irrespective of whether and how legislation limits medical intervention, ordinary people will continue to need to wrestle with dilemmas presented by competing principles of how their own or their children's wellbeing may be promoted.

Tanya Ní Mhuirthile, Dublin City University: "Recognising Intersex Human Rights in Ireland: A Reflection on the Introduction and Impact of the Gender Recognition Act 2015"

In December 2009, the Irish High Court in an ex tempore judgment recognised that an intersex person may have a right to legal recognition as the gender other than that recorded at the moment of birth in *S v An Bord Uchtála*. This was the first acknowledgement in any official source of the existence of intersex in Ireland. The second official statement on intersex was contained in the report of the Gender Recognition Advisory Group (2011) which simply noted that "[v]ery little is known about the numbers of people living with an intersex condition in Ireland" and that "the absence of clear definitions and the variety of conditions encompassed within the 'intersex' terms" (GRAG, p35) would cause difficulty with legislation.

Discussion of intersex featured prominently in the debates and discourse surrounding the introduction of the Gender Recognition Act 2015. The two themes which emerged were the need to provide pathways for recognition in the preferred gender of people with an intersex condition where that differs to the gender on official documentation, and questions surrounding the medical management of intersex conditions.

This paper will trace the evolutions of the discourse on intersex in Ireland. It will analyse the impact that the recognition by the State of the human rights of intersex people has had on the development of public policy on intersex issues. The crucial shift that has taken place in human rights discourse over the past decade or so is the refocusing of the conversation which foregrounds the concepts of dignity and humanity as central to the recognition of the rights claims of intersex people. This paper will assess the impact that this focus on rights discourse has had, and will have, on policy development as it concerns intersex issues.

Celeste Orr, University of Ottawa: "The (temporarily) non-intersex body and the colonial cultural imaginary"

According to Michael O'Rouke and Noreen Giffney, "the intersex body, both pre- and post-surgical inscription, is still, always already, a site of contested being […]. The intersex body is not ontological, but rather hauntological" (2009: x). Even post-surgical or post-hormonal inscription one's intersex status haunts. Intersex cannot be the subject or question of non-existence but of questionable, liminal non-/existence; it is a "phantasm" (Holmes 2002: 175) that is "neither present nor absent" (Davis 2005: 373).

Expanding on this idea, I suggest the phantasm haunts all bodies. All bodies are contested and given "the difference between intersex and not intersexed can be only millimetres" (Holmes 2002: 175) and one can discover that one has intersex traits at any stage in one's life suggests that intersex haunts all bodies. This paper, therefore, reworks the disability adage that able-bodied folks are only ever "temporarily able-bodied" (Clare 1999: 82) to explore the cogency and political danger and/or usefulness of the assertion that non-intersex people are only ever temporarily non-intersex or "normate" (Garland-Thomson 1997: 8).

However, after analyzing the representations of intersex bodies in sport, it appears intersex haunts primarily hyper-able female athletes of colour from the Global South (e.g. Caster Semenya from South Africa and Dutee Chand from India). By synthesizing relevant literatures on colonial notions of women of colour, sport sex testing, and interphobia, I argue, given the (over)representation of these racialized women from colonized nations, the current use of sex testing is not only a tool that institutionalizes interphobia, sexism, and cissexim but also a colonial, imperial tool that reproduces scientific racism and functions to control and define specific nations' and bodies (inter)sex citizenship (see Grabham 2007). In other words, I examine how the intersex phantasm and interphobia is constructed and imagined along colonial, racist, sexist, hyper-/ability, national, and geographical lines.

Marta Prandelli, University of Padova: "Parents, social sciences and human rights: is there a common agenda?"

Within the intersex/DSD field, the historical transition from an optimal gender policy (Money, Hampson & Hampson, 1955) to a patient centred model (Wilson and Reiner, 1998, ISNA, 2006; Asciutto et al, 2011; Liao & Simmonds, 2013) is the result of a debate that led to the regulation of operational guidelines, based on a medical and psychosocial perspective. Equally, the growing attention to the rights and the ethics behind the medical management of individuals with atypical sex development, led governmental organisations, international agencies and NGOs to investigate the state of intersex human rights.

This increasing attention has highlighted the need of further researches, psycho-social and educational policies, awareness raising actions and support and information for all those involved (COE, 2013, 2015; WHO, 2014; CRC, 2014). To achieve this end, a multidisciplinary approach taking into account the points of view of all the "active agents" - individuals, families, activists, health professionals, support groups, bioethicists - is desirable, also in response to the international request to review the different methods of intervention.

