

# **Intersex/Variations of Sex Characteristics and DSD: Citizenship in the UK, Italy and Switzerland**

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**Abstract:** *Citizenship studies is highly relevant to understanding intersex, variations of sex characteristics (VSC), and Disorders of Sex Development (DSD), yet little scholarship exists to date about intersex citizenship. This article outlines and develops the foundations for a distinctive intersex citizenship studies, addressing health citizenship, children's citizenship, legal rights, and breaches of human rights experienced by intersex people and those with DSD. The paper presents original qualitative data from research in the UK, Italy and Switzerland with intersex people and their advocates, medics, and policy stakeholders. It shows that asserting citizenship is crucial for intersex people and those with VSC or DSD. This extremely marginalised population require social, intimate, children's and health citizenship. Intersex citizenship addresses both medical and human rights issues in an integrated way.*

**Keywords:** Intersex, DSD, citizenship, child, rights, gender, sex

## **Introduction**

Intersex people and those with variations of sex characteristics (VSC) face a dearth of citizenship rights across a range of different areas. Infants and children with VSC are routinely subject to invasive, non-consensual medical interventions leading to ‘unacceptable levels of physical and psychological trauma in patients’ (Ferrara and Casper 2018, 1).

Intersex activists have emerged at national and international levels to assert the human rights of intersex people. These rights include the right to freedom from discrimination, protection from torture and other cruel, harmful or degrading treatment, the right to the best interests of children, and rights to health (Horowicz 2017). There have been extensive calls by the United Nations, the Council of Europe, and the European Union to reform legal systems to prevent intersex human rights violations and to redress them. However, at a national level, there is failure to protect children with VSC in most states (Garland and Slokenburga 2018).

This article provides an original contribution in arguing that a citizenship approach may be useful internationally in supporting the human rights of intersex people and those with VSC, because it offers analysis that addresses the full range of factors and processes that impede or support these human rights. There is a large gap in citizenship studies regarding intersex and VSC, which we begin to address. We aim to build a foundation for the future development of intersex citizenship studies, by drawing on established bodies of citizenship theory, integrating empirical findings from an international study with citizenship approaches, and pushing the field forwards in an innovative way.

The term 'Intersex' refers to people born with a combination of sex characteristics (chromosomal, gonadal and/or anatomical)<sup>1</sup> that do not fit the typical definitions of male or female (Lee et al. 2006). The United Nations estimates that between 0.05% and 1.7% of

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<sup>1</sup> Including hormone receptor variants.

infants are born with intersex traits<sup>2</sup>. It should be noted that intersex people, those with VSC, and those with Differences or Disorders of Sex Development (DSD) are a highly diverse group of people<sup>3</sup>.

There is considerable variety in the agendas of intersex activists (Grabham 2007) and across the range of activists and DSD patient advocates (Monro al. 2017). Key issues agreed by intersex activists at a European level include a requirement to stop medical practices such as non-consensual cosmetic genital surgeries and forced sterilisations, and to cease selective termination of intersex fetuses and gender-normalising prenatal interventions. The Fourth International Intersex Forum addressed issues including infanticide, intersex genital mutilation and other harmful medical practices, and a lack of appropriate and consensual health care as well as discrimination in access to education, other services and employment (OII Europe 2017). Some intersex activists are concerned with specific intersectional issues, for instance intersex Christian activists Lianne Simon and Sarah Gillingham raise awareness of intersex and challenge prejudice within faith forums<sup>4</sup>.

Overall, ‘A global and decentralised intersex movement pursues simple core goals: the rights to bodily autonomy and self-determination, and an end to stigmatisation’ (Carpenter 2016, 74). Intersex activist agendas focus on specific rights issues such as non-consensual medical interventions on minors, rather than broader legal reform. As Garland and Travis contend, ‘...differing legal constructions of intersex can entrench vulnerability rather than enhance resilience’ (2018: 590). This is because a focus on formal legal equality (addressing

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<sup>2</sup> HCHR. (n.d.) Fact sheet: Intersex. Retrieved from: [https://unfe.org/system/unfe-65-Intersex\\_Factsheet\\_ENGLISH.pdf](https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf)

<sup>3</sup> This paper uses the terms ‘intersex’ and ‘variations of sex characteristics (VSC)’, however it should be noted that some people with VSC and/or specific conditions such as Klinefelter’s syndrome do not relate to the term ‘intersex’. We include the problematically pathologising term Disorders of Sex Development ‘DSD’ (which is sometimes reframed as differences of sex development) in places as it is used in medical contexts.

<sup>4</sup> <http://www.liannesimon.com/>; <https://badshotleaandhale.org/2018/08/10/being-intersex-in-the-house-of-god/> (both accessed 01.05.19).

individual and local issues) can reinforce existing social inequalities. Substantive equality, that tackles embedded and systemic inequalities, is required for intersex citizenship. The focus of the article will be on rights issues.

The issues facing people with VSC could be remedied at an international level in human rights frameworks, in particular the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights of the Child (UNCRC). Activists have argued for example that under the UNCRC Articles 2, 3, 12, 16, 24 and 37 are breached when genital normalising surgery takes place on infants (see Bauer and Truffer 2014)<sup>5</sup>. Non-essential VSC medical treatments are increasingly seen as human rights abuses, with statements from numerous UN agencies and the Council of Europe (2015; 2019).

We conducted qualitative research in Italy, Switzerland and the UK in order to gain an in-depth understanding of activist and policy perspectives concerning VSC in the three case study countries. We used documentary analysis and semi-structured interviews with intersex activists and patient advocates, NGO, governmental, and medical representatives, and participant observation with the activist organisation *Zwischengeschlecht*<sup>6</sup>. The data used in this article was mostly generated by the 40 interviews that were conducted between February 2017 and December 2017. The activists and advocates were accessed via known gatekeepers using a snowball approach. We attempted to include representatives of each publicly visible activist or advocacy organisation that actively addressed VSC in the three countries. We also sought to include as many medics and policy stakeholders working in the area as possible. The interviews carried out with activists investigated the diversity of views about healthcare provision, agendas and strategies and also the range of actions that have advocated for policy or legal changes. The interviews with NGO, governmental, and medical representatives

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<sup>5</sup> Concerning the German case; see <http://intersex.shadowreport.org/> (accessed 03.05.19).

