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## Editorial Introduction

### Intersex: Cultural and social perspectives

Intersex has been a topic of much discussion in courses on sex and gender in the academy. Much of this discourse has centred on the nature of intersex and how far it challenges the categories of sex and gender. As Emi Koyama and Lisa Weasel pointed out in 2002, this form of academic appropriation risks diverting attention from important social justice issues towards trivial or reductive theorising about social construction. Academic enquiries into the oppression of people with intersex variations may only sometimes be helpful in bringing hegemonic forces of body normativity, prejudice, and sex/gender norms into question. Some scholarship on intersex has attempted to include the *experiences* of intersex people to a greater extent. This research has been empirical (for instance Kessler 1998, Preves 2003, Karkazis 2008, Davis 2015, 2015a, Monro et al 2019, Crocetti et al 2020), autoethnographic or informed by personal experience (Holmes 2009, Morland 2009, Davis 2015, Rubin 2017, Carpenter 2018, 2020, and Malatino 2019) and archival (Griffiths 2018, Dreger 1998). Rather than focussing on what intersex people *are*, this growing body of work has examined the challenges that intersex people face, which include systematic oppression, discrimination and human rights violations (Ghattas 2013, FRA 2015, Carpenter 2016, Crocetti 2020). The emerging field of interdisciplinary intersex studies, therefore, can be characterised by the co-constitution of knowledge with the individuals and communities it seeks to study, as Intersex activists (both academics and non-academics) are important authors in the field. This special issue brings together some of this work and introduces interdisciplinary intersex studies to a wider audience. This editorial provides an overview of intersex issues, paying homage to the activists and academics who have forged the development of this field.

Intersex studies is still emerging as an interdisciplinary area of enquiry. Medical publications have appeared that highlight patient experience and the need to re-examine outdated medical protocols in this light. This body of literature includes studies recommending non-interventionist approaches with children (Bougneres et al 2017) and studies by healthcare providers that stress the cultural forces shaping parental choices (Streuli et al 2013). Critical approaches include analysis of the historical construction of intersex and its medicalisation, including the development of surgical norms (Holmes 2009 and Griffiths 2018a). These complement the work of early authors such as Kessler (1990), Dreger (1998), Chase (1998), and Fausto-Sterling (2000). More recent critical intersex studies include the work of Koyama

(2002), Preves (2003), Cabral (2009), Davis (2015, 2015a), Davis et al (2016), Carpenter (2016, 2018, 2020), Ferrara and Casper (2016) and Das (2020). A clear focus on human rights is central to intersex studies, given the extent of human rights violations faced by people with variations of sex characteristics. Recent writing of this kind includes articles by Ghattas (2013), Carpenter (2016), Bauer et al (2019), Monro et al 2017, and Crocetti et al (2020). Critical legal approaches to sex variance, which also address the human rights issues, include work by Fox and Thomson (2017), Horowicz (2017), Garland and Slokenberga (2018) and Garland and Travis (2018), Travis (2015). Recent psychosocial healthcare research is reviewed in Roen (2019).

This Special Issue of *Culture, Health & Sexuality* seeks to further advance intersex studies, opening up unmapped territory concerning intersex issues. Discussions of social and cultural concepts of “intersex” can lack grounded, “bottom-up” engagement with communities (Koyama and Weasel 2002). In globalized medical practices originating in the West, “male” and “female” are generally presumed to be discrete and homogenous biological categories. However, there are cross-cultural variations in sexed and gendered presentations, both historically and in contemporary societies. Building on these insights, this Issue questions the way in which bodies are conceptualised as normatively male or female, with intersex variations too often framed as abnormalities or at best anomalies to be rendered invisible through management within medical establishments and the private familial realm (Carpenter 2018). Contributions from authors in diverse contexts expose the ways in which legal and medical structures are inadequate in relation to intersex bodies, but also address reform and change (Garland and Travis 2018). By grounding discussion within empirically-based case studies with wide international reach, the Issue highlights debates that have social relevance, thereby not treating intersex as a theory-building trope. In-depth studies are provided in the context of several countries including Belgium, Germany, Israel, Italy, New Zealand, Switzerland, and the UK, with other papers providing an analysis of cross-cutting international concerns (including human rights and religious conceptualisations of sex characteristic variations). Specific issues relevant to intersex theory are explored in a comparative context, including categorization systems of sex, gender and sexuality, the discursive formation of identities, the role of front-line practitioners in creating intersex body-knowledges, the medico-legal framing of intersex, and the international flow of human rights discourses and resistances to these.

