

After the Recognition of Intersex Human Rights

23 – 24 September 2016, University of Surrey, UK

Symposium Report

'After the Recognition of Intersex Human Rights' was a two-day symposium at the University of Surrey on the 23rd and 24th September 2016. The event was organised by David Griffiths (Sociology), Peter Hegarty (Psychology) and Kamila Hawthorne (Faculty of Health and Medical Sciences)

The symposium committee was: 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)

The conference also comprised the third annual meeting of the European Network for Psychosocial Studies in Intersex/Diverse Sex Development.

Objectives

The symposium sought to bring together intersex activists, academics, and clinical practitioners at the University of Surrey. The event was titled 'After the Recognition of Intersex Human Rights' for a number of reasons. There is a sense that recent statements from bodies like the UN represent a positive development for the ongoing struggle for increasing the human rights of people with non-normative biological sex characteristics (for example, In February 2013, the UN Special Rapporteur on Torture issued a statement condemning non-consensual medical interventions on intersex children). As international interventions, there are open questions about what happens *after* these declarations, at national and local levels. Also, the event sought to take a critical approach to these declarations, and to ask how best to *go after* intersex human rights, both at the international level, but also at local levels in places like hospitals, schools and universities.

Summary

The event began with an interactive panel discussion with representatives of the global intersex human rights movement. The panel was organising and convened by **Holly Greenberry** of IntersexUK and **Kimberly Zieselman** of InterACT. The panel included personal testimonies as well as detailed information about the current state of human rights globally, and the work that still needs to be done. Contributing to the panel were **Morgan Carpenter** (OII-Australia), **Miriam van der Have** (Nederlands Netwerk Intersekse/DSD), **Kitty Anderson** (Intersex Iceland), **Daniela Truffer** (StopIGM.org) and **Tanya Ní Mhuirthile** (Dublin City University).

There were ten presentations on day one, with **Natalie Delimata** beginning the symposium by asking how it is possible to separate sex from gender in discussions on intersex, particularly in such a binary society. **Tanya Ní Mhuirthile** reflected on intersex human rights in Ireland, particularly in the light of the Gender Recognition Act 2015. **Fae Garland** continued from a legal scholarship perspective, thinking through intersex embodiment and vulnerability in the law. **Markus Bauer** concluded the first panel by talking through the work of StopIGM.org / Zwischengeschlecht.org, and more than two decades of activism to get the medical profession to see involuntary intersex treatments as human rights violations.

Session 2 began with **Roosa Toriseva**, reporting on her research on the medical treatment of intersex in hospitals in Finland. **Irene Kuzemko** reported data from a project asking whether Russian attitudes to intersex are similar to those towards homosexuality. **Keiko Irie** spoke about movements

in Japan, and some culturally specific issues of identity politics and particularly use of language. **Daniela Crocetti** and **Claudia Balsalmo** spoke about relationships between specific groups for health conditions or diagnoses, and pan-intersex social activism, reflecting on their experience in Italy. The final session of papers on day one focused on current and potential projects. **Elena Bennecke** and **Annelou de Vries** reported on preliminary findings from the European research project “dsd-LIE” and **Ute Lampalzer** and **Katinka Schweizer** spoke about a potential project to create an online information and counselling platform within the Hamburg Open Online University.

The first day ended with a keynote from **Georgiann Davis** from the University of Nevada, Las Vegas. Her talk considered the power in medical nomenclature and diagnoses to affect people’s access to biological citizenship, and the consequences this can have for individuals and communities. After the keynote, there was a brief presentation from **Del LaGrace Volcano** about a photographic art project called “Visibly Intersex”.

Day Two began with **Marion Hulverscheidt** reporting on her patient record based historical research looking at Zurich in the 1950s. **Celeste Orr** spoke about the fact that intersex can be interpreted to “haunt” all bodies, particularly in the light of recent events at the Olympics.

After these presentations, the second keynote speaker, **Kitty Anderson** spoke about her family experience, her activist work in Iceland and internationally, as well as asking: what *grounds* do we go after human rights on? She suggested thinking of intersex human rights challenges as fighting for rights on the grounds of biological sex characteristics. After her talk, **Fabian Vogler** gave a brief introduction to his artistic sculptural work that he had kindly brought and displayed throughout the symposium. This was an exclusive sneak peek of an exhibition he was opening on the 29th of September 2016 at the art centre Espronceda in Barcelona in association with the Rome University of Fine Arts.