<sup>6</sup> <http://zwischenGeschlecht.org/> (accessed 03.05.19).

explored initiatives concerning VSC, perceptions of activist and patient organisations, views of national, EU, and international human rights frameworks, and other pressures experienced, for example, in relation to stakeholders and existing barriers to the rights and agendas of people with VSC. A thematic approach, which draws out topical themes and issues for analytical comparison (Braun and Clarke, 2014) was used to analyse the material gathered through these methods. The research followed strict ethical guidelines which met all EU and national legal and ethics requirements. Data was anonymised except where participants wished to be named in person.

[Table 1 here]

The article begins with a review of existing approaches to citizenship that can be used in building models of intersex citizenship. It then provides analysis of the empirical materials in relation to different approaches to citizenship. We start with legal aspects of intersex citizenship, and then look at several other key interrelated issues: foetal terminations, issues of bodily integrity, citizenship issues for children with VSC, and reproductive citizenship. The paper then addresses overarching issues pertaining to intersex health citizenship. We conclude by summarising key facets of intersex citizenship. The article is focused on the Western/Northern context and does not engage with the many issues facing people with VSC in the global South (see Kaggwa 2016). We recognise the dangers of intersex advocacy and scholarship that fail to interrogate its locational and postcolonial dynamics, risking a reiteration of existing global power inequalities (Rubin 2015); more research is needed to address this.

### **The foundations for intersex citizenship**

The existing literature on intersex citizenship and the citizenship of people with DSD and VSC is very limited. Early discussions of intersex citizenship emphasised the importance of

stopping non-consensual surgeries on minors (Monro 2003). However, Monro's early work places intersex under a broad umbrella of transgender diversity, a move that is highly problematic, as intersex people's issues are distinct from those of transgender people (see Monro et al 2017)<sup>7</sup>. This flawed amalgamation of transgender with intersex is evident in some later citizenship work (McQueen 2014). However, the emphasis in these accounts on bodily autonomy, and access to healthcare if/as desired by the intersex individual, are central to building contemporary intersex citizenship models. Grabham (2007) also developed notions of intersex citizenship, documenting intersex activist critiques of treatment protocols. However, to date, other key aspects of intersex citizenship have been left unaddressed.

Following T.H. Marshall's *Citizenship and Social Class and Other Essays* (1950), citizenship can be seen as three sets of rights: political rights, legal rights and social rights. For intersex people, these rights are critically important, because surgical interventions aimed at making infants and children with VSC conform to sex binaries have led to an erasure of intersex at legal, policy, and cultural levels (see Travis 2015). Whilst, as we have indicated, human rights frameworks to support intersex people exist at supranational level, there is a dearth of legal recognition and protection for this population in most countries. As Horowicz states, 'There is no legal recognition of intersex individuals being recognized outside of the binary biological sexes' and the legal necessity of identification as m or f renders them vulnerable to surgical intervention (2017: 192). Social rights are lacking on a range of fronts, particularly for children and in relation to appropriate healthcare provision (Monro et al. 2017). Because gendered and sexed inequalities structure the lives of people with VSC very heavily, we also include feminist, sexual, and intimate models of citizenship. Together, these approaches form a foundation for the formation of a distinctive model of intersex citizenship.

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<sup>7</sup> Monro's reflexive critique resulted from analysis of activist-scholar literature and data from this project.

Children's citizenship is crucial to intersex citizenship. The practice of non-consensual and unnecessary medical interventions on minors with VSC is a serious pressing issue; '...infant genital-normalizing surgery subjects the intersex child to a brutal form of physical integrity interference' (Horowicz 2017: 185). Children's citizenship entails attention to the human rights of minors, their particular needs for services and benefits delivered to them by both families and wider society, and the obligations imposed on them. As noted by other citizenship scholars: 'Citizenship is of special importance to children, as their sense of belonging and identity develop throughout childhood and their practical rights are far from being fully realized' (Ben-Arieh and Boyer 2005, 35). This assertion is starkly relevant to intersex infant and children's citizenship, as we will document below. The issues are discussed in the literature about intersex. For instance, Horowicz (2017) argues that a legally- and professionally-regulated framework for decision-making concerning infant surgeries is needed, with safeguarding embedded within healthcare provision, whilst Garland and Slokenberga (2018) discuss the problem of incorrect gender assignment at birth, followed by irreversible medical interventions that render the minor unable to actualise later gender choices. Human rights authorities condemn non-consensual gender-conforming childhood interventions (see Garland and Slokenberga 2018) but there is a failure to reform current practices in most countries.

Child participation in decision-making forms another aspect of children's citizenship. Following the Convention of the Rights of the Child; it should extend to all aspects of children's lives (Ben-Arieh and Boyer 2005). More broadly, as Roche (1999), contends, children have less power than adults, so their choices and their possibilities to exercise agency are limited, and 'Children have experienced multiple exclusions from the public world – invariably in the name of their welfare' (Roche 1999, 481). Roche's plea for valuing children's contributions to society and for listening to them is especially poignant in relation

to minors with VSC, whose parents and medics often choose irreversible medical interventions, supposedly for their welfare, whilst they are too young to make an informed contribution to decision-making. Children's participation in decision-making about their medical treatment is supported by Article 24 of the United Nations Convention of the Rights of the Child (UNCRC). The inclusion of children in decision-making processes about them is paramount for intersex children's citizenship. However, there is an absence of discussions regarding children who have VSC in the children's citizenship literature.

A further strand of citizenship studies that may yield some conceptual scaffolding for developing notions of intersex citizenship is that of health citizenship. Ponce et al. address citizenship broadly in a healthcare context; 'it is defined by a person's connection to rights, responsibilities, roles, resources, and relationships' (2016, 161). Clearly, the notion of rights, which is used here to include legal and social rights, is central to intersex citizenship. People with VSC are excluded from full citizenship in many ways, notably due to the pathologisation of VSC within healthcare settings. Medicine still defines VSC as abnormal, and supports their cosmetic 'correction' by 'perpetuating binary framing of sex through surgical intervention' rather than addressing the issue of a lack of social acceptance (Horowicz 2017: 185). As Garland and Slokenburga suggest:

The severe evidentiary deficit of therapeutic benefits of these interventions is significant because it demonstrates that it is known (or should have been known) that the interventions in question are likely to be unnecessary as well as to result in irreversible mutilation of children's bodies' (2018: 6).