By focusing on intersex issues, this special issue opens up a still under-researched field somewhat further. We hope that it will be of particular relevance to those working across the fields of sex, gender and sexuality, including sociologists, cultural theorists, feminists, queer theorists, gender theorists, and particularly scholars working on bioethics, human rights and disability theory. Contemporary intersex studies and activism makes real the dilemmas of grounding social, cultural, and legal categories of personhood in bodily differences. What then do the demands for reform in healthcare settings around intersex tell us about the range of real and imagined human subjects and life-courses that have organised practices in those contexts? And what are the broader social and cultural implications of recognising intersex?

In the nascent field of interdisciplinary intersex studies, terminology (and consequently definitions) have raised a number of difficulties. Whilst most activists and scholars prefer the term “intersex”, others, particularly medical professionals and those working in close

partnership with them have preferred the term “Disorders of Sex Development” (DSD – coined in 2006) or “differences of sex development (dsd)<sup>1</sup>. In 2015, Malta gave legal protection to “sex characteristics”, building traction for the use of the terminology “Variations of Sex Characteristics” (VSC) in legal and human rights discussion. However, it is worth reflecting on the fact that in her work in the UK and Sweden, Lundberg found that only a minority of young people with variations of sex characteristics had heard of the term “intersex” (Lundberg et al 2018). Due to the pathologising connotations of the term DSD for both intersex people (Davis 2015) and lay audiences (Hegarty et al in press), and the potential for VSC to be understood as both innate and acquired, this editorial will use the more common term intersex. Other authors throughout the special issue do, however, draw upon a range of terminology.

In terms of definition, intersex has been described by the UN Office for the Commissioner of Human Rights as an:

...umbrella term used to describe a wide range of innate bodily variations in sex characteristics. Intersex people are born with sex characteristics that do not fit typical definitions for male or female bodies, including sexual anatomy, reproductive organs, hormonal patterns, and/or chromosome patterns” (HCHR 2019).

Whilst the United Nations estimates that between 0.05% and 1.7% of infants are born with intersex traits (HCHR 2019, Fausto-Sterling 2000), these figures are socially constructed in the sense that medical definitions of intersex remain contested (Griffiths 2018). As the UK’s Government Equalities Office recently recognised, surveys in this area are difficult to conduct as they need to contend with the stigma associated with intersex variance. The authors note difficulties with estimating the number of people in the UK with variations in sex characteristics. UK. The reasons for this include:

Firstly, for some, the variation may never be apparent. Secondly, some people may not disclose information when asked, for example via a survey. Thirdly, there exists no consistent definition or approach to collecting data of people with variations in sex characteristics (GEO 2019: 8).

Intersex people face a wide variety of barriers to social justice on the basis of their variance including infanticide and murder (Carpenter 2020) and abortion on the grounds of chromosomal “abnormality” (Jeon et al 2011). Structural inequalities also manifest in the form of surgery and related interventions carried out on babies and children which are typically reported as having poor and/or damaging outcomes (see for example Creighton et al., 2001; Diamond and Garland, 2014) and which may lead to “unacceptable levels of physical and psychological trauma in patients” (Ferrara and Casper 2018, 1). The cultural and institutional oppression of intersex people is apparent in the continuation of non-consensual and medically unnecessary so-called “normalising” surgeries on infants and children. Surgical intervention aimed at making intersex infants and children conform to sex binaries is also linked to the erasure of intersex at legal and cultural levels (Travis 2015). These “invisibilities”

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<sup>1</sup> see Jenkins and Short 2017 for a discussion of terminology and associations.<sup>2</sup> Endosex: a person that was born with physical sex characteristics that match what is considered usual for binary female or male bodies by the medical field.

remain largely unnoticed because of social and cultural forces that render intersex people beyond the protocols and frameworks that protect people in many states internationally. As Davis and Murphy note, “The otherwise healthy intersexed body is situationally made an exception [to usual medical ethical procedures] and physically altered to buttress the sex binary” and sexuality and gender norms (Davis and Murphy 2013, 130). Academic analysis of the processes by which intersex people are robbed of their bodily integrity is required. In particular, it is important to investigate in the ways in which the actors who perpetrate human rights violations and discriminations against intersex people, especially infants and children, are legitimated and protected by dominant social norms and institutions.