After lunch, **Katrina Roen** spoke about some of the dilemmas that surround the question of who should tell children what about intersex, and when. **Julie Alderson** spoke about some of the barriers in hearing the voices of children and young people, and how to negotiate their involvement in health service based research. **Marta Prandelli** looked at the sometimes-competing claims of parents, the social sciences and human rights discourse, asking, is there a common agenda? **Tove Lundberg** concluded this session by asking whether focusing on principles or engaging with dilemmas was the best way to move forward with intersex rights and care.

The final session of presentations began with **Suzanne van Rossenberg**. She spoke about attempting to visualise intersectionality through arts-based practices in intersex and LGBTI activism and human rights advocacy. **Del LaGrace Volcano** and **Erika Alm** gave a joint presentation on intersex interventions in early childhood education.

The symposium concluded with **Ruth Baldacchino** speaking about the recent successes in Malta to ban medically unnecessary early surgeries. They gave a detailed presentation on the history of this move and what it means for global intersex human rights.

There were poster presentations from **Kaz Williams** of Living with CAH, **Paul Dutton** of the Klinefelter’s Syndrome Association, **Markus Bauer** and **Daniela Truffer** of StopIGM.org / Zwischengeschlecht.org, **Sorcha Ui Chonnachtaigh** from Keele University, and **Valentino Vecchietti**, an independent activist and academic.

There were lively and provocative discussions throughout the two day programme, and the participation of every delegate at the event was essential for the success of the event.

Key themes

The symposium benefitted from contributions from a wide range of disciplines including history, psychology, social sciences, cultural studies, law and fine art, as well as representation from clinical practice. Furthermore, the international scope of the event led to contributions from thirteen different countries: Belgium, Canada, Finland, Germany, Ireland, Italy, Japan, Norway, Russia, Sweden, Switzerland, the UK and the US.

Despite the broad range of contributions, fields, and approaches, it became clear that there was a shared commitment to improving the human rights of intersex people, as well as to finding common ground in a complex landscape and making positive changes at local levels. A number of key themes or dilemmas emerged during the discussions:

- **Nomenclature.** With the shift in medicine from intersex terminology to ‘disorders of sex development’ (DSD), there is a shared sense of both the power of words to name and shape individual and group experiences. Is it possible to agree on fixed terms, should language be used pragmatically, or might it be possible to develop a multiplicity of terms that can speak across fields and experiences?
- **Personal narratives.** Delegates at the event, whether experts by virtue of their personal experience of intersex or not, agreed that personal narratives of intersex individuals are essential for improving medical practice and human rights. How might these narratives best be captured? And how then can they be brought into medical practice, as well as into public engagement, in safe and ethical ways?
- **The need for more and better (more ethical) data.** With a lack of good long term follow up studies in this area, the more vocal activists can be negatively framed as a “disgruntled minority”, by the press and the medical profession. Ethical data collection will generate better representations of intersex people’s lives and the effects of medicalization on them that will better support strategies that go after intersex human rights. Again, how do we represent the previously unrepresented, in research?
- **The role for those outside the medical profession.** This is a field structured by intense medical secrecy, which has negative effects on individual’s lives. The medical profession is also over-invested as *the* field that must “manage” intersex. The symposium made clear that there is work to be done in law, psychology, the social sciences, art, clinical practice, and a range of other fields and professions to develop a less medically-centred interdisciplinary understanding of intersex.

Next steps

There have been several conversations about publication plans after the symposium, and we have begun informal enquiries with editors of journals. *Feminism and Psychology* is a strong choice for publishing a special issue; similarly, *Women’s Studies Quarterly* would be appropriate, and would also give us the opportunity to publish visual images. There are a number of collaborations at the University of Surrey that will be directly informed by the symposium. David Griffiths and Peter Hegarty are currently drafting a proposal (to be submitted early 2017) for the Provision for Public Engagement from the Wellcome Trust to add-on to David Griffiths’s fellowship to bring on one intersex activist, Valentino Vecchiotti, to lead on public engagement around David’s historical work. Valentino’s presence at the symposium allowed significant development of this project. That work will also draw on and build engagement with the stakeholder groups represented at the symposium (for example Klinefelter’s Syndrome Association and Living with CAH). Another ongoing project is a

collaboration with InterACT looking at psychological reactions to YouTube videos promoting public awareness of intersex.

Acknowledgements

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Final thanks must go to participants, speakers, and presenters for attending and contributing. Many individuals are volunteers or low-waged, and the organisation committee are very grateful for all the generosity all individuals showed with their time, resources, and personal stories.

David Griffiths (d.a.griffiths@surrey.ac.uk), Peter Hegarty, and Kamila Hawthorne.