Whilst health citizenship in the VSC field revolves around a critique of current medical practices, the notion of resources is also useful to intersex citizenship. The medical focus on the cosmetic aspect of childhood VSC is in contrast the lack of resources for adults, in terms

of both quality medical care and services to address trauma derived from childhood treatment. Resources, if available, could also be used for awareness raising, education, improved client-centred treatment, the training of healthcare and medical practitioners, and of course supporting activist and advocacy organisations. Access to excellent healthcare forms one plank of health citizenship (Gorman 2010).

The feminist citizenship literature is relevant to intersex in a number of ways. Historically, citizenship has been constructed in the 'male image' (Pateman 1988), and one of the major contributions that the large literature on gender and citizenship has made is a critique of the masculinist nature of traditional approaches. Intersex women could benefit from this kind of analysis. Other aspects of feminist citizenship analysis are pertinent, for example the notion of 'redistribution', developed by feminist political scientist Fraser (2000), which could be used to support a relocation of medical funds from surgical to non-surgical care pathways. Importantly for intersex citizenship, feminist models of citizenship challenge the public-private divide that is associated with the Marshallian model. The pathologizing, biomedical model of intersex locates sex variance in the private sphere, away from state responsibility (Garland and Travis 2018). However, gender and sex diversity are not properly addressed within feminist citizenship theories, which often rely on simplistic ontologies where sex/gender are conflated and binary. Normative binaried sex characteristics act to privilege non-intersex people internationally; this majority group avoid the risk of being terminated as foetuses, experiencing infanticide due to having VSC, or enduring medically unnecessary interventions that often lead to major health problems. Normative sex characteristics and the socially ascribed gender roles that accompany them underpin the citizenship privileges that non-intersex cisgender women, as well as men, experience.

Sexual citizenship supplies another resource for developing intersex citizenship theory.

Richardson (2000), using a model of sexual citizenship that concerns sexual rights and duties,

delineates three areas of sexual rights claims: conduct-based, identity-based, and relationship-based. The first of these, conduct-based, includes rights to enjoy sexual pleasure. For many people with VSC, who have experienced repeated violations of their genital integrity, the loss or damage of capacity to engage in pleasurable sex is marked (see Creighton et al 2014). A related, relationship-based concern is that one reason for unnecessary medical interventions on intersex people is a desire, amongst medics and/or parents, to enforce conformity to male/female binaries and heterosexuality (see Monro et al. 2017).

Intimate citizenship is also useful in considering intersex citizenship. Plummer (2001) defines intimate citizenship as a bundle of rights concerning people's choices about what they do with their bodies, emotions, relationships, gender identities and desires. For intersex citizenship, self-determination concerning bodies and identities is crucial. Nussbaum's notion of bodily integrity is highly relevant; this includes '... having opportunities for sexual satisfaction and for choice in matters of reproduction' (1999: 41-42). It has been applied in the VSC field, for instance, Fox and Thomson (2017) argue that embodied integrity should be prioritised when non-therapeutic interventions are being considered for children with VSC; this includes physical and psychological aspects of embodiment. Notions of bodily integrity could also be useful for legal claims supporting intersex citizenship. For example, Horowicz (2017: 215) suggests that 'protection of a person's physical integrity, as a requirement under Article 8 in *X v. Finland*, using the harm threshold approach supported by the authority of *Glass*, could be collectively applied to infant genital-normalizing surgery'.

Taken together, children's, health, feminist, sexual and intimate citizenships provide conceptual scaffolding for developing citizenship analysis using our empirical findings, which are discussed next. The Marshallian elements are largely addressed via the legal citizenship section, whilst intimate citizenship is especially pertinent to the sections on intersex foetal survival, reproductive citizenship, and the right to family life. Health

citizenship is are addressed in sections on health and the right to freedom from non-consensual medical interventions.

### **Legal citizenship**

People with VSC face a profound lack of legal protection in the case study countries, despite the tranche of human rights recommendations that have been brought in at an international level. As Garland and Slokenburga (2018:1) suggest, ‘This particular “compliance gap” between human rights recommendations and law reform stems from a failure of national legal orders to formally recognize the scope of rights that are threatened by non-consensual gender-confirming interventions...’. Arguably, given the centrality of legal issues to intersex people’s citizenship, a return to citizenship fundamentals is required. The key legal issues for people with VSC in the case study countries include a lack of provision to allow for sex and gender indeterminacy when a child is born; a dearth of legislation to prevent unnecessary non-consensual medical interventions of minors; a lack of provision for intersex people to change sex and gender; an absence of legislation to stop discrimination against people with VSC, and the termination of fetuses with VSC. The absence of legal citizenship has major impacts on the lives of people with VSC. UK contributors said, for example:

*...we are completely, not even thought about in UK law, we don’t exist, we have no rights. It’s a very scary thing (Dawn Vago, Intersex UK)*

*...one of the big issues I’ve personally faced is my birth certificate, that was one issue that affected me during my childhood. Because I was registered male at birth and for the first year of my life was, I was male, when the surgeons convinced my parents to*

*bring me up as female, I still had a male birth certificate and it is incredibly difficult to change a birth certificate* (Joe Holliday, Intersex UK)<sup>8</sup>.

Other activists reported difficulties with birth registration, for instance an Italian contributor is dependent on testosterone treatment because of early medical abuse but cannot access free treatment because he is legally registered as female.