Despite these historical changes, the prenatal or neonatal diagnosis is still a critical moment. While parents gained power in the decision making process over the interventions on their children's bodies, they still have few tools to face rapid decisions, often binding on the future of the newborn. Unequipped parents have to act urgently in a climate of great uncertainty due to absence of a concrete psychological support, lack of psycho-educational programs and unknown long term outcomes.

Through a literature review of psychosocial studies with parents of children with atypical sex development, I will examine the main aim of the psychosocial studies performed in the last decades, paying specific attention to the needs highlighted by the international agencies. In order to advance the psychosocial well-being of the families, a question needs to be addressed: do parents, social sciences and human rights have a common agenda?

Katrina Roen, University of Oslo: "Medical disclosure dilemmas and children's rights"

As part of a broad move towards involving patients in their own medical decision-making, and attending to children's rights, there has been a substantial shift towards telling children about any medical diagnosis they might have. This shift is notable in relation to intersex-related diagnoses since the dominant policy in the latter half of the 20th century was to actively keep sex-development-related information from the children and young people (and even adults) to whom it pertained. The present paper examines how health professionals and parents, with professional or personal experience in this area, talk about the process of telling children about their diagnosis. The focus is on how health professionals and parents position themselves in this process of talking with children / young people, and on instances where the process does not go as hoped. A dominant thread running through our interview data is that it is parents' responsibility to talk with children / young people about the diagnosis, not health professionals' responsibility. According to the data, this becomes problematic in instances where parents cannot or will not raise the topic with children, and it becomes problematic when parents try to engage children / young people who seem not to want to be engaged in the topic. A main purpose of this paper is to draw attention to the fact that a proportion of children / young people are now growing up, affected by intersex/dsd, but not being told about it, or only being given sketchy information. This raises human rights and medical ethics issues, and suggests a need for a more active policy of involving children and young people in health-related conversations.

Roosa Toriseva, University of Tampere: "Medical Treatment of Intersex in Finland"

In my doctoral thesis I study the medical history of intersex in Finland. My thesis and this paper focus on how medical professionals working with intersex view and treat intersex in Finland. At the moment there are no official instructions as to how to treat intersex in Finland. Lack of official instructions has led to a situation in which the paediatric surgeon, who is responsible for the treatment of intersex in a particular hospital, can relatively freely define how intersex is treated in that hospital. In Finland, most intersexed people are treated at either Helsinki University hospital or Oulu University hospital, but practices even between these two hospitals differ. While in both hospitals intersexed people are treated when their health is at risk, the chief paediatric surgeon at Oulu University hospital has decided not to operate for so-called cosmetic reasons. That is to say, when the sole purpose of the operation would be to alter the appearance of the person's body.

According to my research, behind these differing practices exist differing views on sex, embodiment and sexuality. I would thus like to discuss these differing views based on three interviews I conducted in 2012. In these interviews I interviewed two paediatric surgeons from both hospitals as well as an endocrinology specialist who occasionally collaborates with doctors from Helsinki University hospital. All participants signed contracts and volunteered non-anonymity. I would like to end my paper with a discussion about the future of medical treatment of intersex in Finland, as there are currently several critical discussions and recommendations made both in Europe and more specifically in Finland.

Suzanne van Rossenberg, Middlesex University: "Visualising intersectionality in intersex and LGBTI activism and human rights advocacy"

The collaboration between lesbian/gay/bisexual/transgender organisations and intersex activists has led to more inclusive activist and human rights strategies. An acronym such as 'LGBTI' represents the construction of an identity politics that constantly (re-)negotiates the meaning of terms. In 'Inclusion, Solidarity, and Social Movements: The Global Movement against Violence' (2006), Laurel S. Weldon concludes that a collective identity within the movement was the result (rather than cause) of collective action and framing. As a result of collective action intersex and LGBTI activists have booked great successes and important, new conversations and alliances have been instigated. However, no word or acronym can represent the diversity and plurality of a group of people, which seems to be especially pregnant for the representation of dsd/intersex dispositions. Feminist theorists (e.g. Elizabeth Cowie in 'Woman as Sign' (1978)) have called categorisation a semiotic, double problem: communication of a category produces that category, which does not immediately trouble societies' dominant attitude towards that category. In other words, for both campaigners and policy makers it is hard to communicate the 'intersectionality' of social inequality. In 'Intersectional and Cross-Movement Politics and Policies' Mieke Verloo (2013, p. 899), therefore, poses the questions: "To what degree can each of the approaches displace categories that are fundamental for reproducing inequality, and to what degree is displacement visibly developed as a strategy?" In my paper I will further contextualise the need for both the labelling and displacement of identities and propose the use of political, feminist and queer art for doing so. I will illustrate this by presenting my own cartoons, which are part of my PhD that applies intersectional feminism to Art History. I also build on my experience as LGBTI activist and author of the first Dutch LGBTI children's rights report (COC Netherlands, 2013).