Intersex rights movements and a range of international organisations and supranational legal bodies (including the United Nations, the Council of Europe and Yogyakarta Principles+10) condemn cosmetic medical interventions on intersex minors and the routine termination of intersex foetuses on grounds of medical “abnormality” (Holmes 2008; Crocetti et al 2020). Intersex activists and advocates have asserted the human rights of intersex people, including the right to freedom from discrimination; the right to protection from torture and other cruel, harmful or degrading treatment, and the right to health (Horowicz 2017; Behrens 2020). However, a cultural shift towards the prioritising of intersex human rights has not become prominent in medicine, where the difference between embodied variation and medical abnormality can be blurred. The terrain is contested, with some actors in healthcare supporting a move towards postponing medical interventions until a child is able to give consent (Schoer et al 2018). However, entrenched and traditionalist medical and social norms impede attempts to change practices to support bodily diversity and to ensure intersex people have equal citizenship to endosex<sup>2</sup> people (Monro et al 2019, Roen and Hegerty 2018). Intersex and VSC therefore foreground a particularly sharp set of inequalities regarding cultural norms, social institutions and health beliefs.

This special issue of *Culture, Health & Sexuality* therefore presents a timely consideration of matters pertaining to intersex and VSC. Theoretically and empirically, the papers it contains aim to facilitate topical reflection on core issues of body normativity, sex and gender categorisation, human rights violations, and the role of social, cultural, and medico-legal systems in the formation of identities. In countries such as the UK, governments are at the early stages of engaging with intersex issues (see GEO 2019) but there is a lack of scholarship to address and inform developments. Numerous UN bodies have called on nations to address rights issues in intersex and VSC medical protocols and procedures. Whilst Malta, Portugal and the US state of California are notable exceptions in having stipulated protections for intersex minors, national legislation is lagging in most nations and there is a pressing need for research about the effects of this on intersex people. The issue’s strengths include its empirically-grounded approach, which allows for a drilling down into the complex issues raised by intersex embodiment (such as bodily self-determination for minors and the globalization of medical standards for biological sex); national and global practitioner approaches to intersex; and the discursive and institutional structuring of sex diversities. By taking an international approach, the issue opens up debates about the globalisation of traditionalist binaried legal and medical approaches to sex diversities, examining these in relation to increasingly globalised intersex rights claims.

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<sup>2</sup> Endosex: a person that was born with physical sex characteristics that match what is considered usual for binary female or male bodies by the medical field.

The papers in this special edition straddle a number of themes of relevance to intersex studies. Together, they provide the data with which to meaningfully analyse the contentious framing of intersex as natural variation versus a difference to be fixed or eliminated from very different disciplinary standpoints. The importance of the co-production of knowledge between intersex and endosex people, which we referred to at the start of this editorial, is addressed in several of the included papers. Limor Meoded Danon and Katinka Schweizer's paper, for example, explores the development of a practical tool for psychosocial care in relation to intersex. Denise Steers, Georgia Andrews, Esko Wiltshire, Angela Ballantyne, Maria Stubbe and Sunny Collin's article examines intersex young people's experiences in Aotearoa/New Zealand. Different perspectives and controversies in the field are identified in Ute Lampalzer, Peer Briken and Katinka Schweizer's short report, with the aim of reflecting on future patterns and processes of care. Marta Prandelli and Ines Testoni highlight the often inexact understandings of general practitioners with respect to intersex, providing context for Daniela Crocetti, Surya Monro, Valentino Vecchiotti and Tray Yeadon-Lee's findings that intersex individuals must negotiate stigma and stereotypes in general care. Crocetti et al. examine what obstacles to the development of agency-based healthcare pathways in the light of human rights frameworks.

In both medical contexts and beyond, human rights remain an important issue for intersex studies. Morgan Carpenter's article analyses the evolution of the Yogyakarta Principles as a means of promoting the rights of intersex people. He also tackles the way in which the DSD reframing of intersex traits enabled the reinscription of medical authority over intersex people, further marginalising human rights claims and related activism. His paper moves beyond this to identify ways in which the language of "sex characteristics" can address intersex rights issues. Susannah Cornwall examines intersex human rights from a different angle in her analysis of Abrahamic religions and intersex. She shows that whilst intersex may challenge key tenets of sex binarism as underpinned by religious norms and cultures, specific features of these religions, notably the idea of diverse forms of embodiment as a gift, can be used to promote and support the wellbeing of intersex people and their human rights. Annette Smith and Peter Hegarty's paper demonstrates the socially constructed nature of human rights claims by looking at the way in which clitorectomies performed on infants identified as female are more consistently recognised as human rights abuses than clitorectomies on infants who are seen as intersex.