Some contributors discussed the difficulties in conducting litigation against medics who have conducted harmful non-consensual medical interventions on minors. They noted the problem with parents being held legally liable for these interventions, and the issue of laws preventing legal action against medics after a period of time has elapsed since treatment. For example, *'the earlier the doctor operates, the more secure he [sic] is from persecution, and that is sending the wrong signal'* (Marcus Bauer, *Zwischengeschlecht*). The possibility of litigation against medical practitioners was discussed by some contributors, but is problematic. For example, it was reported that the possibility of claiming against a medic expires five years after a medical intervention in the UK, so that intersex people who suffered medical abuse as infants and young children have been unable to seek legal recourse.

Whilst there are huge deficits in their legal citizenship status, there is also evidence of intersex people and their allies exercising agency in gaining legal and policy rights. Some intersex activists and advocates work specifically in order to attempt to get international human rights directives transposed into national law, due to perceptions that *'the legal, professional law reform seems to them the only institutional body capable of standing up to medicine'* (Representative, *Genital Autonomy UK*). This work includes the development of protocols which support the international human rights directives. For example, representatives from *Zwischengeschlecht* in Switzerland use a whole range of international

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<sup>8</sup> National government in Scotland, England and Wales are now starting to consider intersex issues, see e.g. GEO (2019).

legal instruments including the Convention on the Rights of the Child to highlight harmful medical practices on minors. This small unfunded organisation has had some success in creating policy changes in Switzerland, for example via the Swiss bioethics statement<sup>9</sup>.

To summarise, legal citizenship is fundamental to ensuring the basic rights of people with VSC. Activists, including those in the case study countries, want changes in national law so that parents do not have the right to consent to interventions that are unnecessary for life. They argue that the affected child should be allowed to grow up with minimal interference, until they can make their own choices regarding their care.

### **The survival of foetuses with VSC**

The issue of life before birth poses particularly tricky questions, interwoven as it is with parental rights concerning choice. At the *Intersex Social Sciences: Activism, Human Rights, and Citizenship* conference (4-5 June 2018, Bologna), there was consensus amongst intersex activists and advocates that parents should have the right to choose whether to bear a child, but that VSC should not in themselves be a reason for termination.

Protection from termination is absent for the many foetuses that are terminated where sex chromosome abnormalities exist (see Jeon et al. 2011). In England, Scotland, and Wales, the Abortion Act 1967 (as amended by the Human Fertilisation and Embryology Act) section 1(1) permits abortion of foetuses that have VSC even up to the due date, because these conditions could classify as a ‘physical abnormality’. In Switzerland, terminations are available up to 12 weeks but later terminations are at the discretion of the doctors and

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<sup>9</sup> NEK-CNE Swiss National Advisory Commission on Biomedical Ethics (2012). *On the management of differences of sex development Opinion No. 20/2012. Ethical issues relating to “intersexuality”*.

[http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK\\_Intersexualitaet\\_En.pdf](http://www.nek-cne.ch/fileadmin/nek-cne-dateien/Themen/Stellungnahmen/en/NEK_Intersexualitaet_En.pdf). Whilst this Ethics Report is not legally binding, it has shaped approaches to care in Switzerland.

parents. In Italy, pathologising terminology is used for VSC when found in a fetus, and abortion is strongly suggested. The impact of pathologisation is illustrated in the following quotes, from Italian contributors:

*I was immediately told by a bioethicist who was at the convention in 2010 that you [interviewer] participated in as well, when I went to talk with her, she told me 'look, [name of interviewee], if you don't hurry up – as we say around here – and do your research you will not find any intersex people because here the fetuses are being aborted'. (Michaela Balocchi, Intersexioni)*

*...the first opinion [diagnosis] had already been communicated and they [the parents] had all aborted. (Luca, Psychologist and Sexologist)*

Some contributors, for example the representative of the Equality and Human Rights Commission in the UK, called for legal reform to change the inclusion of VSC under the category that renders them vulnerable to termination (see above). Others indicated a need for greater information provision and awareness-raising regarding VSC:

*...if people don't understand that a child who's born with DSD or an Intersex variation can have a normal healthy happy life, then they may choose to abort the foetus, obviously. But if they were aware that, you know, their child, what is normal, you know, what's, what is normal nowadays, their child would be healthy and happy and loved and I think that's the most important thing. Maybe if they've been getting incorrect information and advice, maybe they've been looking things up and not being fully informed (Representative, Scottish Executive)*

Some of the patient advocacy organisations emphasised the way in which they help parents to make informed decisions about whether to keep a foetus, for example a representative of a UK Klinefelter's support organisation reported that they receive enquiries about termination

and that after talking to them, most people continue with the pregnancy. These findings indicate a need for intersex social citizenship as well as legal citizenship, for example greater social awareness, education and equalities provision in order for prospective parents to envisage a positive future for their family (see Monro et al 2017).

### **Issues of intimate citizenship and bodily integrity**

Intimate citizenship (Plummer 1995) and bodily integrity (Fox and Thomson 2017) are important for people with VSC. Our research findings need interpretation within the context of medical practice regarding VSC/DSD, which is usually based on the 2006 Consensus Convention guidelines (Lee et al. 2016). These guidelines were aimed at creating patient centred care focusing on the psychosocial wellbeing of the individual and their family, encouraging psychosocial as opposed to surgical interventions. The updated Consensus Convention guidelines (2006/2016) support fully informed consent and decision making, as well as the postponement of surgeries that can be delayed in the interest of prioritizing sexual and reproductive function. Medical practitioners assert that change has taken place, but their claims are unsubstantiated and the guidelines can be seen to actually entrench the medicalisation of intersex (Carpenter 2016). ‘Human rights violations of intersex individuals persist, deeply embedded in a deliberate history of silencing.’ (Carpenter 2016, 74). These take place in medical settings, where intersex people are subjected to interventions designed to make their bodies conform to narrow social norms concerning male and female bodies (Carpenter 2016). The outcomes of surgical procedures and medication on babies and children with VSC are typically reported as being poor and/or damaging (see Diamond and Garland 2014), with a dearth of evidence for their success. Problems are documented concerning a range of interventions, for instance hypospadias surgical procedures have a high complication rate, often necessitating repeat procedures and causing life-long urinary tract infections or repeat fistulas (Lorenzo et al. 2014). Morland (2009), among others, claims that

early childhood cosmetic surgical procedures do not provide the child with a ‘normal’ body and healthy self-esteem, but rather a surgically marked and scarred body, which can lead to difficulties with physical intimacy as an adult. It should be noted that numerous VSC have no documented health impacts<sup>10</sup>, so their pathologisation is irrational. Certain interventions can be vital for physical health, for example in the case of salt-wasting congenital adrenal hyperplasia, however these can be enmeshed with gender-normalising interventions (see Carpenter 2016). Medical practice is not uniform; some medics are critical of unnecessary surgeries (Davis and Murphy 2013) and some medics working in area state that they share concerns about social discomfort towards gender [sic] variances with intersex activists (Cools et al. 2016).