Del Lagrace Volcano, Intersex Scandinavia and Erika Alm, Göteborg University & Intersex Scandinavia: "Intersex interventions in early childhood education"

We begin with the premise that meaningful 'norm critical' interventions that address the cultural insistence on binary gender are required on multiple fronts, including but not limited to the early family environment, pre-school and pediatric health professionals. This presentation would focus primarily on the family and pre-school environments of a handful of queer, gender non-binary, and/or trans families living in Sweden and show what raising kids without the constraints of obligatory gender conformity could look like. We argue that the norm critical approach we advocate here could potentially have positive consequences for children born with intersex traits.

POSTERS AND VISUAL PRESENTATIONS

Fabian Vogler, Fine Art: “Sculpture and presentation: Liquid Gender - Sneak Preview Exhibition”

Inter*sexual and hermaphrodite variations of gender are ancient phenomenons. Nevertheless, they keep on challenging our dichotomous concept of man and woman. Our society could gain a whole lot of opportunities, by widening this concept. Depictions can often be helpful keys for getting people emotionalized.

In cooperation with Dr Katinka Schweizer from the University Medical Center Hamburg-Eppendorf (https://www.uke.de/), I am therefore working on a book about “Inter*depictions”, planned for being published in 2017/18.

We are gathering different interdisciplinary, theoretical positions and approximations, which I will translate into my media - the bronze sculpture. (I am modeling my original plaster shapes by using a specially evolved technique with plaster bandages, casting balloons, which I deform with cut-offs from rubber tubes coming from all kinds of wheels.) A series of exhibitions shall accompany the elaboration and presentation of the book as open basis for the encounter with the topic.

I will be having a solo show - called “Liquid Gender” -, opening on the 29th of September 2016 at the art centre Espronceda in Barcelona (http://www.espronceda.net/en/home/) with curator Caterina Tomeo (http://www.unirufa.it/en/accademia/docenti/) from RUFA (Rome University of Fine Arts).

The first series, so far been created, are the “Inter*Venus-bronzes” (working title) and in the “Minture Menias”:

“Inter*Venus-bronzes” are set into the context of the prehistoric venus depictions (e.g. the Venus from Willendorf, Kostienki, Lespugue). By creating human figures with mixed or inconclusive genitalia in the manner of archaeological finds, I want to claim or postulate the same irrefutable relevance of eternity for inter*sexual shaping.

“Miniture Meninas” relate to the depiction of Infant Margaritha in the painting of “Las Meninas” by Diego Velazquez. By transferring this figure into the three dimensional - into my language -, “Menina” is becoming a kind of icon for the Inter*sexual.

Del LaGrace Volcano, Intersex Scandinavia: “VISIBLY INTERSEX 2016”

VISIBLY INTERSEX is an ongoing collaborative project seeking to make intersex lives and issues visible and legible to the wider public. The objective of this project is to dispel mainstream misconceptions about the experience of being intersex by visually demonstrating that we are not monstrosities but part of the diverse human landscape.

It is my contention that while issues around intersex are slowly entering into public consciousness we are seldom represented on our own terms or shown as a diverse group. The mainstream media tends to focus on only one group, AIS women, who are usually young, white and conventionally attractive. VISIBLY INTERSEX currently has 30 participants from 20 countries, from Australia, New Zealand, Iceland, Uganda, South Africa, Denmark, Sweden and many more. Our gender identities and sexual orientations are as similar and different as the rest of humanity.

VISIBLY INTERSEX began officially in 2011 at the first annual intersex activists forum in Brussels sponsored by ILGA and has continued to the present day. The only funding has been in the form of travel and accommodation sponsorship from ILGA. Only one participant has so far issued a statement to accompany his image but more are on the way. I describe my methodology as a "queer feminist methodology, invested in making work with speaking, as opposed to exoticized subjects."

Poster presentations:

Nina Callens, Ghent University

Paul Dutton, Klinefelter's Syndrome Association

Louise Marshall, University of Lübeck

Daniela Truffer, StopIGM.org / Zwischengeschlecht.org

Sorcha Uí Chonnachtaigh, Keele University

Valentino Vecchietti, Independent activist and academic

Kaz Williams, Living with CAH

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