A number of articles in the issue address particular social, cultural and geographical framings that contextualise the ongoing pathologisation in this arena. Carpenter addresses the need for cultural sensitivity in developing human rights protections to avoid both the risk of neo-colonialist rights framings, and ineffective protections. Cornwall analyses the institutions of Abrahamic religions in some depth in relation to intersex, particularly focusing on constructions of life as gift from God. Smith and Hegarty address clitorectomies as procedures pervasively carried out in medical contexts on intersex minors who are unable to consent. Pieter Cannoot analyses recent experience in Belgium as a case study in demonstrating the complex ways in which law as an institution maintains the medicalisation of sex variations, thereby legitimating continued human rights violations despite some movement towards support for intersex human rights. For Cannoot, Belgian law fails to protect people with VSC, due to the way in which sex is conceptualised in legal terms. Cannoot also addresses the

institution of the family, and the highly problematic substitution of parental consent for the consent of the individual, when it comes to irreversible sex-normalising medical procedures on intersex minors. Both Crocetti et al. and Prandelli and Testoni's articles address how homophobia, transphobia, and other social prejudices are articulated in medical practitioner's discourses on intersex in Italy. Danon and Schweizer reflect on sociocultural themes that impact on intersex people's current status in Israel and Germany and ways to improve psychosocial intersex care using an action research framework.

Agency and bodily autonomy arise as key facets of intersex rights claims, as academic production and human rights work build on each other within this field. Directly or implicitly drawing on critical disability theory, many of the articles highlight the importance of knowledge co-production in this conflictual arena where an unequal playing field for self-determination and bodily integrity still exists. Lampalzer et al's contribution demonstrates some of the complexities faced by intersex people, parents, psychologists and medical professionals in addressing issues of childhood bodily integrity and social and emotional wellbeing. The importance of the concept of agency in elaborating a model of intersex health is central to Crocetti et al's paper. By focusing on young people's experiences, Steer et al. draw out the need for these voices to be integrated in to how intersex is addressed. Danon and Schweizer reflect on how action research can be useful in disrupting biomedical discursive dominance.

The erasure, elision, marginalisation of, and discrimination against, intersex people is a theme that weaves through all of the papers in the special issue. Carpenter elaborates how human rights law seeks to create encompassing protections for these issues. Cannoot's paper shows how cultural and social norms reinforce sex and gender binaries more broadly, leading to hardship in the everyday lives in people with VSC. Prandelli and Testoni addresses how health professionals in Italy understand variations of sex characteristics, reflecting on how lack of knowledge combined with social prejudice impact how professionals act in clinical settings. Parents and healthcare professionals in Lampalzer et al's report discuss difficulties with managing perceived and real discrimination against intersex children, but also foreground some of the values and approaches that can assist in the provision of appropriate care to intersex infants and children. Statements from medical practitioners are juxtaposed against activist and advocate experience in Crocetti et al., highlighting the ongoing overlay of prejudicial framings in how VSC is treated in medical settings and beyond. In a complementary approach, Smith and Hegarty demonstrate how IGM (Intersex Genital Mutilation) is considered more socially and culturally legitimate in the UK than FGM (Female Genital Mutilation), especially among lay people with high levels of statistically greater trust in medical authority.

This issue builds upon the work of academic and activist authors (for example Kessler 1990 and Chase 1998), who first brought the hidden and controversial issue of intersex experience to light. It intends to create further grounding for the field and encourage new research beyond that represented in the following pages. We recognise that academia is unequally structured, and that endosex health professionals and researchers have appropriated and colonised the lives of intersex people in ways that benefit their own careers without proper attention to positive change. Moreover, intersex people who have experienced medical abuse and/or social discrimination do not enter a "level playing field" with endosex people, in

accessing academia and contributing to knowledge production. Collaboration between intersex and endosex people helps to address these issues, and this edition is one such collaborative effort. It is our hope that the writing here will encourage a flourishing of impactful scholarship in this field and beyond, particularly by intersex scholars and their allies, as exemplified by the Innovative Training Network INIA<sup>3</sup> launched in early 2020.

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<sup>3</sup><https://www.intersexnew.co.uk/#:~:text=INTERSEX%3A%20NEW%20INTERDISCIPLINARY%20APPROACHES&text=INIA%20is%20a%20new%20international,a%20range%20of%20key%20sectors>. The INIA project received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 859869.

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