Across the three case study countries, surgical procedures are still being conducted on infants and children too young to give informed consent. For example, in the UK genital surgical procedures that are cosmetic and unnecessary for physical functioning, including operations on the clitoris, continue to be performed on minors (Monro et al. 2017). Early surgical interventions are discussed by activist contributors, for example:

*...physicians publicly making comments...inferring that its not easy for a man to feel masculine if he has to sit down and pee. I would argue its far harder for a man to, it's a far greater issue for a grown male to be precluded for the rest of his life from sexual pleasure and experience lifelong discomfort due to fistulas and repetitive operations on what's sold very simply as a simple operation [for hypospadias]...cutting into someone's penis isn't a simple basic procedure and I think if you spoke to people who have experienced that and the damage and the trauma of living through the*

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<sup>10</sup> See for example <https://www.hfea.gov.uk/pgd-conditions/>

*symptomatic impact of those surgeries, then you would recognise that the whole approach to this surgical intervention needs to stop (Holly Greenberry, Intersex UK)*

*...we don't say no surgeries should take place, but you know, certainly leave the child alone, if the child has a healthy body, there's no point performing cosmetic surgery on an infant who doesn't know if its going to be a boy or a girl, you know. At least let the child grow up and develop into the child it wants to be (Dawn Vago, Intersex UK).*

The dearth of intimate citizenship rights for minors with VSC is not restricted to early non-consensual surgeries. The use of hormone therapy on this group was questioned by some research contributors; it was seen as experimental and liable to failure as a child's identity may change as they mature. Some contributors discussed the damaging effects of sensitivity testing on minor's genitals, inappropriate medical examinations, and medical photography of children's genitals. In addition, the surgical procedure of vaginoplasty requires aftercare that involves vaginal dilation; which is still practiced on infants and children although the 2006 Consensus statement states that it should not take place before puberty. Vaginal dilation can be described as a form of medical rape<sup>11</sup>. Research shows that childhood vaginal dilations can lead to severe psychological problems, as they can be experienced as bodily violations (Ehrenreich and Barr 2005). Our research findings demonstrate criticism of the practice of vaginal dilations:

*A vaginoplasty for a girl who is either a few months or a few years old, what does she need it for? Then she is forced to carry out dilations if she wants to maintain it well, so it doesn't make sense. I have to say, about vaginoplasty... I was called in to provide counseling at another hospital where it was done at the age of a year and a half, and*

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<sup>11</sup> Holly Greenberry, personal communication 12.06.2017.

*we are talking about mid-2000s...this is now undergoing stenosis and the parents are being forced to dilate a child who is not dilated. What does she understand? That is, it's physical violence (Luca, Psychologist and Sexologist)*

The research findings showed considerable variation in the approaches taken by the medical practitioners working in the VSC/DSD field. Whilst some assumed that early surgical and other interventions were the best route, others tried to delay or avoid irreversible interventions. This could be due to changes associated with the (slow) implementation of the Consensus statement, or awareness of the problems with surgery, or because of their knowledge of the prejudice against minors with non-normative sexed bodies. Attempts to delay operations were discussed, for example, by one of the Swiss medics:

*...we try to understand why parents want to have a certain intervention and there I am also involved as an activist or as a person, as a doctor, as a neutral person maybe and we try not to include fears or unspoken, un-reflected social pressures into the decision-making...we want to operate as little and as seldom as possible (Hans Meier, medical practitioner)*

The continuation of bodily violations of minors with VSC for social reasons rather than for essential physical functioning has a number of causes, including traditionalism, professional protectionism and preferences amongst medics, a lack of training, patchy or non-existent national protocols, and secretive practices taking place in an uncoordinated fashion across different hospitals. In some cases, the pathologisation and medicalisation of VSC is supported by religious bigotry<sup>12</sup>, even though this has been challenged by authors such as De Franza

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<sup>12</sup><https://www.christiantoday.com/article/im-an-intersex-christian-and-its-time-the-church-listened-to-me/131867.htm>

(2015) who takes a conservative theological stance in arguing for the inclusion of intersex people by Christians; like other people, they are made in the image of God<sup>13</sup>. Motivations stemming from sex and gender binarism, and related heteronormativity, were highlighted by contributors from the UK and Italy, and reflect assertions in the literature, that ‘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). This phenomena is illustrated in the following quote:

*I carry out a large number of genitoplasty operations when the children are no more than one year old...then before menarche run a check in the operating room and if there is a vaginal tightening we re-operate. This is so the girl feels alright [sic], instead of waiting and saying ‘well if she starts being sexually active then we’ll perform surgery...’ but this makes our girls feel blocked when approaching the opposite sex, because they feel inadequate (Paediatric Urologist, Italy)*

Here, sexual citizenship models which challenge heteronormativity (for instance Richardson 2000) are important; challenging the heterosexist and in some cases homophobic underpinnings of interventionist treatment norms could enable a broader, more inclusive set of practices to evolve that support minors with VSC whatever their eventual sex, gender, and sexual identities. However, another aspect of sexual citizenship, concerning physical, erotic, and sexual comfort and pleasure, is also centrally important; this aspect of sexual citizenship is largely overlooked in the citizenship literature. Notions of self-determination and bodily autonomy, as emphasised in both the intersex scholarship (Carpenter 2016) and in existing intersex citizenship literature (Monro 2003; Grabham 2007) are also crucial; the issue is not just that unnecessary interventions are taking place, but that they are being done before a minor is able to give consent. Overall, people with VSC suffer violations of bodily integrity

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<sup>13</sup> See also Cornwall (2010).

when early medical interventions are conducted on them, and because of this they lack intimate citizenship rights (see Plummer 1995).

### **Citizenship issues for intersex children**

As noted above, the problem of breaches of minor's rights to bodily integrity are a pressing issue for intersex children's citizenship. Some intersex activists name these violations as torture, child abuse, and genital mutilation, and they describe the severe psychological damage that can result (see Monro et al. 2017). A number of contributors also discussed the broader negative impact of repeated medical interventions on a child's wellbeing and education. Some contributors discussed the impact of an absence of social citizenship, for example in the area of education:

*...these children at some point go to school, they go to school and for example the total absence of ... even just a history, intersex history, in books as well as programming, anywhere, the total absence except for little mentions presented as 'monsters' or terrible pathologies or myths, but this total absence in the books is bound to reinforce the stigma, it makes you feel like you come from the moon, somehow. So that is something that should be changed. Spaces set aside and safe places, locker rooms, and so on (Alessandro Comeni, Co-founder OII-IT, OII -EU, Italy)*

The need for involvement of children in decisions made about them is emphasised in the children's citizenship literature (see Ben-Arieh and Boyer 2005). The research findings indicated positive ways forwards in supporting the citizenship of children with VSC. This seemed to be especially developed in Switzerland. For example one medic emphasised the importance of informing children about issues in an age-appropriate way. A further contributor (Hans Meier, Medical Practitioner) said that: *'the guideline is you must ask the*

*child and sometimes even young children are able to participate in decision-making'* and a further medic from Switzerland discussed the need to focus on the individual child's wellbeing and best interests, However, the issue of a child's best interests is contested, as the following quote illustrates:

*...to see if an operation is necessary or not necessary, you have to see the whole bio-psychosocial situation of the child and its family to decide if in this child the, which option, to operate or not to operate carries more risk than the advantages.... So if, yeah, if you don't operate, what will that mean when it comes to puberty and adulthood. If you operate, what does it mean then? What does it mean now for the whole family? What does it mean for the child if the mother is every time shocked when she changes the diapers and these kinds of thing, to address these things together, in a process where you are in interaction with the parents... (Medico-ethical Expert, Switzerland)*

The practice of giving parents control over VSC medical procedures overrides children's citizenship rights, except where parents are able to be child-centred and assert themselves with medics who often pressurize them to support unnecessary medical interventions before the child reaches the capacity to make their own decisions about treatment. The issue of familial pressure on medics to impose sex binarism on minors was a problem in all of the case study countries. However, it was especially marked in Italy, where a number of medical contributors emphasised the supposed impossibility of having a child that did not fit sex binaried norms; this is linked with wider social conservatism. State prohibition of medically unnecessary childhood surgeries, as per Malta<sup>14</sup>, would be a good route to intersex citizenship if it becomes politically possible in the case study countries.

### **Reproductive citizenship and the right to family life**

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<sup>14</sup> Gender Identity, Gender Expression and Sex Characteristics Act (2015).

Another breach of intersex people's intimate, social and legal citizenship rights is in the area of reproductive capacities. Historically, gonadectomies were conducted on minors due to some evidence of a higher risk of cancer than in the general population<sup>15</sup>. However, this is criticized by intersex activists, for example:

*... [forced] sterilisation, its not ethical and its not recognising that person as a being who has a right to reproduce, or who has a right over their own reproductive organs and has a right to whatever reproductive organs they have. They have a right to whatever, because its their bodily integrity, its their body, if, and yes, there is this argument that, you know, cancer can occur, but I haven't seen any data... (Valentino Vecchietti, Intersex rights activist, independent academic, and author)*

Contributors noted that it is not just the loss of fertility which causes problems, it is also the loss of a sense of self<sup>16</sup> and in some cases, for example for people with XXY chromosomes, a need for proactive provision to preserve fertility. Another issue is the high levels of secrecy around the procedures and conditions. For example, an Italian contributor described how a woman who had a variation of sex characteristics was never told, so that '*...she wanted to have children, married and everything and these children never, never arrived, and she was like "well, but how come?" but this was because, fundamentally, they had never told her the truth*'. (Luca, Psychologist and Sexologist). Sterility is unavoidable for some intersex people, but as a Swiss medic suggested, there are ways of conveying this that are more compassionate and honest, such as discussing with a child that they will maybe not have biological children, and that many people do not have children.

The sterilization of minors with VSC is still taking place in the UK (gonadectomies and oophorectomies), but the available data conflates different conditions, making it difficult to

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<sup>15</sup> Though these are contested.

<sup>16</sup> Holly Greenberry, personal communication 12.06.2017.

know why such operations are taking place. One of the Swiss medics confirmed that sterilizing procedures do still take place in Switzerland but that *‘people are more careful now. I think it changed a lot due to the Consensus Statement, which is not clear at all but at least it is something’* (Hans Meier, Medical Practitioner). A similar situation was reported in Italy, where a medic stated that *‘...we wait, especially for some [conditions], we don’t operate to gonadectomise anymore at least until adulthood. Because, we also make the most of the gonad’s functioning to improve the outcome for these patients* (Paediatric Endocrinologist)). However, overall, issues of bodily integrity and the right to intimate and familial life is contingent on the decisions made by medics and the parents of minors with VSC, demonstrating a deficit in intersex citizenship rights.

### **Health citizenship**

Earlier in this article we indicated that health citizenship includes rights to healthcare, as well as broader aspects of wellbeing relating to relationships, inclusion and a sense of belonging (see Ponce et al. 2016). Across the three case study countries, access to appropriate healthcare was a key issue for people with VSC. This included not only non-invasive care pathways for minors with these characteristics, but also surgery and hormone treatment if someone who has the capacity to give consent wishes and/or needs to have these. As noted above however, practice varied in these countries, with a lack of agreed protocol apparent in the UK and Italy. The resourcing of healthcare was also a problem in the UK and Italy, including the provision of effective multi-disciplinary teams, time for sufficient care for affected families, appropriate training for medics and healthcare workers, and information provision and support for affected families. Access to individual insurance for healthcare is necessary in some countries in order to access treatment, but insurance is problematically based on the pathologisation of VSC. There are indications of a lack of care for young people transitioning into adulthood, and for adult intersex people, including specific provision such

as support with mental health problems resulting from unnecessary medical interventions, cancer screening and assistance with hormone management. Overall, a lack of effective data gathering about the treatment of people with VSC was evident.

There was evidence of consultation by medics with VSC/DSD NGOs, for example Living with CAH, AISSG, and dsdfamilies in the UK. This supports notions of health citizenship as including service user's voices in a consultative fashion. However, some intersex contributors and advocates raised concerns that their voices were being co-opted or ignored by medics, who have the power to determine the outcome of patient engagement, as the following quote demonstrates:

*Behind closed doors, they promise you everything and you receive nothing ...this is systematic in my experience and the other thing is like self-help groups and particularly parents, they are dependent on the doctors. When you have your gonads taken out, you need a prescription for the rest of your life. You don't want to upset your doctor, who you are dependent on, on giving you the prescription. (Marcus Bauer, Zwischengeschlecht)*

Another issue for health citizenship is the lack of resourcing for the patient advocacy and activist groups, which could usefully be consulted with to inform healthcare provision as well as providing peer support. This problem was evident in all the countries, with intersex activists who were critical of existing care norms being especially marginalised by some medical professionals.

Overall, health citizenship is especially important for people with VSC for a number of reasons. Firstly, there is a need for healthcare providers to cease medically unnecessary interventions on minors who cannot give consent (see above), and secondly, a concurrent requirement exists for appropriate medical and psychosocial support for intersex people and

affected families at all stages of life. In some cases this means reparative medical care (for example where someone suffers long term trauma as a result of childhood medical interventions) but it can also entail the very specific support needed for people with, for instance, endocrinological conditions or morphologies that put them at greater risk of cancer than the general population. Thirdly, the research findings indicated a strong need for mechanisms to include people with variations in sex characteristics in healthcare policy-making and in the provision of support to others with similar conditions; these need to be properly resourced and the contributions of intersex people and their advocates acknowledged.

## **Conclusion**

People with VSC are a highly marginalised group, who lack citizenship in many ways. This marginalisation is reflected in citizenship studies, which has, to date, largely overlooked intersex. We have returned to Marshall's traditional approach to citizenship in this article, because legal and social citizenship are so fundamental to intersex people. However, this does not get away from the fact that Marshallian models of citizenship ignore sex and gender differences and the ways in which power and processes of social inclusion and exclusion are routed through them. Feminist approaches to citizenship are problematic because they assume a sexed male/female binary to which power and access to resources are attached; this ignores subjects who diverge from a discrete male/female binary and the specific citizenship deficits faced by them. Sexual and intimate citizenship may overlook the issue of actual physical sex and the abuses perpetrated on intersex people due to social norms concerning sexed bodies. However, these approaches are helpful in providing a critique of the heterosexist component of prejudice against people with VSC, as well as providing notions of bodily integrity and sexual rights. Healthcare citizenship, which appears to have developed in a way that is largely distinct from feminist, transgender, sexual, and intimate theories of citizenship, is very useful

for putting together conceptual scaffolding for intersex citizenship. It addresses not only access to appropriate healthcare, but also the importance of mechanisms to ensure that intersex people are properly included in healthcare policy and practice formulation. Similarly, children's citizenship literature provides resources concerning the participation of children in decision-making, and provides insights into the reasons for a lack of citizenship rights, which revolve around the imposition – by parents and medics who have binaried, normative ideas of sex, gender and sexuality – of unnecessary and damaging medical practices on infants and children who are too young to give informed consent.

This article uses data from an empirical study of three countries to inform the development of intersex citizenship that synthesises insights from a number of different models of citizenship. Overall, intersex citizenship is distinctive in its utilisation of several strands of citizenship theory, with the core focus revolving around a need to support the bodily integrity and self-determination of people with VSC. For intersex citizenship to be attained, substantive legal reform and resource redistribution is required. We suggest that citizenship is vitally important to supporting the human rights and wellbeing of individuals with VSC. A robust assertion of the key areas of intersex citizenship including legal, intimate, children's, reproductive and health citizenships, would help to bridge the current gap between activist assertions of human rights and the failure of the state and the medical establishment to protect, support, and include people with VSC as citizens. However, the field of intersex, or VSC, citizenship studies is underdeveloped to date, so we have aimed to map out some foundations for a specific intersex citizenship studies.

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## References

- Ben-Arieh, A., and Boyer, Y. 2005 “Citizenship and Childhood: The State of Affairs in Israel.” *Childhood* 12(1): 33-53.
- Bauer, M. and Truffer, D. 2014 *NGO Report to the 2<sup>nd</sup>, 3<sup>rd</sup>, and 4<sup>th</sup> Periodic Report on Switzerland on the Convention on the Rights of the Child (CRC)* Zurich: Zwischengeschlecht. [www.intersex.shadowreport.org](http://www.intersex.shadowreport.org) (accessed 1.05.2019).
- Braun, V., Clarke, V., & Terry, G. (2014). Thematic analysis. In P. Rohleder & A. Lyons (Eds.), *Qualitative research in clinical and health psychology*. Basingstoke: Palgrave MacMillan.
- Carpenter, M. 2016 “The Human Rights of Intersex People: Addressing Harmful Practices and Rhetoric of Change.” *Reproductive Health Matters* 24: 74-84.
- Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahmed, F., D’Alberton, F., Springer, A., & Hiort, O. 2016. “Response to the Council of Europe Human Rights Commissioner’s Issue Paper on Human Rights and intersex People.” *European Urology* 70(3): 407-409. <http://www.sciencedirect.com/science/article/pii/S0302283816301798>.
- Cornwall SM (2010). *Sex and Uncertainty in the Body of Christ: Intersex Conditions and Christian Theology*. London and New York: Routledge.
- Creighton SM, Michala L, Mushtaq I, et al. (2014) “Childhood surgery for ambiguous genitalia: glimpses of practice changes or more of the same?” *Psychology and Sexuality*, 5(1):34–43. DOI: 10.1080/19419899.2013.831214.

- Davis, G. and Murphy, E.L. 2013 “Intersex Bodies as a State of Exception: An Empirical Explanation for Unnecessary Surgical Modification.” *Feminist Formations* 25(2): 129-152.
- De Franza, M. 2015 *Sex Difference in Christian Theology: Male, Female, and the Image of God*. Grand Rapids, Michigan/Cambridge UK: William B. Eerdmans Publishing Company.
- Diamond, M., & Garland, J. 2014. “Evidence Regarding Cosmetic and Medically Unnecessary Surgery on Infants.” *Journal of Pediatric Urology* 10(1), 2-6.
- Ehrenreich, N., & Barr, M. 2005 “Intersex Surgery, Female Genital Cutting, and the Selective Condemnation of Cultural Practices.”  
[http://www.law.harvard.edu/students/orgs/crci/vol40\\_1/ehrenreich.pdf](http://www.law.harvard.edu/students/orgs/crci/vol40_1/ehrenreich.pdf)
- Ferrara, M., and Casper, M.J. (2018) “Genital Alteration and Intersex: A Critical Analysis.” *Current Sexual Health Reports* 10: 1-6.
- Fox, M. & Thomson, M. 2017 “Bodily Integrity, Embodiment, and the Regulation of Parental Choice.” *Journal of Law and Society*, 44(4): 501-531.
- Fraser, N. 2000 “Rethinking Recognition.” *New Left Review* 3: 107-120. Gorman, D. 2010 “Citizenship, Health, and the Challenge of Clinical Leadership.” *Internal Medicine Journal* 40(11): 1-4.
- Garland, F., & Travis, T. 2018 “Legislating Intersex Equality: Building the Resilience of Intersex People through Law.” *Legal Studies* 38: 587-606.
- Garland, J. & Slokenberga, S. 2018 “Protecting the Rights of Children with Intersex Conditions from Nonconsensual Gender-Conforming Medical Interventions: the View from Europe.” *Medical Law Review*. doi:10.1093/medlaw/fwy039
- Grabham, E. 2007 “Citizen Bodies, Intersex Citizenship.” *Sexualities* 10(1): 29-48.

Horowicz, E.M. 2017. "Intersex Children: Who are we really Treating?" *Medical Law International* 17(3) 183-218.

Jeon, K. C., Chen, L. S., & Goodson, P. 2011. "Decision to Abort After a Prenatal Diagnosis of Sex Chromosome Abnormality: A Systematic Review of the Literature". *Genetics in Medicine* 14(1), 27-38.

<http://www.nature.com/gim/journal/v14/n1/full/gim0b013e31822e57a7a.html>.

Kaggwa, J. 2016 "Understanding intersex stigma in Uganda".

<http://intersexday.org/en/understanding-stigma-uganda/>

Lee, P. Houk, C., Ahmed, F.S. and Hughes, I.A. 2006. "Consensus Statement on Management of Intersex Disorders." *Pediatrics* 118:488–500, doi: 10.1542/peds.2006-0738.

Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., & Mazur, T. 2016. "Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care." *Hormone Research in Paediatrics*, 85(3), 158-180.

Lorenzo, A. J., Salle, J. L. P., Zlateska, B., Koyle, M. A., Bägli, D. J., & Braga, L. H. 2014. "Decisional Regret After Distal Hypospadias Repair: Single Institution Prospective Analysis of Factors Associated with Subsequent Parental Remorse or Distress." *The Journal of Urology* 191(5), 1558-1563.

Marshall, T.H. 1950 *Citizenship and Social Class and Other Essays*. Cambridge: Cambridge University Press.

McQueen, P. 2014 "Enslaved by One's Body? Gender, Citizenship, and the 'Wrong Body' Narrative." *Citizenship Studies* 19(5): 533-548.

Monro, S. 2003 "Transgender Politics in the UK." *Critical Social Policy* 23(4): 433-452.

- Monro, S., Crocetti, D., Yeadon-Lee, T., with Garland, F. and Travis, M. 2017 *Intersex, Variations of Sex Characteristics, and DSD: The need for change*. Huddersfield: University of Huddersfield Press.
- Morland, I. 2009. ‘What can Queer Theory do for Intersex?’ *GLQ: A Journal of Lesbian and Gay Studies* 15(2), 285-312.
- OII Europe 2013 ‘Malta Declaration’ <https://oiieurope.org/malta-declaration/>OII Europe 2017 ‘4<sup>th</sup> International Intersex Forum - Media Statement’ <https://oiieurope.org/4th-international-intersex-forum-media-statement/>
- Nussbaum, M. C. (1999) *Sex and Social Justice*. Oxford: Oxford University Press.
- Pateman, C. 1988 *The Sexual Contract*. Palo Alto, CA: Stanford University Press.
- Plummer, K. 2001 “The Square of Intimate Citizenship: Some Preliminary Proposals.” *Citizenship Studies* 5(3): 237–53.
- Ponce, A.N., Clayton, A., Gambino, M., Rowe, M. 2016 “Social and Clinical Dimensions of Citizenship from the Mental Health-Care Provider Perspective.” *Psychiatric Rehabilitation Journal* 39(2): 161-166.
- Richardson, D. 2000 “Constructing sexual citizenship: theorizing sexual rights.” *Critical Social Policy* 20(1): 105-135.
- Roche, J. 1999 “Children, Rights, Participation and Citizenship.” *Childhood* 6(4): 475-0493.
- Rubin, D.A. 2015 “Provincializing Intersex: US Intersex Activism, Human Rights, and Transnational Body Politics.” *Frontiers* 36(3) 51-84.
- Travis, M. 2015 “Accommodating Intersexuality in European Union Anti-Discrimination Law.” *European Law Journal* 21(2): 180-199.

**Table 1. Sample Characteristics**

	Italy	Switzerland	UK	Totals
Intersex activists	6	2	5	13
Patient advocates	3 (included 1 focus group)	2	5	10
Medics and healthcare professionals	5	2	1	8
Policy and related	1		6	7
Multi-issue activist groups including intersex			2	2
Totals	15	6	19	40